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**University of Southampton**

Faculty of Health Sciences

**What does the process of developing a personal narrative involve and  
how does it contribute to mental health recovery?**

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Thesis for degree of Doctor of Philosophy

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## ABSTRACT

This research is based on the premise that mental health recovery is an unique and individual journey (Anthony, 1993), and that developing a personal narrative can support mental health recovery. In current UK recovery-orientated provision, service users are asked to ‘tell their stories’ within clinical settings as a tool for diagnosis, formulation and treatment plans. There is little current evidence that narrative or narrative development is being used systematically within an NHS therapeutic setting. The aim of this study was to explore the process of developing a personal narrative and its possible contribution to mental health recovery.

This study used a three-phased approach, where the emergent themes informed subsequent phases. Recovery background, study rationale, literature review (overview of narrative and use of media) and methodology are described to provide context to all phases. Phase 1 involved developing and analysing my recovery autoethnography, *‘From the edge of the abyss to the foot of the rainbow’*. Phase 2 used a Participatory Action Research (PAR) approach. 11 co-researchers who had previously developed their personal narratives were recruited to two focus groups to discuss their experiences of narrative development. Six co-researchers continued into Phase 3, which involved three cycles of PAR. The output of the co-production was an eight-session, peer-led Personal Narrative Workshop Programme (to support service users to develop their narrative). This was fully documented – Programme Framework, Scheme of Work and Session Plans.

The integrated emergent themes from the three phases provided the following key findings (all were incorporated into the workshop programme): a realisation of the difficulty of developing a narrative (reliving trauma); the value of developing narrative within a group setting (supports factors such as collaboration and validation); and the role of ‘the voice of others’ in our narratives (implications for relational ethics). Given ‘my insider perspective’, Phase 3 also highlighted methodological issues including: the complexities of using a PAR approach; the multiplicity of roles and tensions of those roles; and the tensions between the PAR process with the need to develop practical outcomes (for the PhD process). A key

element of the Personal Narrative Workshop Programme was ensuring a balanced approach between educational content and the time and space to 'do' within a supportive environment.

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## ABBREVIATIONS

<b>BAME</b>	British, Black, Asian, and minority ethnic
<b>LGBTQ</b>	Lesbian, Gay, Bisexual, Transgender and Queer
<b>OCD</b>	Obsessive-compulsive disorder
<b>OECD</b>	Organisation for Economic Cooperation and Development
<b>WHO</b>	World Health Organisation
<b>GDP</b>	Gross Domestic Product
<b>NHS</b>	National Health Service
<b>HM</b>	Her Majesty's (Government)
<b>CHIME</b>	Connectedness, Hope and optimism about the future, Identity, Meaning in Life, Empowerment
<b>WRAP</b>	Wellness Recovery Action Plan
<b>6PSM</b>	'Six-Piece Story Making
<b>PAR</b>	Participatory Action Research

## **ACADEMIC THESIS: DECLARATION OF AUTHORSHIP**

I, Samantha Robertson declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

### **What does the process of developing a personal narrative involve and how does it contribute to mental health recovery?**

I confirm that:

This work was done wholly while in candidature for a research degree at this University;

Where I have consulted the published work of others, this is always clearly attributed;

Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;

I have acknowledged all main sources of help;

Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;

Parts of this work have been published as: Robertson et al. (2017)

Signed: Samantha Robertson

Date: 1<sup>st</sup> June 2018



## CHAPTER 1: BACKGROUND AND CONTEXT

### 1.1 Introduction

This chapter provides an overview of mental health recovery. This is used to support the rationale for the research question that underpins this study. The incidence and burden of mental illness (from an international and UK perspective) reflects the importance of mental health recovery to society, the economy and the individual. A clear distinction is made between restorative recovery (from a traditional medical model viewpoint) and living a meaningful life with the on-going symptoms of mental illness (the latter is the focus of this study).

An outline of the ‘consumer’ recovery movement is used to provide context to the fact that the concept of recovery is embedded within current UK mental health policy and service provision *No Health Without Mental Health* (Department of Health, 2011). A formal and empirically based conceptual recovery framework (Leamy et al., 2011) that encapsulated three key interlinked domains is described: CHIME Recovery Processes (Table 1.1); Recovery Stages (Table 1.2); and Characteristics of the Recovery Journey (Table 1.3). This framework and the Four Tasks of Personal Recovery (Box 1.1) (Slade, 2009) will be drawn upon throughout this study.

Personal context is also fundamental in this study. As a long-term mental health service user (from 1996) my lived experience reflects the theory, incidence and practice of mental health recovery in general to the specific gap identified for this study – the role of personal narrative development and its possible contribution to recovery. The rationale of this research question is discussed in this chapter.

### 1.2 Researcher Background and Role

I have experience of recovery in terms of engagement in outcome-driven recovery-orientated services. I have received care in primary and secondary (in-patient, day hospitals, hospital at home and community) services. I have used day-care within the third sector. Within my mental health ‘career’ (Kleinman, 1988) I have received individual, group, creative art and medication therapy. Alongside this (and at times

despite these services), I have been on 'my personal recovery journey' (Pilgrim and McCranie, 2013) – an individual process of learning and growth. As a result, I am more self-aware, accepting and autonomous. I have become an agent and decision-maker in my own recovery.

I am an experienced advisory teacher, mental health trainer (University of Southampton, Hampshire County Council and Mind), consultant and mental health activist. I was the Chair of Mind Trustees in my local area (we ran day services within this locality). I am an Accredited Play and Creative Arts Therapist and Certified Clinical Supervisor. From 2010-2013, I was the Service User Involvement Co-ordinator within an NHS mental health trust. In this role, I was part of a team that developed peer support and the Recovery College (Perkins et al., 2012) within the Trust. I also worked with and trained service users to use Wellness Recovery Action Plan (WRAP) (Copeland, 2013) as part of their own recovery journeys and to facilitate others in their recovery.

### **1.3 Incidence of Mental Illness**

The World Health Organization (WHO) defines mental health as:

*'a state of well-being in which the individual realizes his or her abilities, can cope with the normal stresses of life, can work productively and peacefully, and is able to make a contribution to his or her community' (Organisation for Economic Cooperation and Development, 2008)*

The OECD (2014) estimated that approximately 5% of the working-age population experience severe mental health difficulties, with a further 15% affected by more common conditions. In England it was estimated that in 2007, 17.6% of the population met the criteria for one common mental disorder (NHS Confederation, 2008, Mental Health Network, 2014). The mortality rate for these individuals was 0.6% higher than in the general population (Information Centre et al., 2013). Third sector organization Mind stated '1 in 4 people will experience a mental health problem in any given year' (Meltzer, 1995, Mind, 2013a). Although this is the commonly known and accepted incidence of common mental illness in the UK today, it has been suggested that this figure could be closer to 1 in 2 (OECD, 2014). This difference may be due to more openness as a result of wider media coverage,

campaigning (Time to Change, 2015) and a growing willingness for individuals to acknowledge mental health difficulties. In 2012/13, it was estimated that nearly 1.6 million people accessed specialist mental health services (Mental Health Network, 2014).

Alongside the personal and societal loss associated with mental illness, there are also significant economic losses. The OECD (2014) estimated the direct and indirect cost of mental health problems at above 4% of Gross Domestic Product (GDP). Direct health care spending on mental health, accounted for a fraction of these costs to economies with much of the hidden cost due to factors such as reduced productivity at work (presenteeism), absenteeism, sick leave, early retirement and receipt of disability pensions. The 2007 Psychiatric Morbidity in England Report (NHS Confederation, 2008) stated that mental illness continued to be a barrier to paid employment, with 2.3 million people with mental health conditions out of work or on benefits (Mental Health Network and Confederation NHS, 2011, NHS Confederation, 2012).

Underpinned by *The Equality Act 2010* (HM Government, 2010), *No Health Without Mental Health* (Department of Health, 2011) the UK Government's mental health strategy estimated the costs of mental health problems to the English economy at £105 billion with treatment costs expected to double in the next 20 years. *Closing the Gap* set out the priorities for mental health change including improving the quality of service users' lives (e.g. supporting recovery) (Social Care Local Government and Care Partnership Directorate, 2014) which in part is driven by economic imperatives to increase employment, productivity and therefore reduce the reliance on benefits.

#### **1.4 Mental Health Recovery**

As the statistics suggest, mental illness is a burden and loss to the individual, the economy and to society, hence the growing importance of recovery. Anthony (1993, p.1) identified recovery as:

*'a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness'*

Anthony's seminal quote is widely cited as a description of recovery in mental health. It continues to inform: mental health research (Pilgrim and McCranie, 2013); models for service provision and recovery-orientated services (Repper and Perkins, 2003, Shepherd et al., 2008, Slade, 2009, Slade et al., 2014); and government policy (Department of Health, 2011).

Recovery in this context is different from recovery within the traditional loci of the psychiatric (and physical health) medical model, which defines recovery in terms of absence of illness, symptoms or continued need for treatment (e.g. medication) (Whitwell, 2001). The focus of recovery within the medical model is a return to a pre-illness, normal healthy state (Davidson et al., 2007) and a sense of restitution (Frank, 1995). For some service users, this is their desired recovery state, but restitution is not necessary for recovery. Whilst acknowledging that the medical model is still prevalent (even within recovery-orientated mental health systems), restorative recovery from mental illness is not the focus of this study. Anthony's personal journey view of recovery (Pilgrim and McCranie, 2013) is fundamental to this research. If the process of recovery is deeply personal and unique, as Anthony (1993) suggested, it is likely that an individual's definition of recovery is also unique. For many, recovery is about living a meaningful life with or without symptoms of one's mental health problems (Scottish Recovery Network, 2013).

### **1.5 The Recovery Movement**

From the developing consumer recovery movement over the last 50 years (Davidson et al., 2010 ), recovery as a concept came from service users themselves (Repper and Perkins, 2003). In addition, recovery has gained a higher profile due to: the de-institutionalisation of mental health services towards community-based provision; developments within psychiatry; and the 'consumer movement' (Chamberlin, 1978, Deegan, 2001, Repper and Perkins, 2003, Davidson et al., 2010 , Glover, 2013).

The recovery movement is not one homogeneous group. From grassroots, national (Scottish Recovery Network, 2013, NSUN, 2013) and international groups (World

Network of Users and Survivors of Psychiatry, 2015) – it is a term used to describe people who have defined themselves as consumers, survivors, anti-psychiatry, ex-patients etc. - people with lived experience with varying agendas, but generally a sense of injustice relating to their care as service users. Influenced by the assumption of living with on-going disability rather than cure (Anthony, 1993), many had the desire to improve their own lives and the lives of others practically: for example, by creating structured peer-led groups (Pilgrim and McCranie, 2013) to support deinstitutionalized service users.

The recovery movement could be viewed as a political response to a psychiatric system that focused on maintenance (Turner, 2002); a political and radical agenda of fighting for patients' rights against forced treatment, stigma and discrimination. The mental health system was seen as the problem and was therefore a common target. The US civil rights movement (citizenship) from the late 1960's onwards was a key driver in the growing momentum of the recovery movement (Chamberlin, 1978, Davidson et al., 2010 ). Consumer groups (from 1980s/90s) preferred to work with services to promote reform and improvement. Of those people who are active in the recovery movement there are differences in their activism. There are also those who have no interest in being involved in changing the system. They do not consider themselves to be part of the recovery movement. There are others who reject outright working with services. For many, recovery occurs despite mental health services:

*'Many of the people in recovery who fought long and hard for their rights to self-determination and social inclusion distrust the current rhetoric of recovery and transformation' (Davidson et al, 2010, p.186).*

Yet, current UK policy and service provision recovery model is a key consequence of the evolution of the survivor/consumer recovery movement. However, the movement is not without its critics. Tomes (2006) argued that 'the growing attentiveness to consumer perspectives... is a consequence, not a cause, of radical restructurings of the mental health system' (p.1).

### **1.6 Concept of Recovery**

As a concept, recovery has gained widespread acceptance and has been adopted as a policy and practice driver by governments, commissioners, clinicians and third sector organizations (Repper and Perkins, 2003, Shepherd et al., 2008, Department of Health, 2011, Mind, 2013b). There is a danger that the widespread adoption of the term 'evidence-based recovery' (Slade, 2009, Pilgrim and McCranie, 2013, Bird et al., 2014, Slade et al., 2014), has robbed it of its original meaning. It is open to subjective interpretation:

*'Recovery has a multitude of meanings, being an idea, the movement, the philosophy, a set of values, paradigm, policy and the doctrine of change'*  
(Turner, 2002, pp.29-31).

There is an expectation that through the implementation of the *No Health Without Mental Health* (2011) strategy, there will be improvements in indicators such as physical health, morbidity, educational attainment, employment etc. There are on-going concerns regarding adequate resources for services to support individuals to make these changes. As part of this government-led drive for recovery, it has become increasingly incumbent on service users to embrace an externally driven definition of recovery. Service users will recover and will do so in ways prescribed. Recent commissioning of mental health services has resulted in time-limited and outcome-driven service provision - even within more recovery-orientated services. For example, many NHS Trusts have established Recovery Colleges (Perkins et al., 2012, Slade et al., 2014) which offer courses pre-determined by service providers. It appears that the unique personal journey nature of recovery is lost.

### **1.7 Recovery Model Framework**

There are different recovery models and frameworks (Pettie and Triolo, 1999, Andresen et al., 2003, Barker and Buchanan-Barker, 2007, Slade, 2009) that have attempted to explain this complex and nebulous concept. Such models have been used to operationalize recovery in order to be able to quantify 'recovery' and therefore measure it against evidence-based outcomes. Following a systematic literature review of models and descriptions of personal recovery, Leamy et al. (2011) developed a formal and empirically based Conceptual Recovery Framework

which encapsulated three key interlinked domains. Bird et al. (2014) reported on the validity and relevancy of this framework for clinical and research purposes.

### **Three Key Interlinked Domains**

The first interlinked domain covered the recovery processes of connectedness; hope and optimism about the future; identity; meaning in life; and empowerment (CHIME) (Leamy et al., 2011).

**Table 1.1: CHIME The Recovery Processes**

<b>Recovery Processes</b>
<b>Category 1: Connectedness</b> Peer support and support groups Relationships Support from others Being part of a community
<b>Category 2: Hope and optimism about the future</b> Belief in possibility of recovery Motivation to change Hope-inspiring relationships Positive thinking and valuing success Having dreams and aspirations
<b>Category 3: Identity</b> Dimensions of identity Rebuilding/redefining positive sense of identity Overcoming stigma
<b>Category 4: Meaning in life</b> Meaning of mental illness experience Spirituality Quality of life Meaningful life and social roles Meaningful life and social goals Rebuilding life
<b>Category 5: Empowerment</b> Personal responsibility Control over life Focusing upon strengths

The second interlinked domain was the characteristics of the recovery journey (Table 1.2). Leamy et al. (2011) mapped a number of existing recovery models and conceptual frameworks including (Andresen et al., 2003, Slade, 2009) onto the trans-theoretical model of change (Prochaska and DiClemente, 1984) (Table 1.2) under the pre-defined headings of: pre-contemplation; contemplation; preparation; action; and maintenance and growth. Whilst acknowledging that recovery is a uniquely individual process, there was consensus that there seemed to be definable

stages to this personal experience. There appeared to be agreement regarding the cognitive, emotional, behavioural and social conditions that are characteristic and necessary (and their relative importance) for the different stages of an individual's journey of recovery. For those that do progress through the stages, the time required to do so is not fixed – the time taken is unique to the individual.

**Table 1.2 Recovery Stages Mapped onto The Trans-Theoretical Model of Change (Leamy et al., 2011)**

Study	Recovery stages mapped onto the trans-theoretical model of change (Leamy et al., 2011)				
	Pre-contemplation	Contemplation	Preparation	Action	Maintenance and growth
32		Novitiate recovery – struggling with disability		Semi-recovery- living with disability	Full recovery – living beyond disability
73	Stuck	Accepting help	Believing	Learning	Self-reliant
3	Descent into hell	Igniting a spark of hope	Developing insight - activating instinct to fight back	Discovering keys to well-being	Maintaining equilibrium between internal and external forces
44	Demoralisation		Developing and establishing independence		Efforts towards community integration
36	Occupational dependence		Supported occupational performance	Active engagement in meaningful occupations	Successful occupational performance
14	Dependent/ unaware	Dependant/aware		Independent/ aware	Interdependent/ aware
29	Moratorium	Awareness	Preparation	Rebuilding	Growth
78		Glimpses of recovery	Turning points	Road to recovery	
61		Reawakening of hope after despair	No longer viewing self as primarily person with psychiatric disorder	Moving from withdrawal to engagement	Active coping rather than passive adjustment
40	Overwhelmed by disability		Struggling with disability	Living with the disability	Living beyond the disability
35	Initiating recovery			Regaining what was lost/ moving forward	Improving quality of life
59	Crisis (recuperation)		Decision (rebuilding independence)	Awakening (building healthy interdependence)	
43		Turning point	Determination		Self-esteem

The third interlinked domain was the characteristics of the recovery journey (Table 1.3), factors that seemed to acknowledge that the recovery process is unique, is not straightforward and involves hard work.

**Table 1.3 Characteristics of the Recovery Journey**

<b>Characteristics of the Recovery Journey</b>
Recovery is an active process
Individual and unique process
Non-linear process
Recovery as a journey
Recovery as stages or phases
Recovery as a struggle
Multidimensional process
Recovery is a gradual process
Recovery as a life-changing experience
Recovery without cure
Recovery is aided by supportive and healing environment
Recovery can occur without professional intervention
Trial and error process

(Leamy et al., 2011)

Whilst Leamy et al. (2011) described the recovery stages as theoretically linear, this is not always the case in practice. Slade (2009) suggested that a spiral process would be a better description. Whilst Slade's Personal Recovery Framework Model is encapsulated within Leamy et al. (2011) Conceptual Recovery Framework, it is important to acknowledge that it stands alone as well. In his model, Slade (2009) described four tasks of recovery (Box 1.1).

**Box 1.1: Four Tasks of Recovery (Personal Recovery Framework, Slade, 2009):**

1. To develop a positive identity, which may involve regaining hope, developing relationships and starting to challenge and change core beliefs, e.g. feeling worthless and unlovable.
2. To reframe the mental illness.
3. To develop self-management with a consequential reduction in the reliance on professional support.
4. To develop valued social roles through engagement in familial, work and social activities.

Both Leamy et al., and Slade's models of recovery will be drawn upon within this study.

**1.8 Rationale for this Study**

Within the NHS Trust I was employed as an 'expert' service user. As such I developed my recovery narrative (also called a recovery story). I delivered my testimonial of successful recovery (Frank, 1995) to staff, other service users and at conferences. The Scottish Recovery Network Narrative Study (2011) described the importance for an individual's recovery of sharing their narrative. This is supported by accounts from service users with whom I worked (within the Trust) to develop their personal narratives in order to share their story with professionals and other service users. Part of the training I provided was to support service users to tailor their narrative to different audiences and purposes. Many service users who had attended the training commented that developing a narrative and thus reframing their mental health experiences had been beneficial.

The aim of this study is to explore the process and contribution of developing a personal narrative to recovery. Recovery tools such as WRAP - Wellness Recovery Action Plan (Copeland, 2013) and Recovery Star (Mental Health Providers Forum, 2013) are widely used in developing self-management. Alongside developing community links, these tools also promote improving and gaining valued social roles. However there is a scarcity of interventions that support individuals to reframe their experiences through developing a personal narrative. Current service provision does not directly address this potentially crucial task of recovery in any systematic and consistent way, although there has been some recent interest in Narrative

Therapy as a therapeutic intervention (White, 2014, Avon and Wiltshire Mental Health Partnership NHS Trust, 2014) but it appears to be very limited and dependent on individual practitioners offering it as part of a 'toolbox' of interventions.

Developing a personal narrative, often whilst experiencing significant symptoms and living with mental illness, is difficult - especially without support. Access to psychological and creative therapies within the NHS is limited. There is a scarcity of interventions that support individuals to reframe their experiences and thus develop positive identities. This is the crucial gap that the current research aims to bridge. There are a small number of service users within Hampshire (including the researcher) who have systematically developed a personal narrative for a variety of reasons (e.g. for training purposes). Working with some of these individuals, this study aims to explore the process of developing a personal narrative and in doing so, gain a better understanding of how developing a personal narrative contributes to mental health recovery.

### **1.9 Research Question**

**What does the process of developing a personal narrative involve and how does it contribute to mental health recovery?**

This research will utilise this knowledge and understanding to develop a personal narrative workshop programme and to develop a strategy and/or tool to support service users to develop their narratives.

### **1.10 Conventions**

It is necessary to clarify how important terms are used and defined within this study.

#### **Service User or Patient**

There is little consensus on what to call individuals who use mental health services - service users, consumers, patients, psychiatric survivors, or survivors. Different titles reflect different political, economic, social perspectives and historic positions. Most labels are highly stigmatised (Goffman, 1963). The given label also tends to describe the relative position of the individual (including power differentials) within the

relevant model of service delivery. For example, a patient within an institution or a service user of community services. Often the 'label' does not reflect the position of the person, who is labeled, e.g. being a consumer suggests choice is possible in terms of what services they receive and whether to accept services in the first place.

In response to The Royal College of Psychiatrists deciding that 'service users' should be called 'patients' (Christmas, 2013), The Scottish Recovery Network (2014) undertook a short survey which asked what individuals wanted to be described as. The preferred option was '*person with experience of mental health issues/problems/distress*'. 'Service user' is the most widely used term within community services and by the individuals themselves. For the purposes of this study, 'service user' will be used, unless the individual is participating in this research and then they will be called 'co-researchers'.

### **Narrative or Story**

Within the literature, the terms 'narrative', and 'storytelling' appeared to be used with similar meaning and purpose. However, some service users have difficulty with the word 'story', as they feel it suggests 'something made up' and therefore not to be believed. This is particularly relevant with individuals with experience of abuse (Jonker and Jonker-Bakker, 1991, Jones and Morris, 2007). For the purposes of this study the terms 'narrative' or 'personal narrative' or 'recovery narrative' will be used.

### **Personal Narrative v Recovery Narrative**

Like narrative and story, the terminology for personal narrative and recovery narrative appear to be used interchangeably. In the phase 2 focus group discussions, the co-researchers suggested that there was a distinction. A recovery narrative tends to be developed for a specific purpose (e.g. as a testimonial to others (Frank, 1995). A recovery narrative focuses on an individual's recovery journey and emphasises how this has been achieved. It is often used as a training tool. A personal narrative can also include a recovery narrative, but is likely to contain more of a life story and more negative material. For the purposes of this study the terms 'personal narrative' will be used.

### **Use of Pseudonyms**

All individuals and organisations have been given pseudonyms, apart from my husband Don Robertson, who preferred to be named. My son chose 'John Doe'.

### **1.11 Chapter Summary**

Chapter 1 provides an overview of the importance of recovery. This includes a review of factors such as: the incidence and burden of mental illness; current UK policy and practice; the recovery movement; the concept of recovery; and recent theoretical recovery frameworks that are used throughout this study. Adding my personal perspective as a service user, this context allowed the identification of an important gap in understanding around personal narrative development and recovery that provided the rationale and the research question for this study.

## CHAPTER 2 LITERATURE REVIEW

### 2.1 Introduction

Gaining an understanding of the process of personal narrative development and its possible contribution to mental health recovery was central to this study. In order to provide background and context to the literature review undertaken, a detailed overview and critique of the narrative approach was carried out. In particular, relevant aspects such as the concept of narrative truth (Bruner, 1987, Craib, 2003), illness narratives (Kleinman, 1988, Frank, 1995) and the potential benefits of narrative development and recovery are discussed.

Determining the focus of the literature review was a multi-stage process. The purpose of the literature review was to assess the existing knowledge, understanding and research relevant to the research question. Initially, a scoping search for existing literature (using Delphis and the Web of Knowledge, limited from 1990<sup>1</sup> and in English) was conducted to review the literature on how the process of developing a personal narrative could support mental health recovery. This failed to highlight any papers.

The concentration of the literature focussed on content rather than narrative process highlighted the value of this study. In order to conduct a meaningful literature review, it was decided to focus on the different ways an individual could develop a personal narrative using different media (product such as storyboards, journals, photography and performance) to provide structure to the process. The review focused on how different media were used, in what contexts, and what the benefits and problems of using them were. This important information was used as

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<sup>1</sup> This date was chosen as it was before ANTHONY, W. 1993. Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990s. 16. [Accessed 20 08 13]. seminal definition of recovery.

part of the discussions in the phase 2 focus groups and the phase 3 narrative workshop development of this study.

## **2.2 Narrative Overview**

### **Theoretical Overview and Critique**

There was substantial and growing literature on narrative, ranging from different theoretical perspectives, critiques (Bruner, 1987, Polkinghorne, 1988, Bruner, 1990, Atkinson, 1997, Craib, 2003, Hyvarinen, 2008) and discussion of narrative form (Bruner, 1987, Bruner, 1990). The literature evidenced a range of narrative methodologies including autoethnography (Ellis, 2004, Short et al., 2007, Ellis et al., 2011, Short et al., 2013).

Building on the work of Polkinghorne (1988), Bruner (1987) suggested that within a social world, narrative is dominant – it is a sense and world-making process.

Narratives can be temporal, multi-voiced social constructions, which are dependent on individual values and cultural practices. Narratives reflect the interaction of and the social and cultural assumptions of the teller and the audience, such that there is no one ‘true’ narrative but a range of alternative possibilities, (Bruner, 1987). This ‘transformative’ possibility (Atkinson and Delamont, 2006b) had implications for this study: if one acknowledges the idea that an individual internalises their personal narrative, then this process could be used it to support their recovery.

### **Narrative Truth**

Within this social constructivist perspective, Bruner (1987, p.14) stated there were external and internal criteria for narrative construction: of rightness; of how one felt or what one intended; and of coverage. Criticism of this view included the role of omissions and commissions - what is left unsaid and intentions (i.e. the narrative may not be true). Craib (2003) argued that bad faith narratives were possible ‘narratives are not sacred: they can be judged as being more or less true or false, more or less self-serving’ (2003, p.65). Hyvarinen (2008) commented that ‘narrativity always carries with it some sort of tendency to revision’ (p.266).

Craig (2003) suggested narratives could deny agency, when nothing is the fault of the individual but is the result of what has been done by others. This was reflected in Frank (1995) description of the 'Chaos Narrative' (discussed later). Critics argued this raised issues concerning verification and validity (in themselves interpretative constructs). Further concerns included the role of memory retrieval, distortions and wishful thinking (Polkinghorne, 1988, p.117) and outcome interference. The act of telling may distort the narrative, 'a witness to one's own narrative' (Frank, 1995, p.61). If a narrative approach seems unable to guarantee 'the true reflection of the authentic self' as these critiques suggested (in essence, the fallacy of the authentic self), (Atkinson and Delamont, 2006b) argued that this may be equally true with regard to other research methods such as interviews too.

### **Illness Narratives**

'Narrative truth' criticism appeared to underplay the possible therapeutic role of narrative (i.e. the sense that individuals share narratives in order to understand their emotions and to try to make sense of their experiences). Authors such as Kleinman (1988) and Frank (1995) discussed narrative theories or illness narratives derived from marginalised and little-heard groups and individuals. Within any given cultural context, illness has physiological, psychological and social meaning, with significant implications for an individual's sense of self and identity (Kleinman, 1988). Although the illness experience was unique, Kleinman (1988) proposed that living with chronic illness always involved: a sense of loss and grief; uncertainty; economic and temporal loss; and an element of shame and being hidden. The meaning that an individual ascribed to their illness was essentially an attempt to restore order and understanding.

Kleinman (1988) added that there was the possibility that rather than reflecting the illness experience, the personal narrative may contribute to it. This is an important point because if it contributes negatively to the illness experience it is unlikely to support recovery. Factors such as: the medical model environment (perceived power/powerlessness); illness chronicity; type and 'acceptability' of illness (e.g. schizophrenia or cancer); public and personal stigma (Goffman, 1963); employment

and social inclusion; and relationships and roles that are played (the ‘patient’ or the ‘victim’) may contribute to the illness narrative. The individual may become the diagnosis so that the ‘me/it’ integrates. The person is the depressive rather than someone who experiences depression. The illness identity can become a badge of honour – e.g. ‘mental health survivor’. Within mental health services if an individual receives secondary services, they may be perceived as ‘a proper service user’. This has on-going implications for access to services (including specific therapy), social activities (including friendship groups based around mental health), accommodation and the benefits system. Many people fight to hold onto their ‘illness identity or sick role’ because it brings with it the security of what is known. Mental illness itself and possible institutionalisation and infantilisation can make the ‘outside world’ a scary place. Added to this fear factor, recovery models and frameworks (Slade, 2009, Leamy et al., 2011) acknowledge that recovery is non-linear and is hard work. Relapses are possible. Regaining mental health services and benefits are difficult. The illness identity can therefore become a ‘moral career’ (Goffman, 1963).

For others, developing a personal narrative may contribute to breaking free from the ‘illness or sick role’. Frank (1995) suggested that narratives could help repair the damage done by illness and the environment of illness, ‘they need to become storytellers in order to recover the voices that illness and its treatment often takes away’ (Frank, 1995, p. xii). ‘The way out of the narrative wreck is telling stories’ (p. 55). There is a sense that self and identity could be rediscovered through narrative. If illness experience dislocates identity (our past does not predict our present), narrative could have the potential for integration of the past, present and possible futures. This is particularly relevant to this study.

Frank (1995) described three different types of illness narratives: The Restitution Narrative, the Chaos Narrative and the Quest Narrative. The Restitution Narrative described the theme of recovering a pre-illness state (less relevant in this study). The Chaos Narrative described the early stages and/or acute episodes of mental illness, characterised by little agency, understanding, reflection, coherence or control over environment – factors that are perhaps necessary to develop a

meaningful narrative that may contribute to recovery. There appeared to be little sense of recovery, merely survival within a Chaos Narrative. The Quest Narrative described the 'what have I learnt as a result of my illness...' experiences. Quest Narratives make up the majority of published illness, survivor or witness narratives (or testimonies). Frank (1995) stated the Quest Narrative was: transformative (for both the teller and the audience); reflexively monitored which provided meaning and coherence; communicative and dyadic as sharing was important; contingent; productive and allowed for new connections to be made. Both the content and the process of developing a Quest Narrative were linked to recovery and are relevant to this study.

### **Revisiting Narrative Truth**

Retrospective narratives (e.g. quest or testimonial narratives) can give significance and validity to life experiences that are not necessarily truthful accounts. In a critique of Kleinman (1988) and Frank (1995), Atkinson (1997) suggested a recuperative narrative without any accompanying social analysis action (such as in autoethnography) was a wasted opportunity. Atkinson argued that a choice should be made regarding narrative function - the revelatory, emancipatory and therapeutic power of the narrative for the individual and audience or the narrative as a more academically rigorous socially constructed critique. This either/all argument is not necessarily relevant to the individual developing their personal narrative. Like Craib (2003), Atkinson questioned the 'authentic narrative voice' and narrative validity given possible grandiose and romantized tendencies of a narrator.

This raises the question regarding the purpose of narrative development and the appropriateness of the gold standard of 'narrative truth'. Bruner (1987) examined this in terms of folk psychology and the benchmark of canonicity for what is deemed normal or expected in narratives. The concept of breach allowed opening up the narrative to the unusual, to aspects that do not follow the expected form for developing and sharing narrative. For example, breach allows imagination, messy texts (Short et al., 2007, Short et al., 2013) and for individuals who have been marginalized and silenced – as service users often are.

### Narrative Structure

Building on Burke's (1962) work in *A Grammar of Motives*, Bruner (1987) stated narrative form rather than content was important (Table 2.1). Burke (1962) described the five elements of the *dramatis pentad* – a narrative required an act, a scene, an agent, agency and purpose. Bruner added that the further element of 'trouble' (or breach) was required to drive the narrative forward. Trouble occurs when there is a mismatch between any two elements - e.g. a narrative disruption caused by mental illness. This is a key element relevant to personal narrative development in this study.

**Table 2.1 Key Elements of Narrative Structure**

Burke	Bruner	Elements
Act	Action	What was done or took place?
Scene	Setting	Where or when the action took place - context?
Agent	Agent	Who did it?
Agency	Instrument	How did it occur?
Purpose	Goal	Why?
	Trouble	What drives the drama?

Lahad (1992) added that stories from different cultures all contained common elements. In developing an assessment tool for stress and post traumatic stress disorder (PTSD), Lahad and subsequent researchers (Dent-Brown, 1998, Dent-Brown and Wang, 2004) used storyboard techniques and the 'Six-Piece Story-Making' (6PSM) tool to support individuals to develop their projected stories (Table 2.2), which helped determine therapeutic interventions.

**Table 2.2: 'Six-Piece Story-Making' (6PSM), Lahad (1992)**

1. A main character in some setting
2. A task for the main character
3. Obstacles in the main character's way
4. Things that help the main character
5. The climax or main action in the story
6. The consequences or aftermath of the story

### Narratives and Mental Health Recovery Research

In the literature, autoethnography (as a form of personal narrative) has been used by individuals to describe their lived experiences and/or their recovery: living with bulimia (Tillmann-Healy, 1996); surviving child sexual abuse (Fox, 1996) and

schizophrenia and mental health recovery (Deegan, 1987, Deegan, 1988). Other media used included: blogging (Mind, 2013b, Recovery Stories, 2013); self-published e-books (Bailey, 2013); graphic memoirs (Stickley, 2012); storyboards (Dent-Brown, 1998); and sharing lived experience and personal narrative at conferences and teaching on education and training courses.

Given the assumption that personal narrative is important, there appeared to be limited literature on how the process of developing a personal narrative could support recovery. Literature appeared to focus on the results of the process – i.e. the content of personal narratives to identify recurring themes of recovery such as: regaining a sense of identity (Wisdom et al., 2008, Scottish Recovery Network, 2011); agency (Holm and Severinsson, 2011); and the importance of the familial/socio/cultural context (Kalathil, 2012). Five studies on the 6-part story method (Dent-Brown, 1998, Dent-Brown and Wang, 2004), offered some explanation about the process of developing a narrative in that individuals (with a diagnosis of Borderline Personality Disorder, BPD) found the ability to use a projective story technique useful as it allowed them to distance themselves from their own experiences. Clinicians used the stories as an assessment tool. Again the focus was on the context of the narrative.

Using a mixed-methods approach, Lysaker et al. (2010) explored whether the process of developing a personal narrative was a unique contributory factor in recovery from schizophrenia or were other factors such as hope also required. There were a number of important weaknesses within the study, which the authors' acknowledged: the limitations of the methods chosen - one semi-structured interview; the sample used; and the generalisability of the findings. The authors discussed how these limitations might be overcome if the study was to be replicated. For example, the study required participants to develop a personal narrative in one 30-60 minute interview. However, Moen (2006) suggested that narratives emerge, evolve and are multi-voiced co-constructions. The authors used descriptors such as 'fullness', 'richness' and 'quality', which is questionable when so little time was spent on the process. There was no opportunity for refinement,

reflection and developing the narrative. Although, no evidence was found in the literature determining the length of time that developing a personal narrative should ideally take. Also, Lysaker et al. (2010) used a sample that was already enrolled on a wider study (developing a cognitive behavioural therapy for schizophrenia), which could suggest self-selection (with participants not necessarily right for this study) and a willingness to please the researchers. This raised the question of free will and obligation to participate. Another concern related to the participants who were mainly veterans (69% were recruited from a VA medical centre) and therefore generalisability of results to the wider population. Roe et al (2006) added that people with severe mental illness may need to construct and then tell and continue to tell the story, deepening that story, re-positioning themselves as people who can narrate their own story while making efforts to successfully engage in daily life.

### **2.3 Media and Narrative Development: A Literature Review**

This part of the literature review explored the different ways an individual could develop a personal narrative using different media (product) to provide structure to the process. The review focused on how different media were used, in what contexts, and what the benefits and problems of using them were.

#### **Search Strategy**

##### **Step 1: Search**

Using Delphis (a single interface which searches the University of Southampton's electronic and print collection [Webcat] and other academic subscription paid resources) (University of Southampton, 2014) a number of searches were conducted (Table 2.3):

- Therapeutic approaches to recovery
- How the process of developing a personal narrative supports mental health recovery
- Personal and disrupted narratives
- Mental health recovery models

**Table 2.3 Search Terms**

Initial Search	Search	Search Terms
<b>Therapeutic Approaches to Recovery</b>	<b>TCPB</b>	<b>T-therapeutic, C-recovery, P-product, B-mental health</b>
How the process of developing a personal narrative supports mental health recovery	ABCDEF	A-personal narrative, D-process, E-developing, F-support
Personal Narrative	AXYB	X-disrupted, Y-physical health
Mental Health Recovery Models	QM	Q-mental health recovery, M-model

[Tables for Search TCPB have been included in appendices for illustrative purposes].

For each search term, the on-line version of Roget's Thesaurus was used to create a list of relevant synonyms (supplementary search terms). These are shown on mind maps for each search [Appendix 2.1]. The initial search was limited to records from 1990. Subsequently, other limits (e.g. In English and Psychological and Health Journals) were added when the number of hits was excessive (for example, the initial search for Diary resulted in 29,593 hits). The number of hits and papers to be followed-up was documented on the Search Recording Sheet [Appendix 2.2]. This process was carried out for each sub-search and then collated into the Summary Literature Search Strategy [Appendix 2.3].

### **Step 2: Detailed Paper Review**

Each paper carried forward from step 1 was tabulated in the Detailed Paper Review. Papers that appeared irrelevant (limited connections to present subject and context) were eliminated at this stage (Table 2.4). This provided a detailed overview of the literature [Appendix 2.4].

**Table 2.4 Examples of Papers Included and Excluded in the Literature Review**

Examples of papers included	Examples of papers excluded
<ul style="list-style-type: none"> <li>• Journal articles <ul style="list-style-type: none"> <li>- from 1990</li> <li>- in English</li> <li>- in Psychological and Health Journals</li> </ul> </li> <li>• Key words in abstract</li> </ul>	<ul style="list-style-type: none"> <li>• Books, book reviews and unpublished theses</li> <li>• Education papers that focused on pedagogy, teaching and learning, language acquisition and impairment and assessment</li> </ul>

<ul style="list-style-type: none"> <li>- Narrative, narrative process and method</li> <li>- Storytelling</li> <li>- Recovery and recovery models</li> <li>- Mental health</li> <li>- Media (e.g. diaries, blog and storyboard</li> <li>- Oral histories etc.</li> </ul>	<ul style="list-style-type: none"> <li>• Papers focused on performance as achievement rather than 'performance as a narrative tool'</li> <li>• Papers focused on product such as dentistry sealants and technological developments</li> <li>• Clinical interventions in dentistry and physical health</li> <li>• Papers focused on diary as a method to record data (e.g. food intake)</li> </ul>
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### **Step 3: Thematic Analysis**

Of the papers chosen for follow-up, a preliminary thematic analysis was conducted, using paper 'description', 'setting' and 'key words'. The paper record numbers from step 2 were used to ensure continuity [Appendix 2.5].

### **Step 4: Papers for inclusion**

For each theme, the relevant papers from the separate searches were added together. E.g. photography and photo-journals had 22 papers. Further assessment of relevance, resulted in 10 papers being included in the final literature review [Appendix 2.6].

### **2.4 Review of the Identified Literature**

Different media (e.g. diaries, art or storyboards) could be used to provide structure to the narrative development process. How different media are used; in what contexts; the benefits and problems of using particular media and their applicability to this research were explored. Results relating specifically to mental health recovery were limited; therefore research from a variety of subject areas, disciplines and settings were analysed (Table 2.5).

**Table 2.5 Subject Areas, Disciplines and Settings of Research Papers Used**

<ul style="list-style-type: none"><li>Physical health and nutrition (chronic pain, HIV/AIDS, cancer and brain injury - use of and value of diaries)</li><li>Commercial (advertising, computer graphics - use of and value of storyboarding)</li><li>Mental health (paranoid schizophrenia, bipolar disorder, PTSD, depression)</li><li>Learning and developmental disorders</li><li>Education, professional and clinical training (nurses and teachers - use of reflective journals and their impact on practice)</li></ul>
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Papers ranged from philosophical, theoretical, technical, RCT's and varying qualitative methodologies (e.g. case study, grounded analysis and thematic analysis) with different data collection methods (e.g. interviews and diaries). There were: geographical and temporal differences; historic review and reminiscences (i.e. war veterans); and interventions offered over specified time period (i.e. single point and different stage interviews). Settings included: group psychotherapy, counselling, group care homes, education and clinics. The results are summarized in Table 2.6.

**Table 2.6: Number of Papers (Narrative, Storytelling and Product) Included in Literature Review – 198 papers in total:**

Media	Papers	Media	Papers
Art	14	Journal	11
Autoethnography/ 1 <sup>st</sup> person/life stories	26	Narrative	32
Blog	8	Photo-journal/ photography	10
Clay	2	Poetry/ performance/ creative activities	5
Conversation	3	Quilts	2
Creative Writing	3	Storyboards	15
Diary	51	Storytelling	16

There appeared to be no literature on tapestry, graphic art or presentations as ways of developing narrative. This was surprising, given that in practice service users are often asked to share their lived experience through presentations at conferences and training.

## **2.5 Emergent Themes from Literature**

From the literature review four key themes emerged:

1. Developing a more positive sense of self through the process of reframing experience
2. The importance of narrative and sharing narrative
3. The therapeutic benefits of using media within 'therapy' or just 'doing' it, e.g. phototherapy or taking photographs
4. Methodological issues and challenges relating to qualitative research and using different media to develop personal narratives.

### **1. Developing a More Positive Sense of Self**

An important aspect of recovery (Andresen et al., 2003, Slade, 2009, Leamy et al., 2011) is developing as an individual. Bell et al. (2009) suggested narrative therapy could be used to develop stories as vehicles of change. Developing and sharing a personal narrative could have therapeutic benefits such as a more positive sense of self and a growing sense that change is possible.

Reframing techniques are used in clinical interventions such as Cognitive Behaviour Therapy (CBT) (Beck, 1960s) and Solution Focused Brief Therapy (SFBT) (de Shazer and Berg, 1970s) where individuals are trained to reframe experiences without necessarily understanding why the process of reframing is important. The reframing process within the development of personal narratives could have different purposes that are relevant in recovery.

Reframing can allow sense to be made of what has, and is happening through the development of new meanings and insight – continually interpreting and reinterpreting experiences (Bruner, 1987). Integrating experience with new understanding can provide the necessary coherence and platform for further recovery. Anthony (1993) said the experience of mental illness can be catastrophic (especially in the first instance), and can often result in significant and enduring loss of sense of self. At the time, there is often little or no understanding as to why this catastrophe has occurred and how one can prevent it from happening again (Frank,

1995, Chaos Narrative). Reframing the mental illness and subsequent on-going experiences can be an important part of an individual's recovery journey. Reframing can provide an opportunity to reflect on an individual's experience of mental illness. The first stage within many recovery models characterized feelings of denial, confusion, despair and self-protected withdrawal (Andresen et al., 2003, Leamy et al., 2011).

Reframing could support the development of a more positive identity, with the growing ability of the individual to distinguish between the 'me/it' (Slade 2009) such that the illness (and the diagnosis) is not all pervasive: to develop a sense that being in crisis may be just a phase. Reframing the mental illness could also support the development of valued social roles and self-management where individuals become key agents in their own recovery (Slade, 2009). Frank (1995) and Kleinman (1988) added that people could be stuck within certain illness narratives. These factors are relevant within recovery. Reframing through narrative development could support recovery and is therefore an important aspect to explore within this study.

Moen (2006) suggested that the process of reframing within personal narrative development allowed flexibility. As narratives are essentially dialogical (Bakhtin, 1981), the narrative could differ depending on time and audience. There is no single, static or dominant narrative – human knowledge of the world is relative (Moen, 2006). An individual's knowledge and identity could evolve as new experiences and insights are added. The narrative is continually constructed and revised. Within the context of recovery, Kerr et al. (2013) suggested a meaning-making model that developing a personal narrative could be viewed as a 'transitional process' or 'transformational process' towards living a meaningful life. This view seems to be supported by other recovery models and frameworks (Leamy et al., 2011). Potentially the role and meaning of reframing may be important as a process that supports recovery.

## Acknowledging Lived Experience

*'We can write our own words, but as service users/survivors we are written about. Our lives are recorded, reinterpreted, they stagnate in official documents. Major decisions are made that may have coercive elements couched in seemingly benign language. When we feel unsafe, we don't show ourselves easily, and are often misunderstood' (Kalathil, 2012, p.6)*

Developing a personal narrative is important because it acknowledges and offers validity to lived experiences. There was evidence in the literature of individuals writing about their life, experiences, illness, recovery, key events and relationships (Deegan, 1987, 1988, Glover, 2013). Different terminology, reflected in differences in technique, intervention and product are used to describe this process (e.g. Bowers and Buchanan's (2007) Guided Autobiography and Alschuler (1997) life-stories). Whatever the approach, the underlying aims tended to be therapeutic: an exploration of emotions and self-awareness; meaning creation (Kalathil, 2012); reframing experiences; developing narrative coherence (Saavedra, 2010); and social connections (Burnell et al., 2009). Alschuler (1997) described life-stories (biography and autobiography) as healing tools for adults with mental illness. This approach encourages sharing narrative, thus potentially widening social and familial networks, although Alschuler (1997) does not provide any evidence to support this or whether the participants benefitted.

Developing a personal narrative can support the recovery of an individual's voice – the voice often silenced by the illness, oppression and discrimination (Kalathil, 2012). Narrative may help the individual to articulate the loss and trauma whilst at the same time offering an insight to others. If during the development process, there is a focus on the advantages, such as lessons learnt (in line with aspects of the 6-part story method and the Quest Narrative), then the personal narrative may become a recovery narrative. There is a sense that new maps for an individual's recovery journey may then have been constructed (Brown and Kandirikirira, 2007).

## **2. The Importance of Narrative and Sharing Narrative**

Macias (2009) suggested that sharing the narrative with others is a universal process of narrative development that can allow an individual to make meaning and provide structure to experiences. The Scottish Recovery Network Narrative Study (Scottish Recovery Network, 2011) described the importance for an individual's recovery of sharing their story.

The interplay between the narrator and listener is essential in the construction of narrative (Frank, 1998, 2000). This may be important in developing a more positive sense of self and social connections (Saavedra, 2010). For the sharing process to have real meaning - the 'voice' of the narrator is 'heard'; the audience plays a vital role too, as active, authentic listeners (Slade, 2009). Kempson and Murdock (2010) suggested developing a narrative that has a meaningful structure (e.g. when, where and with whom?) provided coherence that allowed the narrative to be more readily understood by others. Pennebaker and Seagal (1999) said making coherent sense of experiences was an important part of the psychotherapy process, concluding that writing served the function of organizing complex emotional experiences. However, their conclusions were based on three '15 minute writing sessions' over three days within a therapeutic setting. It is difficult to assess the longevity of the therapeutic benefits. The intervention was based on a writing approach that has inherent limitations. For example, there were assumptions of adequate literacy and level of English. Participants may not feel comfortable or able to express themselves in writing. This could mean that the sample was self-selecting. Cognitive functioning, including language skills could be impaired when unwell or medicated – other media such as art or photography, or using a range of media might have usefully been considered (Bartlett, 2012). It seems the medium used may have been chosen for expediency rather than for the participant's benefit. Offering a range of media may open up participation to more people.

Bruner (1984) added that individuals made sense of the narrative of others through the process of reframing it in terms of their own life experiences. This is relevant when the narrative is 'disrupted' due to illness, bereavement or other life events.

Reframing allows the individual to contextualize, and helps to develop new meanings for their mental illness experiences and their subsequent life. Reframing can provide sense to otherwise senseless experiences, and thus support recovery. Roe and Ben-Yishai (1999) added that people with severe mental illness may need to construct and then tell and continue to tell the story, deepening that story, re-positioning themselves as people who can narrate their own story while making efforts to successfully engage in daily life. The literature described the impact of mental health and disrupted narratives, particularly in relation to schizophrenia (Deegan, 1987, Deegan, 1988, Deegan, 1995, Roe and Ben-Yishai, 1999, Deegan, 2001, Lysaker et al., 2006). Other contexts were drawn upon to consider what happens to the individual's sense of self when the narrative is not coherent. Examples included: living with chronic physical illnesses such as HIV/AIDS (Baumgartner, 2001); living in difficult familial contexts (Skinner et al. (1999); and Kempson and Murdock (2010) study of adult siblings who 'storied' the psychological presence and power of a deceased infant sibling never known.

### **Use of Media: Diaries and Journals**

There was substantial research in the use of diaries in a variety of settings including: mental health adults (Dunkley et al., 2014); younger and older persons; physical health (pain, living and coping with chronic conditions (Gonzalez and Lengacher, 2007, Furness and Garrud, 2010); nutrition; as method; therapeutic uses; education (reflective uses); paper v digital uses; clinical (nurse practice); counselling; and family therapy. For this literature review, it was important to distinguish between: diary as a method to record data (e.g. food intake), which was excluded from this review; and diary as a method to discuss process and/or the therapeutic benefits of diary usage as a tool for expression. There appeared to be little evidence of diary or reflective journal use to develop personal narratives to support recovery. There was a question of the compatibility of more private media such as diaries and reflective journals being suitable for narrative development, when the important elements of sharing and co-collaboration are less likely to take place.

There is potential for diaries and journals to be used as part of the process of developing a personal narrative. For example, in providing a mechanism for integration and meaning making, journals offer potential benefits over the traditional diary (as a record of events). Bartlett (2012) added:

*'what people write in their diaries is likely to be accurate accounts of what they did and how they felt at the time. Moreover, participants using this method have the time and the space to think about what they want to express and how they want to express it' (p.1718).*

There are benefits to mental health too: space, time, reflection can all lower anxiety; and the written word can allow for rehearsal, integration of ideas and new meaning development (Lent, 2009). Stone (2006) pointed out that whilst in the midst of acute mental illness, language, reasoning and insight are often absent – therefore using the diary to record mundane aspects of day to day living are in essence 'exercises in 'voicing' and the 'beginnings of re-establishing the relationship with self and the I''. Alternatively the journal could be used after the development of the personal narrative as a way of reflecting on the process. In their study of women with depression in Finland, Laitinen and Ettorre (2007) reported intensive diary writing helped meaning-making, enhanced the therapeutic process, allowed participants to become more self-aware, become experts in their own condition and allowed their voices to become visible and visceral. A focus of the study was the possibility that depressed women could become active agents in their recovery rather than just recipients of treatment. The study was set up using time-limited, professionally-guided self-help groups based on a workbook and self-help exercises. The aim was to offer a therapeutic intervention incorporated into a daily regime in order to reduce numbers seeking psychotherapy. This could be viewed as a contradiction, given that the groups were professionally led.

There were also concerns about the suitability of diary as method. The authors concluded being literate was not sufficient for all participants to engage with diary writing. Less than 50% completed the diary. Equally concerning was the fact that the researchers kept the diaries and offered photocopies to participants if required. This calls into question ownership of the material and issues around self-worth

when participants are offered photocopies of their own work. These were important points for consideration in the narrative workshop development of phase 3. Given these concerns, the focus of their study resonates with this current research. There is an underlying assumption in the research question that the development of a personal narrative is an active choice and a choice that might support their recovery.

### **Digital Stories**

Digital stories are powerful, personal, multimedia (combining meaningful audio, images, music and video) mechanisms for developing and sharing personal narrative (Rossiter and Garcia, 2010). They can be used as part of an individual's recovery process and as a teaching tool for clinicians, service users and conference delegates. The process is creative and allows the individual to look at things through a different lens – which can allow for new connections to be made. Choices continually need to be made about what to include and to exclude (this is true of all narrative development and will be dependent on the potential audience). Digital stories are tools that can allow a more anonymous voice that is once removed from the author. However, digital stories take time to develop, need I.T. equipment and a degree of skill and an audience to share with. They also tend to be more of a snapshot, rather than an emerging and evolving narrative.

### **Storyboards**

Following on from Lahad (1992), subsequent research with 6PSM used projected story development as a tool to assess pessimism and coping strategies for individuals diagnosed with Borderline Personality Disorder (Dent-Brown, 1998, Dent-Brown and Wang, 2004). The 6PSM has been used as an assessment tool, with a 'professional' giving step-by-step instruction. There could be an issue of generalizability. Lahad developed the tool in Israel (within a continually troubled context) and Dent-Brown used it with a particular group. This does not necessarily preclude its use with other client groups. The value is the storyboard technique and the projective story elements, so there is possible applicability for this research. Developing a personal narrative could be overwhelming on different levels. The enormity of the task could mean there is difficulty in knowing where to start and

what to include. An important issue will be how to support the possible emotional response whilst developing a personal narrative. Using the 6PSM tool to develop a projected story allows distance to be created between the story offered and what it may represent. Potentially, projected story techniques could allow the individual to work at their own pace, which is important in the context of this research.

The use of storyboard techniques has a number of advantages, especially when working with individuals (with impaired language and cognitive skills). Developing a storyboard involves: sequencing 'key frames in temporal order' - important in developing coherence within the narrative; a visual format (Davis, 2004, Lien and Chen, 2013); framing; storytelling; and compression of ideas in a universally understood language. A storyboard can be used as a planning tool that helps to organise ideas in order to make the whole process less overwhelming. Using a storyboard also allows rehearsal and refinement. Mullet et al. (2013) (an adult learner within a narrative psychology and critical theory perspective) added that stories allow the individual to reinterpret, reframe, retell experiences and thus develop new perspectives.

### **Blogging**

Personal narrative has been a fundamental tenet of the modern self-help movement (Sommer, 2003). Narratives are relational, purposeful and constructed within cultural conventions and help the individual to locate themselves within their world (Jones, 1999). There is growing use of the therapeutic or personal blog (a combination of Web and log) as a space to write, reflect and to share issues (Burnell et al., 2009, Bronken et al., 2012). Thompson (2012) examined a number of on-line blogging communities (organised around specific mental health issues e.g. schizophrenia or depression) hosted by a commercial organisation ([www.healthyplace.com](http://www.healthyplace.com), 2015). Thompson concluded writing a blog allowed individuals to make sense of wellness, their disorder and to gain a sense of self-identity. She added that blogging helped to influence how individuals utilised their expert knowledge and engagement in self-care.

There were concerns relating to Thompson's study including the setting.

[HealthyPlace.com](http://HealthyPlace.com) is a commercial American site (whose primary aim is to sell products). There were issues with the veracity of information and those posting within blogs, in particular the objectivity of the blogger. The study was based on a review of 28 home page introductions (non-interactive biographical information), which the site used as entrance tests to confirm legitimacy (the right to blog on the site). The blogs themselves were not analysed. Essentially Thompson appeared to base her conclusions about the therapeutic value of blogging on introductions rather than the content and the issues raised within the blog. There were issues regarding confidentiality and the repercussions of when information is shared. This is relevant when the blog is deeply personal. Unlike journal or diary writing, blogging can be interactive. This might not always be complimentary and could have negative psychological effects, although Thompson (2012) added that maintaining an open blog (which allowed for responses), significantly improved adolescents social-emotional difficulties. Likewise, there could also be psychological and emotional consequences for the reader of a blog. Thompson's (2012) analytical tone caused concern. It seemed to be less objective, which resulted in a lack of confidence with the study. For example, 'Phil' talked about writing authentically and then wrote in the third person. Thompson suggested that Phil '*undermines his own promise of authenticity through this classic narrative tool that creates distance from the self*' (p.100).

### **Performance**

Performance/dance/drama can also be used to develop a narrative – a physical embodiment of the story (Ellis, 2004). Yonge (2005) added a spiritual dimension to the aforementioned therapeutic benefits of those who have experienced trauma. Service user voices were facilitated through a variety of media - music, storytelling, writing, theatre and dance, promoting inclusivity. 'Cardboard Citizens' (cardboardcitizens.org.uk, 2015) uses a 'forum-theatre' approach (performance used to showcase 'difficult to talk about' subject matter such as stigma and psychosis). There is on-going research of the efficacy of Forum Theatre. The benefits of performance could also be relevant in other settings such as: physical health -

drama and breast cancer (Mattsson-Lidsle et al., 2007) and prison populations (Williams and Taylor, 2004).

### **Creative Writing - Value of Creating Distance in Narrative**

King et al. (2012) described the use of crafted writing as a: diversionary tool, as a 'window into the unconscious', allowing creativity, working with metaphor and imagery and as an alternative means of communication. Creative writing can be prose or poetry, fictional (therapeutic story) or non-fictional (autoethnographic, life story, etc.). Literature suggested that creative acts such as writing have significant psychological, emotional and social benefits - specifically how depends on each individual (Pert, 2013).

Metaphors are pervasive in everyday language and interactions (Mills and Crowley, 1986). Parker and Wampler (2006) concluded that negative effect and feelings were reduced through use of metaphor – although the control group (given psychoeducational information rather than a story) had a similar positive effect. Rubin (2009) used heroic mythology to develop projected stories in a counselling setting. Scofield, (2005) used therapeutic storytelling to work through his own emotional difficulties whilst practicing as a counsellor. Developing or reading a story through metaphor (therapeutic storytelling or projective storytelling), could be a useful method of creating a personal narrative as this technique can create a distance that some may find helpful in working through difficult emotions and trauma.

### **3. The therapeutic benefits of using media within 'therapy' or just 'doing' it**

Creative therapeutic intervention (such as art therapy or poetry writing) involves the individual being with others within a designated therapeutic space guided by a professional who often determines what is created (the product). Creative therapeutic intervention may be both process and product creation. This study is focused on the process of developing a product – a personal narrative.

#### **Art**

The literature emphasised developing the narrative within a therapeutic environment. This seemed consistent across all media reviewed. For example, the

literature explained 'art therapy' as a methodology (Riley, 2009, Schaverien, 2011); as a treatment for trauma (Glaister, 2000) and other psychiatric disorders, such as schizophrenia, mood disorders (Richardson et al., 2007, Caddy et al., 2012) and addictions (Siporin, 2010). In order to provide outcome-based evidence there were attempts to quantify the therapeutic value of using art and other creative art therapies (Caddy et al., 2012). They concluded that creative activity had therapeutic value - benefits being self-esteem, self-worth and self-efficacy (Heenan, 2007, Stickley et al., 2007); acts as a distraction (Reynolds, 2000, Bedding and Sadio, 2008); and can be structured time with purpose (Mee and Sumsion, 2001).

### **Poetry**

McArdle and Byrt (2001) and Gustavson (2000) outlined the role and efficacy of poetry therapy. Tolton (2004) described the effects of writing poetry as; gaining understanding of self and others through development of new meaning; develop self-expression and self-esteem and as an outlet for strong emotion - the goals of poetry therapy developed by the National Association for Poetry Therapy ([www.poetrytherapy.org](http://www.poetrytherapy.org)). Poetry can have the advantage of brevity. Linstrom (2009) used poetry therapy with counselling students to support academic and therapeutic goals. She did not report on how she introduced poetry to the students, what the results or benefits were or how it impacted on student practice. As art, many people would feel uncomfortable about using poetry because they believe that they are no good at it.

### **Photography**

Photography can be similarly used as phototherapy (Stewart, 1979) - 'doing' photography as self-expression which can provide a safe, non-verbal way to deal with difficult emotions. Phototherapy is used for different therapeutic purposes, such as: viewing photographs from different view-points (Broom, 2009); and re-enactment phototherapy - importance of embodiment and transformation (Mind, 2013b, Scottish Recovery Network, 2013). Prag and Vogel (2013) suggested that therapeutic photography had the ability to transcend culture and language differences. Research on the efficacy of phototherapy was limited (Glover-Graf and Miller, 2006). In an exploratory paper, DeCoster and Dickerson (2014) systematically

identified 23 evidence-based best practice interventions using photography in mental health social work practice (typically case-studies or single group design evaluations). All reported practical or theoretically significant psychosocial improvements.

There is also some evidence within the literature of: personal therapeutic photography (Jo Spence's camera therapy, (Dennett, 2009, Dennett, 2011, Dennett, 2013); participants taking photographs that are then used in a variety of ways; 'photo-elicitation (Gauntlett and Holzwarth, 2006, Hodgetts et al., 2007); photo-voice – what's the story behind the photo? (Gauntlett and Holzwarth, 2006); and as a tool for social action, within marginalised groups (Cabassa et al., 2013).

Photography could be used as a visual tool to support narrative development. Erdner and Magnusson (2011) described photography as a method of data collection for people with long-term mental illness to document their 'life worlds'. They suggested that photographs were powerful in themselves. There is less need for language because photography can transcend the need for verbal explanations (Glover-Graf and Miller, 2006 - substance misuse). Photographs can access emotions that might be unreachable when using language alone, which is potentially true when people are acutely unwell. Photographs also allow distance. Photographs can act as sounding boards (like storyboards). An advantage that photography could have over artwork is that many people believe that they have little or no art skill. Taking a photo seems more achievable. Bartlett (2012) wanted to engage participants (with dementia) in a meaningful way, thus offered a modified diary interview method that included audio and photographic input. By allowing the participants to choose a medium that they were more comfortable with could result in richer results and a lower drop-out rate (referencing Laitinen and Ettorre, 2007- less than 50% diary completion rate).

#### **4. Methodological Issues and Challenges in Utilizing a Narrative or Storytelling Approach**

##### **General Issues with Recovery Research**

There were two important general issues relating to the literature review that were highlighted by the Lysaker et al. (2010) study. Firstly there appeared to be an over-reliance on exploring schizophrenia and using participants with schizophrenia at the expense of other mental health conditions. One can be left with a skewed view of mental health and an unclear view of the validity and generalizability of results. Secondly, different philosophical and theoretical paradigms were used to support hypotheses and research questions, which do not fit into what is actually being explored or described (i.e. quantifying a qualitative process). Lysaker et al. (2010) used correlations and regressions to statistically support their hypothesis, yet when one considers the fundamental weakness of developing a narrative in a short one-off interview and the potentially biased sample of mainly male veterans it is difficult to have confidence in their conclusions.

##### **Reliability, Validity and Generalizability:**

The broad brushstroke of literature within this review required significant synthesis of different theories, ideas, practices and outcomes across different philosophical and theoretical paradigms, contexts and settings, in order to determine what was relevant to this research question. There was the further challenge of terminology inconsistency, i.e. using different terms to mean similar things. Leckey (2011) raised the difficulty with measurement of outcomes when the terminology of what was being measured was itself unclear and nebulous. As a result, there were issues regarding reliability, validity and generalizability. In a systematic literature review of the therapeutic effectiveness of creative activities on mental well-being (11 studies), Leckey (2011) concluded that there were reported psychological benefits including improved social networks, but there was little evidence and little commonality between the studies to enable generalisations.

Caddy et al. (2012) concluded that despite the evidence of the benefits of creative arts, much of the research was based on small-scale, qualitative, community based

research studies. They suggested also that quantitative research in the in-patient setting was lacking and most empirical trials of art therapy shared a number of methodological weaknesses. For example in their exploratory RCT of art therapy as an adjunctive treatment in schizophrenia, Richardson et al. (2007) reported that art therapy had a statistically significant positive effect on negative symptoms (Scale for the Assessment of Negative Symptoms), but concluded that the study was underpowered and had a sub-optimal level of treatment, so judged the results as inconclusive.

There were concerns about approaches that used writing (e.g. creative writing, projective stories, diaries, journals and blogs). Literacy skills are not always developed and/or stable in people who are learning disabled, non-native speakers, children, in dementia and acute mental illness phases. Some papers measured the level of literacy as an inclusion requirement (Lysaker et al., 2010) but this, itself, is exclusive. In a study of Alzheimer's caregivers, Valimaki et al. (2007) raised concerns about the consistency, content and qualities of diary entries even though participants reported on therapeutic and pleasurable benefits of writing the diaries. This raises the issue of explicit and implicit assumptions of how researchers expect participants to use chosen media within their studies.

### **Who owns the products Created in Therapy?**

When an individual is engaged in 'therapy', the product (e.g. art, along with the therapist notes) generally are added to the unseen case notes. This raises the issue of ownership, and therefore the ultimate value of the individual's work. If an important element of developing a personal narrative is the ability to reflect, rehearse and reframe experiences so as to develop new meanings, then having access to the work (e.g. art, stories or storyboards) is important. If an individual's work is held in inaccessible case-notes, or only available at certain times (perhaps at the end of the therapeutic intervention), then the value of the work could be minimized and many of the therapeutic benefits lost.

When an individual is particularly unwell, therapists could provide additional support by co-creating (as in stories) or producing the narrative themselves ((ICU diary studies (Egerod et al., 2007, Roulin et al., 2007, Jones, 2009, Egerod and Christensen, 2009, Egerod and Christensen, 2010, Gjengedal et al., 2010)).

Ownership of material as well as a consideration of whose reality the narrative represents is a relevant concern. However, during acute illness phases, it is likely that little material could be produced without the additional support of the therapist/nurse/peer worker. Within the literature, the diary intervention (e.g. diaries written by ICU staff to support patients in their recovery) appeared to be absent in mental health but could be useful (when a service user is acutely unwell, psychotic, heavily sedated etc.) to support reframing, communication and familial understanding.

## **2.6 The Process of Developing a Personal Narrative**

This literature review highlighted the importance of not being too prescriptive in media choice, considering how individuals develop their personal narrative and the importance of fitting the media to the participants rather than the participants to the media (Valimaki et al., 2007, Sargeant and Gross, 2011). The review also highlighted the possibility that the choice of media in itself could affect the process of developing the personal narrative (Table 2.7). As a result, the method of creating a personal narrative was further considered in the phase 2 and 3 focus groups.

**Table 2.7: Factors to Consider in Choosing and Using a Medium to Develop a Personal Narrative**

Factor	Comment
• Is literacy required?	<ul style="list-style-type: none"> <li>Diaries, journals, blogging and poetry assume literacy and confidence with working with written word.</li> </ul>
• Level of cognitive function or impairment	<ul style="list-style-type: none"> <li>When unwell, many service users have difficulty with concentration, coherence, sequencing and temporal ordering. Media that allows rehearsal, refinement and reflection (such as storyboards and journals) can be useful.</li> <li>A visual format may be useful to help planning, framing (Davis, 2004, Lien and Chen, 2013), organising ideas</li> <li>A visual format could provide further memory triggers, new perspectives and new meanings (Mullet et al., 2013).</li> <li>Media such as photography can produce instant results.</li> <li>Can seem less overwhelming.</li> </ul>
• Public or private	<ul style="list-style-type: none"> <li>Blogs and presentations are particularly public and can result in unfavourable feedback. Blogging sites can have a limited safety net, if not properly administered.</li> <li>Being heard can be therapeutic and help to break down stigma and develop a better understanding and empathy in others.</li> </ul>
• Creating distance	<ul style="list-style-type: none"> <li>Especially at the start of the process, service users may need a degree of distance from what they are producing (working with metaphor, creative writing, storyboards and photography could be used in this way)</li> </ul>
• Confidence and interest in using media and technology	<ul style="list-style-type: none"> <li>Many service users believe that they have no skill or have had previous bad experiences with media such as poetry, photography and art, as a result could be fearful of using it.</li> <li>Trying something new, may be useful in accessing difficult material or opening it up to new meanings</li> </ul>
• Time, cost and access to equipment	<ul style="list-style-type: none"> <li>Important logistical considerations</li> </ul>

## 2.7 Chapter Summary

Slade (2009) suggested that recovery is understood from a constructivist perspective and that narrative is fundamental to the human experience. In this chapter, a detailed overview and critique of narrative was provided as background to the study as a whole. In particular, the concept of narrative truth (Bruner, 1987, Craib, 2003)

and illness narrative theory were discussed as linking narrative theory to the present study's exploration of developing narrative to potentially support recovery.

Kleinman's (1988) illness identity and Frank's (1995) different types of illness narrative (especially Testimony narratives) appeared to be particularly relevant. In relation to this narrative overview the potential benefits of narrative development for recovery were explored.

The narrative overview gave context to the literature review which focused on the different ways an individual could develop a personal narrative using different media (e.g. storyboards, journals, photography and performance) to provide structure to the process of developing a narrative. The review focused on: how different media were used; in what contexts; and the benefits and problems of using them (summarized in Table 2.5). Key themes emerged from the literature review, which highlighted the value of narrative development in terms of the importance of reframing lived experience in order to develop a more positive identity and importance of sharing narrative and being heard. The literature review highlighted issues such as the balance between the therapeutic benefits of using media within therapy and just 'doing it' - process or product (possibly the difference between structured narrative therapy or an individual keeping a journal, painting or blogging). The issue of ownership of narrative content was also raised within this context too (within a therapeutic setting, the content tends to remain with the professional). The review highlighted a number of methodological issues and challenges relating to qualitative research related to using different media to develop personal narratives (Lysaker et al., 2010, Leckey, 2011, Caddy et al., 2012, Thompson, 2012).

As an exploration of the process of developing a personal narrative and the contribution to recovery, this study seeks to consider whether this process supports the reconstruction of self and how the process of narrating, reframing and possibly retelling supports an individual's sense-making of their life and mental health experiences. The extent to which this can be used as a positive and empowering exercise, which in itself supports the journey of recovery is also explored. In Chapter 3 the methodological approach including the three research phases and

methodologies used within this study (Autoethnography and Participatory Action Research using focus groups) is outlined and discussed.



## CHAPTER 3: METHODOLOGY

### 3.1 Introduction

This study aimed to explore the process of developing a personal narrative in order to utilise this knowledge and understanding to develop a personal narrative workshop programme. Given the research question and the aims and objectives, an overview of the study design (the three study phases) is clearly outlined. A narrative approach was used as the over-arching methodology for this study. Drawing on elements from different narrative research approaches (such as narrative content, uses, dialogic relationships and environment), this chapter examines in detail the methodologies used to carry out this study: autoethnography (phase 1) and participatory action research (PAR) using focus groups (phases 2 and 3). Ethical considerations, which underpinned the study design, such as working with vulnerable co-researchers, complete this chapter.

Whilst, the methodology of this study clearly falls within qualitative research, autoethnography is not currently mainstream.

### 3.2 Research Question

**What does the process of developing a personal narrative involve and how does it contribute to mental health recovery?**

### 3.3 Study Aims and Objectives

In light of the literature review (chapter 2) and the research question, the core study aims and objectives were:

#### Box 3.1 Core Study Aims

1. Develop and analyse my mental health autoethnography
2. Explore the experience of service users who have already developed a personal narrative.
3. Explore the contribution that developing a personal narrative has made to their mental health recovery.
4. Utilise the resultant evidence to develop a personal narrative workshop programme, with the aim of supporting other mental health services users to develop a personal narrative.

**Box 3.2 Core Study Objectives**

1. Using an autoethnographical approach, produce my personal narrative and carry out a thematic analysis (Phase 1) (Braun and Clarke, 2006).
2. Set up and run 2 focus groups using a Participatory Action Approach to explore the experiences of mental health service users who have already developed a personal narrative (Phase 2).
3. Undertake a thematic analysis of the evidence collected in the focus groups (Phase 2) (Braun and Clarke, 2006).
4. Use the knowledge and understanding gained to develop a personal narrative workshop programme (Phase 3).
5. Set up and run 1 focus group (from co-researchers in the Phase 2 focus groups) using a Participatory Action Approach to support the development of a personal narrative workshop programme (Phase 3).

**Box 3.3 Supplementary Questions and Topics of Interest**

In order to explore the process of developing a personal narrative and its contribution to mental health recovery, the following questions and topics were addressed:

1. The Individual's experience of developing a personal narrative.
2. Whether developing a personal narrative contributed towards their mental health recovery?
3. If so, in what ways did it contributed to their recovery? (Explore both positive and negative aspects)
4. What media were used (i.e. storyboards, photography, presentation etc.) when developing their personal narrative?
5. What role did the media have in the development of the content and meaning of their personal narrative?

It is expected that the trialling and implementation of the personal narrative workshops and the subsequent development of a personal narrative framework will continue post doctorate.

**Box 3.4 Possible Post-Doctoral Research Objectives****Post-doctoral objectives:**

1. Pilot a personal narrative workshop.
2. Set up and run a series of developing personal narrative workshops.
3. Use semi-structured interviews to reflect on the experiences of the process of developing a personal narrative with workshop participants.
4. Develop self-help and/or peer supported Personal Narrative Framework, which can be used by an individual to develop a personal narrative.

### **3.4 Methodological Approach**

#### **Research Paradigm and Perspectives**

A narrative inquiry perspective was used as the over-arching methodology for this study. Polkinghorne (1988) stated ‘the narrative is regarded as the primary scheme by which human existence is rendered meaningful’ (p.1). Essentially, narrative research is concerned with the meaning that is developed and attached to the narratives told (Moen, 2006). Chase (2013) noted that, as a methodology, narrative inquiry was ‘still a field in the making’. Chase (2013) suggested ‘it is easier to identify complexities and multiplicities in the field of narrative inquiry than it is to identify commonalities’ (pp. 73-4).

As a term, narrative inquiry may be used to describe multiple approaches to carrying out research involving narrative. Research could focus on what the narratives are about - the content, plot and characters of the lived experience, for example using storyboards and the 6PSM method (Lahad, 1992, Dent-Brown, 1998, Dent-Brown and Wang, 2004). Within this ‘story and the life’ narrative approach, research may be used to support individuals to focus on their identity development so that there may be less reliance on their illness persona (Kleinman, 1988) or to help improve their lives (perhaps through access to narrative therapy (White, 2014). Another strand of narrative inquiry research has focused on using narrative as a vehicle for social action (Riessman, 2008). Chase (2013) suggested sharing the narrative with others (both speaking and being heard) was crucial. Also, individual narratives could be used as a counter to preferred cultural and societal discourse – the little story not being lost to the big story (Chase, 2013). For example, Jo Spence’s camera therapy portrayal of her breast cancer countered the prevailing medical model rhetoric (Bell, 2002, Riessman, 2008, Dennett, 2009, Dennett, 2011, Dennett, 2013). A further approach within narrative inquiry research has focused on narrative practices – how the dialogic interplay (Bakhtin, 1981, Riessman, 2008) and the specific environments and audiences can influence the narrative of individuals – what can be said and left unsaid (Chase, 2013). Another narrative approach allows the researcher to be a part of the research either as an acknowledgment of similar life experiences shared with

participants (Behar, 1996) or central to the research itself - as in autoethnography (Deegan, 1988, Ellis, 2009, Coleman, 2011, Clarke, 2015).

It appears that there is no unique way to carry out research using a narrative inquiry perspective (Chase, 2013). The key is deciding what might be the best research approach that allows the research question to be explored. Within this study, given the intention that the research process and strategy be emergent and formative (hence the different phases of the study), drawing upon aspects of the different narrative approaches (described above) was crucial. Given that the research involved an exploration of the process of developing a personal narrative, it was likely that aspects such as: what narratives contained; how they might be used; the effect of dialogic relationship and environment; and my role as an insider researcher might emerge. This then informed the specific methodology used in the phases (Phase 1 - Autoethnography and Phases 2 and 3 - Participatory Action Research using focus groups). The rationale for these methodologies is discussed in detail later in the chapter.

Given the underlying pragmatism (Chase, 2013) used in this study design, an interpretative bricoleur approach (Denzin and Lincoln, 2013a) was then used to interpret the emergent data. The subject matter of this study was not readily located within one paradigm. This bricoleur position (Denzin and Lincoln, 2013a), acknowledged the interdisciplinary and interactive process which underpinned this study (economic, social, geographic, political, cultural and mental health factors were relevant). A thematic approach (Riessman, 2008) which drew on different paradigms such as Post Modern, Constructivist and Feminist (Denzin and Lincoln, 2013b) was used to analyse the narrative in each phase.

The post-modern paradigm reflected the sense that there are many different ways of knowing and that no one way should be privileged (Wall, 2006). This concurred with the sense that narrative truth should be dependent on rightness, of how one felt or what was intended and on coverage (Bruner, 1987). The literature suggested that narratives are social constructions dependent on the telling and retelling to

others. This view is reinforced by the multiple ways of carrying out research within the narrative inquiry approach. Focussing on mental health raised feminist issues such as: power and power imbalances (doctor and service user) and the dialogic relationship. For example, speaker and listener could collaborate or struggle for control over narrative meaning. Additionally, the importance of lived experience in this study (and as a reaction to the dominant medical model narrative and evidence-based therapy provision), situatedness and reflexivity of the post-modern paradigm (Flick, 2009) were also important. Finally, it is necessary to acknowledge my role as researcher. As a mental health service user, an insider perspective was taken.

### **Phases and Methodologies of this Study**

To understand the process involved in developing a personal narrative, an autoethnography and participatory action research (focus groups) was undertaken. Figure 3.1 provides an overview of this study.

**Figure 3.1 Phases and Methodologies used in this study**



### **The Study Phases**

The understanding of the factors involved in the process of developing a personal narrative gained from carrying out the autoethnography (Phase 1) informed how the focus groups were carried out (Phase 2). The emerging analysis and reflection of the

autoethnography and the focus groups informed the development of the workshop programme (Phase 3).

### **Box 3.5 The Phases of the Study**

#### **Phase 1: Autoethnography**

Produced and thematically analysed my own mental health recovery narratives 'From the Edge of the Abyss to the Foot of the Rainbow'.

#### **Phase 2: Focus Groups using Participatory Action Research**

Examined the experiences of mental health service users:

- Drawn from one NHS mental health Trust (within the county of Hampshire, UK, but excluding Portsmouth) who had previously developed their personal narratives, through service user involvement-training programmes.
- Other Service Users who have developed their personal narratives in other forums such as: a Recovery College, peer training programmes and other peer networks.

#### **Phase 3: Focus Group using Participatory Action Research**

Developed a workshop programme (using Participatory Action Research) that will be used to support mental health service users to develop their personal narratives.

It is hoped that the workshop pilot (Phase 4), the workshop delivery and individual participant reflections (Phase 5) and the further development of the Personal Narrative Framework (Phase 6) will be carried out as post-doctoral research.

### **Box 3.6 Possible Post-Doctorate Research**

#### **Phase 4: Piloting and subsequent running of workshops**

#### **Phase 5: Reflective Interviews**

Reflect on the experiences of the process of developing a personal narrative with the workshop participants.

#### **Phase 6: Further develop the Personal Narrative Framework**

A peer supported framework, which can be used by an individual to develop a personal narrative.

### 3.5 Phase 1 Autoethnography as Methodology

*'Autoethnography is an approach to research and writing that seeks to describe and systematically analyse (graphy) personal experience (auto) in order to understand cultural experience (ethno)' (Ellis et al., 2011, p.1).*

Ellis et al, (2011. p.2) suggested that 'as a method, autoethnography combines characteristics of autobiography and ethnography'. Autoethnography implies that a narrative is being used for a purpose beyond simply telling a story. In autoethnography, there is a significant element of reflection and reviewing lived experience: using hindsight; 'epiphanies' or times of 'existential crises' (Ellis, 2009). The process of autoethnography contextualises personal experiences within existing cultural practices and shared experiences. This may support better understanding for both insiders (cultural members) and outsiders (cultural strangers) (Ellis et al., 2011). This could result in making personal and social change possible for more people.

As a methodology, autoethnography is embedded in post-modern philosophy and is linked to the growing debate about reflexivity and voice in social research (Wall, 2006). As a method of inquiry, it is both a process and a product, which challenges the 'ontological, epistemological, and axiological limitations' of traditional social science research (Ellis and Bochner, 2000, Ellis, 2009). Criticisms of autoethnography appear to largely follow from its unwillingness to follow traditional social science research conventions e.g. there are concerns about the lack of fieldwork, sample size and not using any control group (Fine, 2003, Delamont, 2009). For example, critics have suggested that theoretical and analytical rigour is less important than emotional descriptions and 'therapeutic "naval-gazing" (Madison, 2006 cited in Ellis et al, 2011, p.8). All are criticisms reflected from a more traditional qualitative methodological lens which autoethnography does not lay claim to. Wall (2006) considered whether 'autoethnography is less of a method and more of a philosophy, theoretical underpinning, or paradigm, aimed at restoring and acknowledging the presence of the researcher/author in research, the validity of personal knowing, and the social and scientific value of the pursuit of personal questions'.

Denzin & Lincoln acknowledged a 'crisis of representation' in a number of publications from the mid 1980s, which questioned traditional scientific research. They suggested that 'the studied world can be captured only from the perspective of the researcher' (Denzin and Lincoln, 1994). Advocates of autoethnography 'take a different point of view towards the subject matter of social science' (Ellis et al., 2011 p.8) in terms of: the role of the researcher; the reasons for the research; and the presentation and analysis of research material. The traditional role of the objective researcher is questioned because the researcher is located within a particular cultural and research paradigm, which can influence the research and analysis. In autoethnography, the researcher acknowledges the impact that they have on research: becoming part of the research so that the output of the research becomes one of shared meanings. The researcher may become the witness (Ellis, 2009). Within the rejection of traditional social science methodology there is a political dimension of the role of the researcher as an exploiter (Ellis, 2007 , 2011). For example, the participants may be used to achieve the researcher's study objectives and may not accrue any benefits from the research themselves. This may to a degree be neutralised if the researcher is a part of the culture that is being studied and remains within the culture after the research is completed.

Bochner (1994) suggested that value-laden stories, not theories are central in autoethnography. As a consequence, Ellis et al (2011, p.1) said that universal truths and generalisations are not only impossible but also not relevant. Autoethnography as method emphasises the production of meaningful, accessible and evocative research from lived experience (e.g. mental illness). It introduces unique ways of thinking and feeling (Adams, 2008). Autoethnography may be viewed as a feminist methodology in that it is concerned for others (Ellis, 2009). For example, autoethnography offers voice to traditionally silenced and marginal groups, thus presenting a political dimension (Ellis, 2004, Ellis et al., 2011). It can challenge traditional power dynamics and threaten the status quo. Authors such as Deegan (1987, 1988, 1995, 2001) and Glover (2013) have used autoethnography to effect change in mental health provision and policy.

### **Benefits and Challenges of Autoethnography as Methodology**

Autoethnography aims to create a 'reciprocal relationship' with its audience because it is the audience's response that gives the work legitimacy (Denzin, 2014). The dialogue between narrator, narrative and audience is crucial (Ellis, 2009). This reflects the biggest challenge to autoethnography as method. Positivist terms such as reliability, validity and generalizability are replaced by verisimilitude (trustworthiness and credibility) (Ellis et al, 2011). Bruner (1987) suggested the external and internal criteria for narrative validity should lie with a sense of rightness, of how one felt or what one intended and of coverage – verisimilitude. Craib's (2003) view of narratives of bad faith countered this, by suggesting, not all narratives are trustworthy. It is up to the individual to determine the verisimilitude, the narrative truth and therefore legitimacy of a narrative – what does the narrative mean to them? Generalization is important in as much as the autoethnographer can use personal experience to illuminate (general) unfamiliar cultural processes (Ellis and Ellingson, 2000, Ellis et al., 2011).

### **Why Autoethnography for this Study?**

To explore the contribution that the process of developing a personal narrative could have to an individual's mental health recovery, the starting point was my own personal narrative. In my autoethnography:

*'I am both the author and focus of the story, the one who tells and the one who experiences, the observer and the observed, the creator and the created' (Ellis, 2009, p.13)*

To add context, I located my lived experience of mental health recovery within a cultural, social and political setting (Chapter 4). I hoped that my autoethnography would offer readers an insight into my world 'to use what they learn there to reflect on, understand, and cope with their own lives' (Ellis, 2004 p.46).

Autoethnography as a methodology, offers thick descriptions (Geertz, 1973), reflexivity, elements of vulnerability, equity, social justice and transferability. Writing my personal narrative, giving voice to my 'often silenced and secret' experiences and making public my private voice forms the basis for the work in the focus groups phases (two and three) of this study.

### **3.6 Phases 2 and 3: Participatory Action Research as Methodology**

The themes emerged from phase 1, informed the focus group discussion material in phase 2. This, in turn, informed phase 3 focus group work. The methodology of Participatory Action Research (Ie May and Lathlean, 2001) was used to conduct the focus groups in phases 2 and 3.

#### **Participatory Action Research as Methodology**

Participatory Action Research (PAR) as a methodology is not easily defined. Ie May and Lathlean (2001) suggested a number of possibilities: a research design (experimental); a method for generating new data; a management or development tool (organisational); and as a mechanism for empowerment. Each is located within a different theoretical perspective on society. Meyer (2000) wrote that PAR was particularly suited to identifying and developing potential solutions to problems. As a process, it brings together action and reflection, theory and practice in continuous cycles until the study is completed. PAR represents emergent research design and knowledge; working with practical issues; participation and democracy (Meyer, 2010).

The role of the researcher and focus group facilitator is important in PAR (Meyer, 2010). The researcher describes the problem (e.g. reaction to evidence-based one-size fits all medical model mental health recovery) and area of focus (developing a personal narrative). A research question and possible supplementary research questions are developed. From this point, the focus groups are central. With the facilitation of the researcher, the focus groups co-produce ideas and themes (that will inform the personal narrative workshop development in phase 3 of the study).

#### **Benefits and Challenges of PAR as Methodology**

Participants are co-researchers in PAR. The group can become key agents of change (Meyer, 2010). The group determines the focus of the work and data generated is co-produced. This can go part way to addressing issues of powerlessness and lack of control as it encourages a more democratic process (Winter and Munn-Giddings, 2001). As a process it is dialogic and multi-voiced (Denzin and Lincoln, 2013b) and as such group dynamics, (including potentially dominant voices) and the role of the

focus group facilitator (with its inherent power concerns) should be monitored through self-reflection (Meyer, 2010). Group work and group dynamics have the benefit of being generative. Often the group can be greater than the sum of its parts. The potential shared experience, possible collaboration and group reflection within the focus groups, may all add to the richness of the emergent data. From a position of situatedness (the focus groups included service users who had developed personal narratives), focus groups have the potential to generate new meanings and understanding through the process of debate and discussion (le May and Lathlean, 2001). Focus groups also have the potential of supporting less-vocal members to gain confidence and to gain a voice.

As well as the possible ethical challenges, there are other challenges associated with PAR because it can require more input from co-researchers throughout the research cycles. Studies could be stopped prematurely and/or sabotaged because of changes to co-researcher attendance or involvement (co-researcher joiners and dropouts). There could be further challenges regarding lack of resources (including time commitment and money). The focus groups within this study were time-limited. For phase 2, the two focus groups met once, so this mitigated these potential issues. In phase 3, the focus group met three times over three months. Attendance varied (Table 6.1), but co-researchers were able to participate through reading transcripts and offering comments via email. As a self-funded project, the co-researchers were asked to offer their time freely. However, it was hoped that the co-researchers would benefit in other ways from taking part in this study. Out of pocket expenses was offered but rarely accepted with co-researchers stating that they were happy to take part because the study was important to them and that they felt that they were giving something back.

As with autoethnography, verisimilitude was used to judge the validity of data generated in PAR. le May and Lathlean (2001) added that it was important to judge the potential of a study by using the following criteria:

**Box 3.7: Criteria to Judge the Potential of an Action Research Study (Ie May and Lathlean, 2001)**

- How can I use these findings within my clinical practice?
- What benefits will the implementation of findings have on stakeholders?
- What are the risks of implementing findings?
- What are the risks of not implementing findings?
- What are the opportunities and constraints of implementation?

**Focus Groups**

*'The purpose of a focus group is an in-depth, open ended discussion that explores a specific set of issues on a predefined topic' (Goodman and Evans, 2010)*

Some of the benefits and challenges with focus groups have been highlighted in Table 3.1.

**Table 3.1: A Summary Table: Advantages and Disadvantages of Focus Groups as Method (Goodman and Evans, 2010)**

Potential Advantages	Potential Disadvantages
<ul style="list-style-type: none"><li>• Can identify complex problems and area for further work – Exploratory</li><li>• Co-researchers can respond to findings and offer alternative explanations - Illuminatory</li><li>• Generative – develop new meanings</li><li>• Does not assume any degree of literacy</li><li>• Safety in being part of a group</li><li>• Co-researchers can modify own ideas and views in light of group discussion</li><li>• Good for discussion difficult topics such as mental health</li><li>• Synergy of the group</li></ul>	<ul style="list-style-type: none"><li>• Can be expensive</li><li>• Can be time consuming</li><li>• Choice of location can exclude</li><li>• Can be susceptible to researcher manipulation and bias</li><li>• Reliance on skill of facilitator</li><li>• Individual domination</li><li>• Possible exclusion of certain co-researchers due to difficulties of working in a group</li><li>• Group setting can be intimidating</li><li>• Consent may be withdrawn at any time</li></ul>

A further challenge regarding focus groups (and other methods such as interviews) is the validity of the data generated. Narratives are social and cognitive constructions. Factors such as omissions, retrieval, aggrandizing and lying can all have an effect on data generated (Craib, 2003); therefore verisimilitude will be used to determine validity. Narrative truth – the evocation and meaning of the co-researchers experiences for themselves and others, is important (Bochner, 2002).

### **Why PAR for this Study?**

The PAR focus groups in phases 2 and 3 of this study were central to the generation of data, ideas and the development of the Personal Narrative Workshop Programme. Working with co-researchers who are situated within the culture of recovery and have experienced developing their own personal narrative ('experts by experience') was important in being able to explore the development process itself and whether developing a personal narrative contributed to their recovery.

### **3.7 Key Ethical Issues**

Ethical considerations were key factors in both the design and implementation of this study. These ethical concerns included: working with vulnerable co-researchers; my welfare as the autoethnographer and the welfare of the co-researchers; anonymity within a focus group setting; and the role of the researcher and relational ethics.

### **Vulnerable Co-Researchers**

Service users can be regarded as vulnerable adults (Tee and Lathlean, 2004, Lathlean et al., 2006, Tee et al., 2007). As such, care should be taken for engaging and working with service users (Tee and Lathlean, 2004). Such attributes include: developing and maintaining trust; assessing competence to and continuing to participate (process consent used by Tee et al., 2007); and managing interpersonal and group dynamics. These factors are relevant considerations for all co-researchers (not just vulnerable adults). These factors have to be balanced against possible over-benevolence and patronization. It is important not to make assumptions about an individual's willingness and ability to participate based solely on the fact that they are service users. This could deny the individual's agency, autonomy, justice and the opportunity to participate in and benefit from participation in research (Tee and Lathlean, 2004). Participation and continuing participation should be collaborative decisions, but with the following considerations:

**Box 3.8: Summary of Consent and Participation Considerations**

- Used the study inclusion and exclusion criteria (Table 6.2)
- Prior to the start of the focus group, co-researchers were asked to identify a significant other (relative, friend, or professional) to whom they can speak if they needed to.
- At the start of each focus group, co-researchers were asked to give their consent by signing a consent form. They were informed that they could take a break or leave the focus group at any point (and have their part in any data collection destroyed).
- A co-facilitator (registered mental health practitioner) was available for the duration of each phase 2 focus group to support any individual if necessary. As phase 3 was concerned with developing an educational framework, it was not necessary to have a registered mental health practitioner present.
- As an experienced teacher and focus group facilitator, the researcher monitored the focus group throughout and was prepared to stop the focus group, if necessary.

**My welfare as the Autoethnographer**

As a service user and the author of the autoethnography, I was a vulnerable adult too (and subject to all the considerations above). At the outset, I was aware that I would be writing about traumatic experiences yet at the same time this process was a key part of this study. An exploration of my mental health experiences and recovery journey and most importantly analysing my process in creating my autoethnography were the foundation of the whole study. It was important to put in place steps to minimise possible risks associated with developing my autoethnography. Box 3.9 outlines the steps taken.

**Box 3.9: The Steps Taken to Minimise the Welfare Concerns**

- Before beginning the process of creating my autoethnography, I discussed the idea fully with my care co-ordinator (from a NHS Trust), my carer (Husband), my supervisors, and my mentor and key supporters.
- I kept a process diary and had a wellness plan (WRAP).
- The reflexive nature of the study required vigilance and honesty.
- I took regular breaks; used my support network and my wellness plan.
- If I felt that I was becoming unwell, I stopped and took advice.

**Ensuring the Emotional Well-Being of Co-Researchers**

In order to balance potential benefits of participating with potential risks (including co-researchers experiencing further trauma), it was important to plan carefully (Box 3.10) and be reflective throughout the process.

**Box 3.10: Ensuring the Emotional Well-Being of the Co-Researchers - Carrying out Phase 2 and 3 Focus Groups**

**Joining Instructions:**

Each co-researcher was sent joining instructions, which included:

- A map of the room location
- The format for the focus group
- Information that the focus group will be recorded and that consent will be taken at the start
- Who the co-facilitators were (the researcher and supervisors)
- Co-researchers were asked to arrive 15 minutes before the start of the focus group

For each focus group (about 2 hours with break for refreshments):

- Time was available before the focus group start (30 minutes). This enabled co-researchers to arrive, have a chat (including anxieties about the focus group), have a coffee, settle in and ask any questions.
- Time was allowed at the start of each group for a brief check-in. This was an opportunity to tell the rest of the group how they were. This allowed the facilitator to gauge the 'emotional temperature' of the group.
- Time was allocated to do a warm-up activity (the majority of the co-researchers knew each other and knew me well).
- Time was allocated to develop the group agreement (rules etc.).
- Time was allocated to reiterate the outline of the study, the reason for the focus group, to discuss continuing consent and ownership of data generated.
- Focus Group in session - themes developed from initial autoethnographic work.
- At the end, allowed time to do a group de-brief and check-out (to make sure the co-researchers were alright). At this point co-researchers were reminded of the importance of taking care of themselves, to talk to someone if needed and/or to use their nominated supporter.
- The facilitators were available after each focus group (30 minutes) to talk to anyone who required it.

**Confidentiality and Anonymity**

There were further ethical challenges regarding using focus groups in phase 2 and 3 of this study. Maintaining confidentiality was a concern, because of the group element (there was an element of trust that the co-researchers did not share what was discussed within the group, with 3<sup>rd</sup> parties). The development of group rules minimised this risk (Tee et al., 2007), ensuring continual agreement with rules at the

start of any focus group work and offering debriefing at the end of each focus group work. This was done in each focus group (Box 3.9).

A further concern was anonymity of co-researchers and location. This was discussed at the start of the focus group. University ethics requirements superseded individual wishes. Some of the co-researchers did not want anonymity as they already shared their narrative in different forums and wanted their contribution to be acknowledged publically, however university ethics required anonymity. Only one co-researcher chose their pseudonym. This raised an ethical response in that the denial of the use of their real names could be seen as a further silencing of their voice.

### **The Role of the Researcher**

My role as researcher was to a degree problematic. I determined: the research question; the study design and the initial starting point of the focus groups were dependent on the emergent themes from phase 1 autoethnography. Therefore the basis of the focus groups (in phase 2) was not co-produced. This could give rise to issues such as feelings of inequity, unwillingness to participate fully, exploitation and lack of control, especially in relation to ownership of the data generated. Tee et al. (2007) dealt with this by making it clear that any data collected would potentially be used (provided consent was still there) for the study and any potential future uses (such as publication and for teaching purposes). At the same time his co-researchers equally held ownership of their own contributions which they could use as they wished. This shared ownership was made very clear at the start of each focus group. All the data generated (including the full transcription and the thematic analysis produced by the researcher) were shared with the co-researchers for comment and for their future use.

### **Relational Ethics Reflections**

Bruner (1987) said narratives are multi-voiced social constructions. Any narrative contains the voices and narratives of others. Whilst the vignettes (my autoethnography) were my narrative, they were the stories of others too (Ellis, 2009). They were about relationships and interactions. Writing about shared

experiences, even when written from a particular point of view could have significant implications for the on-going relationship. The status quo was affected. Unconscious and invested power dynamics or ways of interaction were questioned.

This raised a number of relational ethical issues that were not covered by ethics approval procedures for this study. In writing my narrative and the subsequent thematic analysis (for phase 1), I realised how 'messy writing about intimate others' was (Ellis, 2009, p.10) , and continues to be. The boundaries that may be apparent between strangers are blurred and difficult to distinguish when lives are intertwined. I have written about intimate others with who I have shared history; whom may have contributed to difficult experiences; and with whom I have on-going relationships. Yet, in order to understand and reframe my lived experience, it was necessary to include their role in my narrative. Ellis (2009) suggested that writing about intimate others was a balance between: the burden of writing about oneself; the ethical responsibilities towards those being written about; narrative truth and any obligations towards the audience.

Writing and then analysing my narrative was often traumatic – reliving complex, emotional experiences. At times, the writing process was visceral (Ellis, 2009, Poursanidou, 2015) – evoking bodily sensations, my environment, physical interactions and emotional distress. There was little sense of self-care towards the wounded storyteller (Poursanidou, 2015, Robertson et al., 2017). This has possible implications for this study in terms of what mechanisms are put in place to support vulnerable individuals to develop their narratives (phase 3). I was used to sharing my 'recovery story', yet I felt a tremendous burden of writing my autoethnography. In using the autoethnography and analysis as the foundation for the subsequent phases of this study, this burden continues. This may have implications for insider/service user research within critical autoethnography, when the research requires continual contact with deeply distressing material.

My narrative is the narrative of identifiable others (family, friends, colleagues and mental health professionals). Two individuals in my autoethnography were my

husband and son. Both gave consent to be included. I asked other family members to co-produce a shared narrative – to offer their interpretation and insight to often shared familial experiences. This was declined, as they preferred the status quo to be maintained. Do they have the right to reply to my narrative? Can they choose not to be included? Could they be anonymised and/or fictionalised? It is important to assume that anyone may read our published work (Ellis, 2009, Robertson et al., 2017). My husband did not want a pseudonym - it would have been difficult to anonymise him. As other people may read my autoethnography, how do I as the autoethnographer support him given the possible reaction of others? My son chose the pseudonym John Doe. We discussed how the name John Doe promoted interest, which a more neutral name (e.g. John) would not. He chose to remain John Doe. Whatever his chosen pseudonym, he would be still recognizable as my son.

Writing about intimate others had implications for phase 3. Discussion and consideration about how individuals include others within their narratives and the possible effects of this would be required. This may involve: negotiating - taking the narrative back to the 'storied others' and asking for comments (Ellis, 2009, Poursanidou, 2015); producing multiple-voiced narratives (McHugh, 2015); fictionalising the narrative (Campbell, 2015); mindful slippage (Medford, 2006); or writing and not sharing or publishing (Ellis, 2007, Poursanidou, 2015). There appeared to be no universal principle in writing about intimate others, other than 'do no harm' (Ellis, 2007, p.5). There are potential benefits to writing about intimate others but perhaps part of the reframing process may need to be an exploration around blame and guilt between the narrator and those storied.

There were also relational ethical considerations around being an insider researcher for the focus groups thematic analysis. Ellis (2007) suggested relational ethics were about mutual respect, dignity and connectedness between the researcher and the researched. This caused me further emotional response and tension. I have on-going relationships with some of the co-researchers. They were sent the focus group transcription and the thematic analysis for comments and process consent. I wrote the analysis very carefully. I was also aware that the comments made within the

focus groups had to stand for themselves. I had some knowledge of their lived experience beyond what was shared with the focus group. I was careful not to use any insider knowledge in my analysis. What was shared in the focus groups, I attempted to analyse at face value – this added to the complexity of the task. I wanted to be non-exploitative, to do them justice and be respectful of their contribution.

### **3.8 Chapter Summary**

This chapter described the methodological approaches used in this study. The three-phase structure, where data emerged from the previous phase necessarily meant that the decision-making process about carrying out subsequent phases was on-going. This necessitated a pragmatic and bricoleur approach (Riessman, 2008, Denzin and Lincoln, 2013b). Given the over-arching methodology of a narrative approach (Chase, 2013) used to underpin this study, autoethnography and PAR focus groups were chosen to carry out this study. These drew on a number of different narrative research approaches. There were elements of exploring narrative content in order to explore the personal narrative development process. Also in assessing its contribution to mental health recovery, aspects such the dialogic relationship and the environment that the narrative was developed and used were explored. Further, the emergent data was then analysed using a number of perspectives: post-modern, constructivist and feminist – all used to draw out different aspects and meaning within the narratives and their development.

Ethical considerations such as: welfare of myself as autoethnographer (Robertson et al., 2017) and the co-researchers; working with vulnerable co-researchers; and confidentiality and anonymity were key factors in both design and implementation. During the data collection and analysis (phase 1 autoethnography (chapter 4), and phase 2 PAR focus groups (chapter 5) and phase 3 (chapter 6), it became apparent that relational ethics - the impact of research on on-going relationships (Ellis, 2007, Ellis, 2009) - was of significant importance. In particular, writing about intimate others within my autoethnography, my role as an insider researcher/facilitator in the focus groups and considering how to support others to include their intimate

others within their narratives (in phase 3-workshop development). This on-going tension of writing about and the inclusion of intimate others will be further reflected upon in each phase chapter.

## CHAPTER 4 PHASE 1 AUTOETHNOGRAPHY

### 4.1 Introduction

This chapter describes phase 1 of this study. This includes a detailed account of the process used to write my autoethnography - *From the Edge of the Abyss to the Foot of the Rainbow: A Mental Health Recovery Autoethnography* (Robertson et al., 2017) and the thematic analysis procedure used (Braun and Clarke, 2006) to analyse the emergent data. As a result of the thematic analysis, a number of narrative development considerations emerged. These are highlighted in the text. As phase 1 informed phase 2 focus groups, these discussion points were taken forward to the phase 2 focus groups. These points are summarised in Table 4.4.

### 4.2 Method

In order to complete phase 1 of this study, two tasks were undertaken:

- Writing my autoethnography in a series of vignettes.
- A thematic analysis of the content of the vignettes and my writing process.

#### Writing the Autoethnographic Vignettes

A vignette is 'a short piece of writing that expresses the typical characteristics of something or someone' (Cambridge Dictionaries Online, 2016). As a method of writing, the vignette as a 'short and incomplete' snapshot seemed appropriate as much of my mental health lived experiences felt chaotic, piece-meal and lacking any sense of coherence (Frank, 1995, Robertson et al., 2017). Each vignette was a visceral photograph that had a huge impact on my life and my sense of self. Using memorable quotes and statements (that other people said to me – the voice of others within my narrative) as a starting point; I developed a series of 54 vignettes (Box 4.1) that described memories of my lived experience.

The vignettes were written over three months (November 2014 – January 2015).

Writing involved an emergent and fluid process. At the outset, there was no clear expectation of content, other than it would include recollections of personal experiences and relationships. It felt important not to have fixed ideas on how writing the autoethnography should progress. The full vignettes are in Appendix 4.

**BOX 4.1: Categorisation of the Vignettes****The Hopeless Narratives****Part A: Sowing the Seeds – Painful Memories (11 vignettes)**

1. 'You've ruined my life' (Earliest memories)
2. 'Take the rocking horse with you – she doesn't play with it' (Late 1960s)
3. 'I think that me Dad is dead' (November 1976)
4. 'All that I have invested in you' Part 1 (1976-79)
5. 'Where's the other 2%' (1976 – 1990 Mum's death)
6. 'All that I have invested in you' Part 2 (1979-80)
7. 'All that I have invested in you' Part 3 (Late 1983)
8. 'Don't worry she doesn't like anyone' (January 1985)
9. 'By the way, I've moved' (Easter 1984)
10. 'I need you to be strong' (May 1984)
11. 'All that I have invested in you' Part 4 (1988)

**Part B: Beyond Despair (3 vignettes)**

12. I don't know who you are anymore!' (June 1996)
13. 'I don't know if I can do this anymore' (October 1996)
14. 'I can't let you leave' (October 1996)

**Beginning the Long Assent Narratives****Part A: One Step Forward – One Step Back (13 vignettes)**

15. 'Play the game – stop being challenging' (Feb 2003 In-patient in a psychiatric hospital)
16. 'Go kill yourself then' Part 1 (March 2003 In-patient in a psychiatric hospital)
17. 'She's trouble – stay away from her' Part 2 (March 2003 In-patient in a psychiatric hospital)
18. 'You have a lot of anger' (March 2003 Still in the psychiatric hospital)
19. 'How are you feeling today' – ward round (March 2003 Still in the psychiatric hospital)
20. 'Sam, you won't get into America again' (March 2003 In-patient in a private psychiatric hospital)
21. 'If you don't behave, I will change your diagnosis to BPD' (March 2003 Private psychiatric hospital)
22. 'There's nothing out there for people like you' (June 2003 In-patient discharge)
23. 'You shouldn't have another baby' (2004)
24. 'I think that you should take lithium' (2006 In-patient in a psychiatric hospital)
25. 'You have no choice' (from 2003 – 2012)
26. 'Hold out your hands' (2003-2010 Friday Group)
27. 'I've just seen in the paper that your sister has died' (2012)

**Part B: Moving Onwards and Upwards (7 vignettes)**

28. 'You are worth saving' (2004-2006 CBT one-to-one)
29. 'You've had your moan, now let's get to work!' (c2005 Care Co-ordinator meeting)
30. 'Keep the silence going' (2009-2011 Psychodynamic Therapy Group)
31. 'You have one of the best support networks that I have ever seen'
32. 'You don't know the power that you have over others' (2012 Work)
33. 'Mum, you don't like wearing hats' (August 2012)
34. 'I would prefer the teashop by the sea' (December 2014)

**Thriving Not Surviving Narratives**

**Part A: Lessons Learnt – Doing Things Differently (10 vignettes)**

- 35. 'Look it up on the internet' (October 2012)
- 36. 'Come back and end the group properly' (2011 Psychodynamic Therapy Group)
- 37. 'You aren't doing too much are you' (2002-On-going)
- 38. 'Leave your service user hat at the door' (2013 Work)
- 39. 'You are a service user not a professional' (2013 A recovery college)
- 40. 'I think that I need to increase my meds' (November 2014)
- 41. 'Your pay grade isn't high enough to support you in doing a PhD' (June 2013 Work)
- 42. 'There's nothing that I can do for you' (May 2012)
- 43. 'It's alright for people like you' (December 2013)
- 44. 'Do you hide her meds?'

**Part B: Epiphanies (5 vignettes)**

- 45. 'I bet that you are borderline' (2011 Work)
- 46. 'I wished that she had just killed herself' (2012)
- 47. 'You've found your voice' (July 2013 Work)
- 48. 'Don't you know that I am borderline?'
- 49. 'The old Sam'

**Part C: Moments (5 vignettes)**

- 50. 'Life is too short – bring only the best wine' (August 2014)
- 51. 'Sam you are so naughty' (November 2014)
- 52. Getting Back on The Horse
- 53. 'That is why we are so attracted to you' (January 2015)
- 54. 'You are an inspiration'

The first vignette written was '*I don't know who you are anymore!*' (V.12). This marked the recognisable start of my mental health difficulties, in terms of someone else noticing my distress. From this point, the vignettes were written in no particular order. Initially, I had some quotes that I thought would become vignettes (and had planned to write them up first), but as the writing process progressed more memories and therefore quotes emerged. One recollection triggered another. The order in which I wrote the vignettes was largely down to what I felt able to address at any particular time. It was necessary for the time to be right. It was a tough and exhausting process. Ellis (2009) summarised:

*'as an autoethnographer, I tell a situated story, constructed from my current position, one that is always partial, incomplete, and full of silences, and told at a particular time, for a particular purpose to a particular audience'* (p. 13)

**Vignette Data Sources**

Alongside my memories, a number of different sources were drawn upon in order to write the vignettes. These included:

- Visual narratives that had been developed and used for conferences, teaching and training purposes (2010-2014). These presentations had focused on my recovery journey, specifically on perspectives of spirituality, the maternal role, resilience, working with professionals, modelling sharing my recovery story for other service users and the public and private personal of mental health (testimonial or quest narratives, Frank (1995)).
- Artwork
  - A picture drawn whilst an in-patient (first admission) on a psychiatric ward ('*Go kill yourself then, Part 1*', V.16). Unable to sleep, it was drawn in the middle of a winter's night, using charcoal (charcoal and crayons were the only art supplies that were allowed in my ligature-free room).
  - A time line detailing from 1996-2015 (my recognized mental health journey to date) was drawn prior to writing the vignettes (Fig 4.1-3). Above the line (drawn across the centre of the page), were my positive experiences (holidays, going back to work and exams passed) and below the line, all the negative ones (including hospital admissions). The timeline was useful for ordering events and providing a more global, contextual impression of my recovery journey. This tool could be useful within phase 3 narrative workshop development programme.
- A formal discussion with my husband (Don) about the general content of the vignettes (Source 1, detail below). This discussion was recorded and transcribed (Transcription City, January 2015). The main purpose was to determine whether he felt that there was anything missing. A particular omission - '*You've had your moan, now let's get to work!*' (V.29,) concerned the relationship I had with a care co-ordinator who was pivotal in my recovery. He said that there did not seem to be any positive vignettes (above the time-line experiences). I wrote the vignettes 47 - 54 as a sequence of reflective pieces – a sense of 'what I had learnt' and 'where I am now'. Perhaps, providing a more accurate, rounded view of my lived experience and possibly a better reflection of my narrative truth (Bruner, 1987).

### Process Data Sources

The purpose of carrying out my autoethnography for this study was to experience developing a personal narrative and to then explore my process in doing so.

Alongside the vignette content, other sources of data were used in the subsequent analysis:

**Source 1** – After my first vignettes draft, a discussion with Don about the content. He did not want to read the vignettes. I read out the titles. If it was not clear what the title referred to, I provided a brief overview of the general content and the episode that sparked the vignette. I wanted his opinion and a sense of whether he thought that the vignettes (as a whole) were complete and reasonably balanced. He had lived through most of the events described in the vignettes (as my husband and at times my carer). He offered suggestions: about what he thought I had missed out (e.g. Vignette 29) and suggested reordering some of the vignettes:

*'I think that there is a part, which is just putting bits into some kind of structure and timeline or some kind of, you know, the drawing that you did, the curve [the time line Fig 4.1-3]' (Don, Source 1).*

He remembered things differently to how I did, '*I always picture it around half-term time*' (Source 1). There was a sense of the co-constructed (Ellis, 2009) and dialogic (Bakhtin, 1981, Chase, 2013) nature of narrative. This discussion informed the sequencing and categorisation of the vignettes into three sections: The Hopeless Narratives; Beginning the Long Assent Narratives; and the Thriving Not Surviving Narratives (Box 4.1).

**Source 2** - A specific supervision meeting. The completed vignettes were discussed and I presented my meta-recovery narrative (previously used at conferences and in training). This supervision discussion was recorded and transcribed (Transcription City, January 2015).

**Source 3** - A Process Diary was written over a 17-month period from the start of my PhD journey (October 2014 – February 2015). The diary reflected my experiences of

developing and writing the vignettes (often detailing the visceral and emotional consequences). The process diary documented my research journey in choosing autoethnography as a method and building a case to use it within this study. I used the diary to reflect on being a PhD student who is also a service user, within a Faculty that trains mental health practitioners. The perceived power imbalance between service user and professional that I had experienced (which was described in a number of the vignettes including 'if you don't behave, I will change your diagnosis to BPD' (V.21)) to becoming research colleagues with mental health professionals felt like a major cultural shift. In addition, all the supervision sessions throughout this time were included and reflected upon.

#### **4.3 Data Analysis**

##### **Rationale for Phase 1**

It was important to acknowledge that another researcher could not replicate Phase 1 of this study. Whilst sharing similarities with the recovery journey of others, the content that emerged was unique to me (Slade, 2009, Leamy et al., 2011). This autoethnography explored my experience of mental health recovery (since 1996) and earlier life experiences. The '*Hopeless Narratives*' (Part A: Sowing the Seeds – Painful Memories) provided contextual background – life experiences that contributed to my mental health difficulties.

It was necessary to be clear about the rationale for undertaking Phase 1 of this study, the underpinning assumptions, and the researcher decision-making process when conducting a rigorous thematic analysis. This study was an exploration to gain an understanding of the process and the possible contribution of developing a personal narrative to mental health recovery. This informed the development of a personal narrative workshop programme in phase 3.

An inductive approach to thematic development and analysis was required. The process also needed to be reflexive (Braun and Clarke, 2006, p.82). Themes were generated from the data, rather than using the data to fit a pre-existing range of themes (to match a theory). Given that one of the underpinning assumptions of the

study is that recovery is unique to the individual, it was equally valid to analyse any contradictions and idiosyncrasies that arose whilst developing and defining themes. Reflexivity was needed to assess aspects that emerged from the autoethnographic process such as content omissions and the impact of writing the vignettes on the researcher's mental well-being (Ellis, 2009).

### **Data Analysis Procedure**

Thematic analysis is a method used for identifying, analysing and reporting themes within data. Braun and Clarke's (2006) six-phase thematic analysis approach (Table 4.1) was used to analyse the data generated from the autoethnography vignette content and process (phase 1). In particular, the thematic analysis considered the data (content and process) in relation to the Conceptual Recovery Framework (Leamy et al., 2011, Bird et al., 2014). This enabled me to consider to what extent my recovery journey experience supported and/or differed from recovery model theory.

**Table 4.1: Six-Phase Thematic Analysis Approach (Braun and Clarke, 2006)**

Phase 1	Data familiarisation
Phase 2	Generating initial codes
Phase 3	Developing themes
Phase 4	Reviewing themes
Phase 5	Defining and naming themes
Phase 6	Producing the analysis

Table 4.2 showed how the six phased thematic analysis approach was applied to the vignettes and the process data sources of this study.

**Table 4.2: Phase 1 - Six Phase Thematic Analysis Approach (Braun and Clarke, 2006)**

Phase	Procedure	Vignette Content Analysis	Creating Vignette Process Analysis
1	Data familiarisation	Wrote the vignettes (Box 4.1 and Appendix 4).  Read and reread vignettes.	Listened to the recordings of discussion with Don Robertson (DR) (Source 1, S1) and supervision session (Source 2, S2). Read and reread the transcriptions.  Read and reread Process Diary (Source 3, S3)

2	Generating initial codes	<p>Printed vignettes with line numbers. Cut up text into single units of text. Each unit had a line number in order to link it back to text. All the codes were placed in a single folder.</p>	<p>Each data source (discussion with DR), supervision session and the Process Diary (S1-3) was printed with line numbers. Treated each source separately, the text was cut up into single units of text. Each unit had a line number in order to link it back to text. The codes from each source were placed in three separate folders.</p>
3	Developing themes	<ul style="list-style-type: none"> <li>Each unit of code was read and then placed on a table. Similar or the same codes were put together. Each pile was securely clipped together.</li> <li>Each bundle of codes was reread. A theme was given to each bundle. During this part of the process, some codes were reassessed and placed in themes that appeared a better match.</li> <li>Each theme descriptor was also reassessed to determine that they were suitable matches to the codes.</li> <li>The frequency of codes in each theme was noted: <ul style="list-style-type: none"> <li>Vignette Content (Appendix 4.1)</li> </ul> </li> <li>The themed bundles were replaced in their folders.</li> </ul>	<p>For each data source:</p> <ul style="list-style-type: none"> <li>Each unit of code was read and then placed on a table. Similar or the same codes were put together. Each pile was securely clipped together.</li> <li>Each bundle of codes was reread. A theme was given to each bundle. During this part of the process, some codes were reassessed and placed in themes that appeared a better match.</li> <li>Each theme descriptor was also reassessed to determine that they were suitable matches to the codes.</li> <li>The frequency of codes in each theme was noted: <ul style="list-style-type: none"> <li>Source 1 (Appendix 4.5)</li> <li>Source 2 (Appendix 4.6)</li> <li>Source 3 (Appendix 4.7)</li> </ul> </li> <li>The themed bundles were replaced in their folders.</li> </ul>
4	Reviewing themes	<p>The theme bundles were placed on the table and were rearranged into similar themes or themes that appeared to go together:</p> <ul style="list-style-type: none"> <li>Vignette Content (Appendix 4.2)</li> </ul>	<p>For each data source:</p> <ul style="list-style-type: none"> <li>The theme bundles were placed on the table and were rearranged into similar themes or themes that appeared to go together:</li> <li>Source 1 (Appendix 4.8)</li> </ul>

			<ul style="list-style-type: none"> <li>- Source 2 (Appendix 4.9)</li> <li>- Source 3 (Appendix 4.10)</li> </ul>
5	Defining and naming themes	<ul style="list-style-type: none"> <li>○ The themed bundles from the vignette content were placed on the table. The themes were rearranged into similar themes or themes that appeared to go together. These were called the themes (The full list of sub-themes which were grouped together under the themes in 4.3): <ul style="list-style-type: none"> <li>○ Relationships</li> <li>○ Context</li> <li>○ Communication</li> <li>○ Identity</li> <li>○ Power and Control</li> <li>○ My Journey</li> <li>○ Impact of Mental Illness</li> <li>○ Emotions and Behaviours</li> <li>○ Lessons</li> </ul> </li> <li>● A Frequency of codes table was produced for Theme and sub-theme groupings (Appendix 4.4).</li> <li>● A Mind map was created which showed the complete process of theme development (Appendix 4.4)</li> </ul>	<ul style="list-style-type: none"> <li>○ The themed bundles from each separate data source were added together and placed on the table. The themes were rearranged into similar themes or themes that appeared to go together. These were called the themes (The full list of sub-themes which were grouped together under the themes in Appendix 4.11). The themes were placed into two groupings: <ul style="list-style-type: none"> <li>● <u>Content Themes with Process</u> - including themes: <ul style="list-style-type: none"> <li>○ My Journey</li> <li>○ Communication</li> <li>○ Identity</li> <li>○ Relationships</li> <li>○ What have I learnt?</li> </ul> </li> <li>● <u>Process Themes</u> – including themes: <ul style="list-style-type: none"> <li>○ Reflections on my process of writing autoethnography</li> <li>○ Creating vignettes</li> <li>○ Methodology</li> <li>○ Reflections on the process of others</li> <li>○ What I have learnt as a result of writing the vignettes.</li> </ul> </li> </ul> </li> <li>● A Frequency of codes table was produced for both Theme groupings (Appendix 4.12)</li> <li>● A Mind map was created which showed the complete process of theme development (Appendix 4.13)</li> </ul>

6	Producing the analysis	<p>The Themes from vignette content and process were reviewed and merged into one set of meta-themes:</p> <ul style="list-style-type: none"> <li>○ Context</li> <li>○ My Journey</li> <li>○ Impact of my illness</li> <li>○ Identity</li> <li>○ Relationships</li> <li>○ Emotions and behaviours</li> <li>○ Power and control</li> <li>○ Communication and voicing my narrative</li> <li>○ Lessons learnt</li> <li>○ Reflections on my process of writing autoethnography</li> <li>○ Creating vignettes</li> <li>○ Methodology</li> <li>○ Reflections on the process of others</li> <li>○ What I have learnt as a result of writing my vignettes</li> </ul> <p>Each theme was discussed and analysed in the current UK social, cultural and political and theoretical context.</p> <p>The thematic analysis was used to develop the possible topics for the phase 2 focus group discussions (detailed as 'possible focus group discussion points' as they arose within the text).</p>
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### **Naming the themes and sub-themes**

The theme and sub-theme names (for both content and process analysis) were chosen as over-arching descriptors of the individual codes subject matter. Box 4.3 provides a detailed overview of the sub-themes that were added together to make up each theme.

Some of the themes - 'relationships', 'what I have learnt', 'time' and 'journey' - emerged in both the content and process coding. The theme labels were generic, with the codes describing different aspects of the theme itself and reflected varying uses. When I reviewed the codes that made up the different '*time*' themes (for example), I realised that there were subtle differences in how the codes were used within the source texts.

In the Content Themes, the theme of 'Relationships' is used to describe the main players and the interactions that took place, whereas 'Relationships' within the Process Themes, described the influence, perceptions, role of others in my recovery etc. The concept of time included references to 'time', 'time-line' and 'time-span'.

Likewise, themes related to 'my journey' were also referenced as my 'recovery journey'. During the initial coding process I wasn't aware that I was using different sub-theme names to bundle together similar codes. This became apparent as I developed the themes for each strand (Content Themes, Content Themes in Process and Process Themes) and produced Mind Maps (Appendices 4.4, 4.8-4.11) and then merged the content and process meta-themes for the analysis.

Some of the theme names may seem pejorative. For example the theme of Emotions and Behaviour is made up of sub-themes such as 'Good Behaviour and Bad Behaviour' (vignette content themes). The theme names given reflected the experience at the time - often experiences accentuated by lack of knowledge, insight, therapeutic input and subsequently acquired wellness tools (Ellis, 2009).

#### 4.4 Findings

Table 4.3 is a summary of the themes and sub-themes that emerged from the vignettes and from my process of writing the vignettes.

**Table 4.3: Autoethnography (Content and Process) Themes and Sub-themes used in the Analysis**

	Themes	Sub-themes
1	Context	Background, places, home, dates and time, time-context, personal narrative and recovery narrative, meta-narrative, achievements, internal and external drivers and juxtapositions
2	My Journey	Recovery journey, journey, memories and regrets
3	Impact of my illness	Impact of mental illness, internal and external world, symptoms, treatment, diagnosis, medication and physical
4	Identity	Sense of self, stigma, labels, stereotypes, work, public v private persona, roles we play and no hope
5	Relationships	John Doe, Don, the role of Don, friends, relationships, dad, mother, mother and family, family, collaboration, connections, collusions, didn't want others to know and others views of me, other's perceptions of me, public vocalisations, external drivers, external, collaborative working and motherhood

6	Emotions and behaviours	Bad behaviour, good behaviour, negative emotions, positive emotions, trauma, suicide, safe, endings, abandonment, escape, punishing myself, comfort and aloneness
7	Power and control	Power, play the game, waiting, expectations, disappointment, choice and conformity, control, agency, empowered and activism
8	Communication and voicing my narrative	Communication, recovery narrative, narrative and personal narrative, voicing my narrative, can not voice/ no language for and what does recovery mean to others?
9	Lessons learnt	Ambivalence, hope, no regrets, default position, understanding, knowledge, work at recovery, good enough, recurring patterns, core values, epiphanies, acceptance, positive change in me and reflections, doing things differently, growth, medication, all or nothing, working, work, suicide, public v private, acceptance, activism, core values, mindfulness, emotions, default thinking, realisations, choice and conformity/compliance
10	Reflections on my process of writing autoethnography	Reflections on my process
11	Creating vignettes	Breaking things down into parts, finding where things fit, adding things together, what goes in? omissions, connections, collaborations, memories (differing) and idea
12	Methodology	AE, recovery theory, thematic analysis of methodology and supervision
13	Reflections on the process of Others	Reflections on the process of other's and what am I going to ask others' to do?
14	What I have learnt as a result of writing my vignettes	What have I learnt? talking about very difficult topics, trauma, reliving trauma, reframing, the impact of writing stuff and putting myself out there

### Reflection

After, further reflection and re-reading the analysis, I realised that many of the original sub-themes from Table 4.3 where not formally discussed within the analysis or had been discussed within other sub-themes. There seemed to be significant duplication and therefore some degree of redundancy. I amalgamated these sub-themes (Table 4.4). This is a truer reflection of the actual analysis.

**Table 4.4: Autoethnography (Content and Process) Themes and Sub-themes used in the Analysis**

	Themes	Sub-themes
1	Context	Background, places, time and my narrative
2	My Journey	Recovery journey
3	Impact of my illness	Impact of mental illness; internal and external world
4	Identity	Sense of self, stigma and roles we play
5	Relationships	John Doe, Don, relationships, family and external drivers
6	Emotions and behaviours	Emotional response and suicide
7	Power and control	Power and control; expectations
8	Communication and voicing my narrative	Communication, voice and sharing my narrative
9	Lessons learnt	Positive changes in me, on-going tensions and reflections
10	Reflections on my process of writing autoethnography	Revisiting trauma, creating distance and my writing process
11	Creating vignettes	Writing the vignettes, collaborations and making connections
12	Methodology	Autoethnography as method
13	Reflections on the process of Others	Reflections on the possible process of other's
14	What I have learnt as a result of writing my vignettes	What have I learnt?

(Appendix 4.14 shows the amalgamation of sub-themes).

The emergent themes (Table 4.3) were interpreted within this researcher's experiential framework of adult mental health services (Primary, Secondary, In-patient and Third Sector) within Hampshire from 1998 to the present day. The themes were analysed in relation to: the recovery processes of connectedness, hope and optimism for the future, identity, meaning in life and empowerment (Table 1.1); the recovery stages (Table 1.2); and the characteristics of the recovery journey (Table 1.3) described in Conceptual Recovery Framework (Leamy et al., 2011). This enabled me to consider to what extent my recovery journey experience supported and/or differed from current recovery model theory.

### **Theme 1: Context**

**Sub-themes:** Background, places, time and my narrative

This theme was the starting point of my autoethnography analysis. Providing context was the foundation to the unfolding narrative. This theme describes how

factors such as time can be used in a multitude of ways. For example time as a concept was used to provide additional information (for myself and any potential audience) and to aid narrative development.

#### **Sub-theme: Background**

The '*Sowing the Seeds – Painful Memories*' vignettes (1-11) were written to provide context to my mental health experiences and my on-going recovery journey (Leamy et al., 2011, Bird et al., 2014). Context, places (including home), dates and time sub-themes provided 'thick descriptions' (Geertz, 1973, Geertz, 1993), contextualization and temporization of the vignettes. This offered a degree of coherence (Macias, 2009), wholeness and order (Saavedra, 2010) to the narrative of my lived experience. In terms of the recovery process, this context may help reflection, growing understanding and developing insight (Ellis, 2009). The sense that contextual information was important to the narrative highlighted an awareness of the importance of narrative practices (what is needed to make a good narrative) and narrative environments (the audience). Adding context and coherence to my narrative may help potential audiences in being able to reflect on my lived experiences and their own (Chase, 2013).

The experiences, memories, emotional responses and interactions with others described in the vignettes took place in particular locations at particular times. Often simple and mundane descriptions of everyday life provided useful background: '*the council estate*' (V.1); '*market stall gift*' (V.2); '*winter's dark*' (V.3) and; '*never enough money*' (V.6). Some descriptors such as '*hammer*' (V.1) – the choice of weapon for my violent brother, the '*broken TV*' (V.15) – the lack of resources in a psychiatric hospital and '*shoes*' (V.20) – a prelude to possible sectioning, are more sinister, evocative, emotion-laden and hint at important issues such as power and powerlessness.

#### **Sub-themes: Places**

'Places', including home, seemed to reflect how far I have come '*scholarship girl from the backend of nowhere*' (V.50) and how much I have changed, '*I am more than Gosport*' (V.37). My transformation (due in part to differences in educational

opportunities, subsequent life choices, career path and where I lived) has differentiated and put me at odds from my wider family, '*you can take the girl out of Gosport but you can't take Gosport out of the girl*' (V.50). We have a different life view and values set (V.34). I am an outsider within my own family.

Home represented a place of safety in the vignettes, '*I am coming home*' (V.17). When my Mother moved without telling me, I was devastated '*I have nowhere to go back to*' and '*I had no home*' (V.9). My anchorage was lost and my mental equilibrium took a severe beating. Given my later understanding regarding my difficulty with attachment and abandonment (Bowlby, 1969, Bowlby, 1973), this was unsurprising, but at the time I had no understanding of this.

#### **Sub- theme: Time**

The concept of time fulfilled a number of different functions within the process of writing the vignettes and within the vignettes themselves. At the start of developing my autoethnography, I drew my 'recovery journey' as a time-line (Figs 4.1, 4.2 and 4.3). Purposely, I did this relatively quickly as I did not want to over think it. It gave me a sense of the ordering and logical, sequential placement of the vignettes.

**Figure 4.1 Time-Line (From 1996 – 2015)**

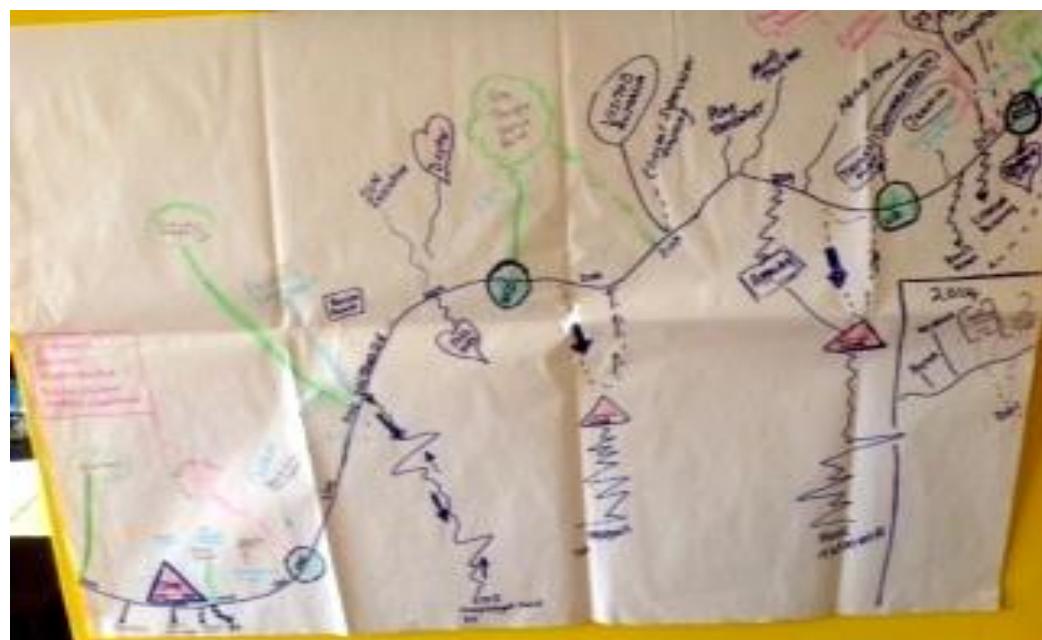


Fig 4.2 – The Beginning of My Journey

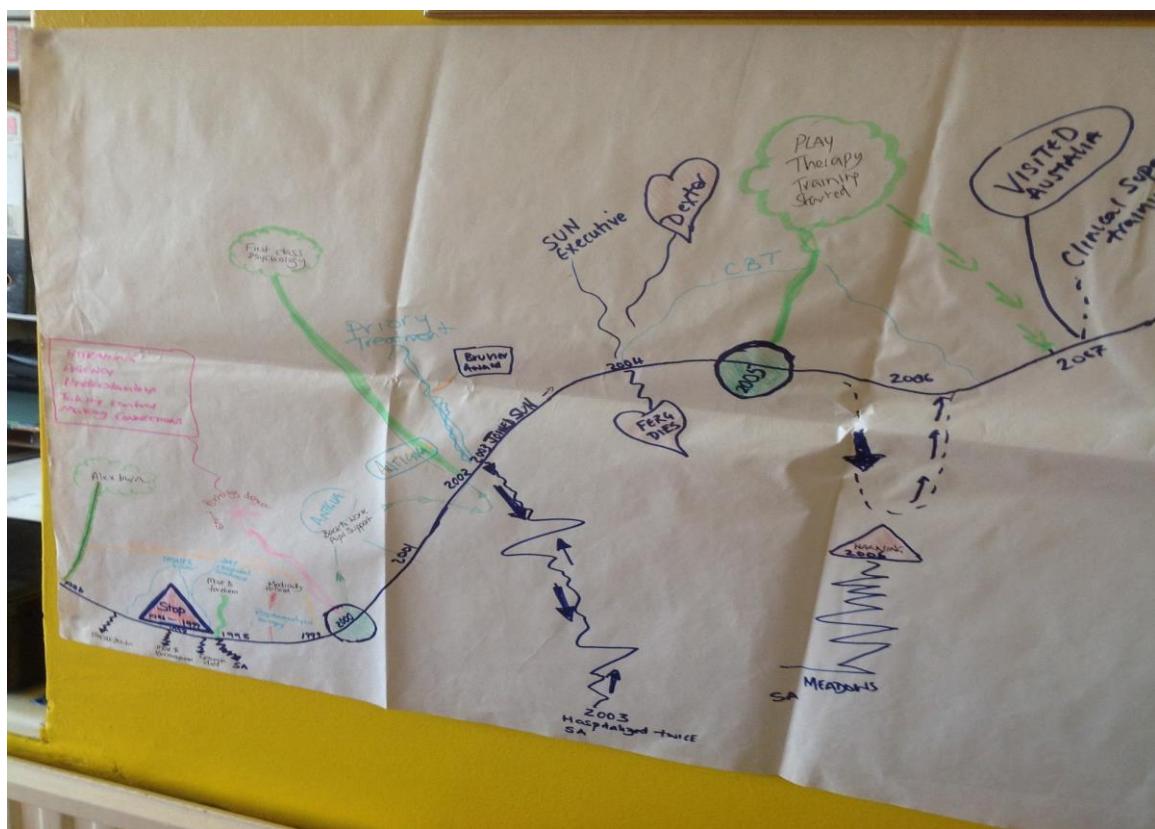


Fig 4.3 – The More Recent Parts of My Journey



Developing the time-line may provide a narrative development structure similar to storyboards (Davis, 2004, Lien and Chen, 2013) which allowed an ordering of experiences and memories to take place – a series of concrete, anchor points from which the individual parts of the personal narrative can be developed. The linearity of my time-line suggested the sense of recovery, of moving forward. It was a useful device to see what progress has been made – especially useful when writing about or acknowledging positive things or achievements are often so hard to do.

I placed ‘positive’ events, experiences and memories above the line and ‘negative’ ones below the line. This visual tool supported a key recovery process of reframing, (Leamy et al., 2011). I realised how much was above the line and how much I had achieved given the catastrophic disruption that I had had to my life (Bruner, 1987, Leamy et al., 2011). Equally the ‘time-line’ also showed the length of my ‘recovery journey’, *‘I feel that I have lost years to this illness, years of lost identity and meaning...’* (Source 3, S.3). Acknowledging my achievements reflected two-step cognitive processing. First, the default thinking that I had to overcome, *‘I had to go through the first core belief, you’re rubbish’* and *‘core conditions’* (Source 2, S.2). Second, acknowledgement of my internal drivers that contributed to these achievements, *‘I’m not one of the sheep...resilient...doing things differently...I’m the driver in my recovery’*, (S.2). Developing a time-line enabled me *‘to reflect on my journey’* (V.48), of my *‘lived experience’* (V.48) and an acknowledgement that my *‘recovery journey is light and shade’* (V.52), of both achievements and regrets (V.6 and V.50).

The use of a time-line to develop a personal narrative raises the point of what a personal narrative should include. The terms ‘personal narrative’ (Anthony, 1993) and ‘recovery story’ are used interchangeably, but are they synonymous? In my time-line, I put all positive experiences above the line and all negative and difficult experiences (for example, deaths, suicide attempts and hospitalizations) below the line. They are all a part of my lived experience and provided learning and understanding, but should they be included in a recovery story? These were important discussion points in the phase 2 focus groups.

**Possible Focus Group discussion point:**

Is developing a time line a useful first step?

Using 'time-span' (across time), rather than specific points in time within my 'recovery journey' allowed a sense of reflection, of gaining insight and developing a sense of understanding (Ellis, 2009) across the whole recovery process – a sense of looking back and learning from experiences and seeing experiences in different lights (Leamy et al., 2011, Bird et al., 2014):

*'They gave me charcoal so I was drawing otherwise I'd kill myself and even, you know, actually, even then, the thoughts were, "Is it okay just to do it? Or is it a coward? Would Don and John Doe be better off?" But and this is where I am now...well look, you go back to this and you think God, how do you get through that?" But actually encompasses probably about ten years, but in that time I did my psychology degree and I also got the Bruner award. I did my postgrad psychotherapy training, I was an advisory teacher, you know, I ran my own business. So even there... And so if you think about back to the quote from Anthony, "It's living with, but living.'" (S.3)*

*'You can see why I'm so screwed up now! And why college was so important. It was my escape without understanding why. And luckily enough I met Don too! So rediscovering you takes me back to that special time but with the wisdom and insight that we have now' (S.3).*

The concept of 'time' provided a similar scaffolding role (Vygotsky, 1978) as 'journey' to the coherence of the narrative. Using 'time' contextually, I was able to place experiences on a time-line of the 'recovery journey' (Fig 4.1) to highlight when things happened, as points of reference for any possible audience and myself. Using time in different ways added to the 'thick descriptions' of the vignettes (Geertz, 1973). For example, '*... actually when I was in [the local psychiatric hospital] for the first time, which was between February 2003 to April 2003*' (Source 1, S.1). I used 'time' to place or chunk similar things together, such as '*...a time of turmoil*' (S.1). Time was used to describe when events took place, '*middle of night*' (V.3) and '*dark, drizzly mornings*' (V.4). It highlighted fixed points '*best summer for years*' (V.50) and '*I was 10 years old*' (V.3). Time was also malleable – from a sense of ' *fleeting moments*' (V.23) to '*ad infinitum*' (V.22) and '*eternity*' (V.21). Without the context of time, it could appear that things happened in a vacuum that is then difficult to relate

to and as a consequence have less potential to make a difference to others (Ellis, 2009).

### **Sub-theme: My Narrative**

The time-line (Fig 4.1-3) allowed me to focus on what I was trying to achieve (with regard to writing my vignettes) – whether the narrative would be a tale of woe or whether some potential learning (for myself and others) could occur. Essentially the difference between a chaos narrative (a series of descriptions of flows of consciousness at a single point in time, with little awareness and understanding) and a testimony or a quest narrative (which use the understanding and insight gained by trying to make a difference to others – an important core value):

*'It's a sense of what was it like? So you had a trigger and what was it like, and these were the kind of things, that, you know, were happening but with no knowledge of what was going on' (S.2)*

Drawing the time-line (Figs 4.1-3), creating the vignettes (V.1-54) and presenting my meta-narrative to my supervisors (S.2) raised the important point of whether a personal narrative is the same thing as a recovery narrative. In the vignettes, there was an emphasis on telling the story of why I became a service user (*The Hopeless Narratives 1-14*); experiences, memories and anecdotes of being a service user (*Beginning the Long Assent Narratives 15-34 and the Thriving not Surviving Narratives: Lessons Learn - Doing Things Differently 35-44*); and then reflective vignettes around epiphanies, what I have learnt and moments that emphasis hope, growth and living a meaningful life (*Thriving not Surviving Narratives: Epiphanies and Moments 45-54*). The time-line charted my journey from 1996 to the present, the positive experiences above the line and the negative below, essentially as statements of fact - a personal narrative that included elements of my recovery journey.

Over time, I had developed a number of different narratives. Using the basic storyline of my recovery journey, I added and emphasised aspects dependent on the purpose of the narrative and its intended audience (Frank, 1995). My narrative that emphasised spiritual aspects of my journey was different from the narrative of my

relationship with mental health services. To enable my supervisors to understand the context of the vignettes and my 'recovery journey', which would aid our discussion, I developed a meta-narrative (S.2), which I shared with them. This meta-narrative was made up of all the narratives that I had developed, with the intention that the narrative was an informative and balanced one.

The questions they asked me, allowed rehearsal, clarification and elaboration on why I had placed events and experiences where I did:

*'...the recovery, it is a journey, it is a part, and that at times, it's still quite a fragile thing but it's been about working with external factors like the services but also it's very much a part of where I am and you could still see people that are very stuck and very much dependent on services that they become the diagnosis and not the whole person. But for me, my internal motivation is really important and I write about it in there in terms of...' (S.2)*

I had to explain why I had used certain metaphors to describe different aspects, '*Wonder-woman.... Burning the candle at both ends, travelled the world, etc.*' (S.2). This dialogic discussion (Bruner, 1987) allowed shared meaning through a process of negotiation to develop:

#### **Discussion thread 4.1**

*Supervisor 1 – When you are now and you're looking back...  
Me – You can contextualise...  
Supervisor 1 - ....it and label it in and put it in...  
Me – yeah, but then it was just....  
Supervisor 2 – It was just a trigger. (S.2)*

The meta-narrative (S.2), whilst acknowledging my descent into mental illness and my subsequent difficulties, emphasised what has supported me in my recovery - hope, tools learnt, doing things differently etc. I concentrate on what factors moved me forward. My meta-narrative is my 'Recovery Narrative or Story'.

#### **Possible focus group discussion points:**

- Is a personal narrative the same thing as a recovery narrative?
- What should a Personal Narrative (PN) or a Recovery Narrative (RN) include?
- Are the development processes similar/different?

The process of developing and writing my Autoethnography as the first phase of my research has helped clarify the subtle differences and the sense that we may label something as 'xxx', but the content may not actually match the label. As part of the phase 2 focus group work, it was crucial to discuss the interchangeable use of 'personal narrative' and 'recovery narrative'.

**Possible focus group discussion points:**

- Should the workshops be supporting individuals to develop 'recovery narratives' where the emphasis is on moving forward and what is needed to move forward or a 'personal narrative' where the content is whatever the individual wishes it to be?
- Do you need to revisit trauma or concentrate on the learning and personal development aspects?

The difference in emphasis could have important implications regarding its contribution to an individual's mental health recovery.

**Possible focus group discussion point:**

It also may have an impact as to whether the workshops need the support of a therapeutic professional environment or can safely be carried out by individuals with the support of peers (with/without training) in the community

These distinctions were important issues considered in phase 2 and phase 3.

It was easier to write about difficult, traumatic and catastrophic events in the vignettes – an overall description of a life ruined. This though was not a true reflection of my life or my recovery story. Although I found it hard to write about my achievements (and failed to include many of them in the first draft of the vignettes) they are a part of my personal narrative. So to include them in the vignettes allowed a more balanced picture to be presented. My achievements were factual, described with no embellishment – they stood for themselves, '*psychology degree and Bruner Award*' (V.52), '*scholarship girl*' (V.50) and '*Chair of Mind*' (V.37). Acknowledging achievement was and is deeply uncomfortable for me. However I did not want to represent myself as a no-hope victim, stereotypical and stigmatized mental health service user either. The vignettes highlighted the complexity of being me: my history, my experiences, my personality, my achievements - a service user

and a human being within a particular social and cultural setting (Goffman, 1963, Slade, 2012, Kleinman, 1988). Often, there were no clear answers, only juxtapositions. '*I want to leave, I stay*' (V.30); '*light and shade*' (V.52); '*conformity v flexibility*' (V.39); '*carer v partner*' (V.44) and '*you can't have one without the other*' (V.38).

**Possible Focus Group discussion points:**

- How do we support people to include positive things?
- How does the personal narrative (PN) or Recovery Narrative (RN) that we develop represent a true reflection of ourselves?
- Do external drivers such as stereotypes, stigma, relationships and roles get in the way? – A mirror or a mask?

Context as a theme raised a number of discussion points for the phase 2 focus groups and practical issues that needed to be considered in the phase 3 workshop development, including the potential value of using time-lines and distinguishing between a recovery and a personal narrative. There was a sense that there needed to be a significant discussion and/or training element within the workshops to understand what the process of narrative development was about. It seemed important individuals should have the opportunity to consider what they would want to achieve (a personal narrative and/or a recovery narrative) before actually starting to develop a narrative itself.

**Theme 2: My Journey**

**Sub-theme:** Recovery journey

The metaphor of a 'journey' or a 'recovery journey' is often used to describe an individual's experience of mental illness and recovery. Unlike the medical model definition of recovery as an absence of illness or symptoms and/or a return to a 'pre-illness state' (White, 2000, Whitwell, 2001, Davidson et al., 2007), recovery from mental illness can be a continuous yet staged process (Table 1.2: Recovery Stages) which may be life-changing (Leamy et al., 2011). This journey is to some degree reflected in various recovery models such as the Conceptual Recovery Framework (Leamy et al., 2011). Such models, assumed a sense of linearity in the

recovery process, which is not always the case in practice, but given the perceived enormity of the task of developing a personal narrative, the 'journey' metaphor may be a useful step in developing a personal narrative.

#### **Sub-theme: 'recovery journey'**

The concept of 'recovery journey' was used in different ways that allowed for context and a coherent flow to my narrative. This was useful as it supported my reframing and reordering process (Bruner, 1987, Leamy et al., 2011, Bird et al., 2014) which contributed to my understanding and growing insight of my experiences, *'For me, my recovery journey has emerged from catastrophic illness.....'* (S.3). This metaphor supported reflection and reminiscences of memories and regrets.

The 'recovery journey' as a concept was used to provide context. An initial setting the scene was important – how the vignettes fitted together whilst at the same time making it clear that I was still on the recovery journey. The journey is not a neat beginning, middle and end:

*'recovery journey, life at the beginning, starting the journey, getting back to a reasonable life and into actually really living the life I want to live' (S. 1)*

This was an important consideration for the workshops.

#### **Possible focus group discussion points:**

- In developing their personal narrative, are service users being asked to produce a single snapshot of a never-ending process?
- Should developing a personal narrative be a one-off event?
- Is developing a personal narrative/recovery narrative an evolving often piece-meal project and that omissions are okay too?
- What might this feel like? Hopeful for the future?

The concept of the 'Recovery Journey' was also used as a means of sharing my narrative with others (Mills and Crowley, 1986). Given the uniqueness of any recovery journey, the use of the word 'journey' drew on commonalities and shared social and cultural worlds (Slade, 2012). This is particularly useful when the narrative itself may contain really difficult content (experiences that are not

universally shared such as psychosis or suicidal ideation) (Parker and Wampler, 2006, Ellis, 2009). If the narrative just described negative experiences that few could relate too, then the audience is potentially lost or merely voyeurs. By putting similar experiences within a framework that is readily understood by all (the journey), there is possibly a better chance of other's sharing and understanding our narrative.

An intriguing aspect of developing my autoethnography and undertaking the subsequent thematic analysis, was the part that this process played in my continuing 'recovery journey' itself:

*'The process of reflecting on my journey as a PhD student and reflecting on my process academically is challenging. Charting the process and its impact on my recovery journey is intriguing. I know that undertaking this research is a huge goal in terms of my recovery anyway. Charting and navigating the highs and lows and how I cope with them, how I use my tools, how my progress mirrors recovery models is huge. This is not about naval gazing (Sparkes, 2002, Lockford, 2002) but about contributing to a body of knowledge and making a difference to me and to others' (S.3)*

I found the whole process of thinking about, writing the vignettes and the thematic analysis extremely tough (much more than I had anticipated given my experience of sharing my narrative). During the process of writing about my experiences, I relived the trauma again (Ellis, 2007). I believed that I had dealt effectively with the trauma through extensive therapy, but the act of writing it caused me to relive it. I wrote the vignettes 'in the moment' with messy text (Short et al., 2007, Short et al., 2013), raw language and graphic descriptions – unedited and unsanitised which probably contributed to the degree of trauma that I felt. There was no sense of reviewing the material through a protective filter or with any degree of distance (Lahad, 1992, King et al., 2012, Pert, 2013).

I also found that the positive vignettes at the end of the Autoethnography, which described lessons learnt, meant that I had still to revisit the trauma in order to write about the positive aspects (Robertson et al., 2017). Undertaking the thematic analysis of both content and process involved reliving the trauma again:

*'I was minded of the reality that I live with and my suicide idealisation and I had*

*a light bulb moment which I had never thought about before – my mum constantly talked about a desire not to be here and more often than not I was the only one in the room listening to it and therefore having to hold the enormity of it..... Another memory, it's Christmas - To keep opening presents. Later I came to realise that the mountain of presents from her and my sisters was all about competing to buy love and knowing that this would never work. A clear reason, why I struggle with Christmas to this day. The later memory is - I remember huddling around a Calor gas heater in the hall, revising for my exams – with the constant internal and often external voice of my mother about the cost of the heating and her fear of finding the money to pay for it. Money or lack of it was a continual theme during this time. As was the overwhelming and ever present need to be grateful. I have recently wondered that, part of my difficulty is that she died before I reached maturity, so that I was never able to discuss this with her. All I have are my projections – which makes it incredibly hard to forgive her'. (S.3)*

*'As I reflect on the time from 1996 – 2010, it is easier to concentrate on the horror, the despair, the sheer emptiness and waste – the black hole. It is easy to remind myself of the loss, the hopelessness – my constricted and constrained world. The mental patient – the nut job – the shirker, the lazy bitch... yadda, yadda, yadda. To relive these tortuous times in all their monochrome glory. Yet in this same time, I also achieved many things. I find it harder to remember or acknowledge these counterpoints. I had to be reminded by Don. As I think about them now, I am unable to put any of them into vignettes – only straightforward prose will do. A list of 'didn't she do well', 'not bad for a nutter'..... It is either this or leave them out' (S.3).*

This had important implications about the level of support required for participants in the workshops. I had planned to write about my mental health experiences a few years previously. I was unable to write a single word. I was not ready to see it in black and white. I abandoned the attempt, never certain that I would return to it.

**Possible focus group discussion points:**

- Is there a right time to develop a narrative?
- The role of the media used?
- Would a series of pictures on slides allow enough distance in being able to develop the narrative?

**Theme 3: Impact of my illness**

**Sub-themes:** Impact of mental illness; internal and external world.

**Sub-theme: Impact of my mental illness**

The impact of my mental illness was a contextual description that was and continues to be multi-faceted. It reflects issues surrounding symptoms, treatment, diagnosis, medication and physical side-effects. This theme described '*the descent into*

*madness*’ (V.13). The mental and psychological symptoms, behaviours, emotions and relational changes were overwhelming, incomprehensible and at times at odds with each other; ‘*empty of all emotion*’ (V.37) and ‘*walking dead*’ (V.14) to ‘*overflowing emotion*’ (V.17). There were debilitating physical effects such as ‘*hypersomnia*’ (a number of years when I slept for up to 20 hours a day), ‘*fantasising sleep*’ (V.23) and constant fatigue as if I was ‘*zombiefied*’ (V.24) and ‘*walking through treacle*’ (V.25). Self-care was beyond me, an act of punitive self-punishment. A life truly disrupted, hopeless and beyond repair. My sense of self lost (Frank, 1995, Frank, 2002).

#### **Sub-theme: Internal and external world**

In the Conceptual Recovery Framework, Leamy et al. (2011) suggested that a key recovery process was connectedness - developing relationships with others (including peers) and being part of a community. As time went on social isolation occurred - self-imposed or as a consequence of the illness. It is still something that I struggle with. It was characterised by ‘*disconnection*’ (V.21) and ‘*disassociation*’ (V.32) from family, friends, colleagues and the world. I was unable to be a wife and mother for long stretches of time – I became the child and the cared for. I was ‘*non-functioning*’ (V.25), an ‘*automaton*’ (V.14), medically retired from work (in a field that I enjoyed and was good at – teaching – a rising star who was predicted to go far). As Frank (2002) suggested, a person of potential ‘*wasted*’ (V.22). Reduced to nothingness, insular, self-obsessed and lost. My chaotic internal world expanded ‘*retreated further into myself*’ (V.10) as my external world shrank. There appeared to be a real separation of the ‘*outside world*’, ‘*not my world*’ and ‘*scary world*’ (V.21) and me. It wasn’t a safe place inside my head either: ‘*sane world disappearing*’ (V.21), ‘*full blown confrontation with myself in my head*’ (V.43) and ‘*severe superego*’ (V.36). A significant and on-going task in my recovery was to re-enter the external world and increasingly take a more active role in it (Leamy et al., 2011, Bird et al., 2014, Slade et al., 2014)

Mental illness and recovery are not static concepts. The recovery process is gradual and often a struggle (Leamy et al., 2011). At times, my illness was and is acute. This

led to suicide attempts and mental health assessments (regarding possible sectioning (V.20). I had three in-patient admissions, three to day-hospital and one to Hospital at Home. They were times of being '*broken down into component parts and sellotaped back together*' (V.22). Hospital was a place of safety, '*The [local psychiatric hospital] – a holding facility*' (V.20), '*24 hour observations*', (V.20) and '*a ligature free cell*' (V.16). Hospital was also a place to learn new tricks, '*no sharps*' (V.15). Hospital encouraged speedy institutionalisation '*to eat the slope*' (V.15). Hospital was a place that '*I needed to stay*' (V.20) which reinforced my disconnection from the wider world and accentuated the 'other'. An acute phase resulted in changes and increases in my medication regime – a non-functioning or at best an automaton shuffling through the day on autopilot, which didn't fit well with regaining my place in the world and my recovery.

At other times, my illness has been chronic (which recently resulted in an additional diagnosis of 'Traits of Borderline Personality Disorder'), life altering and a constant burden. Medication and its side-effects such as '*no libido*' (V.25) and '*lithium toxicity*' and '*manic, loud vocalising a stream of consciousness*' (V.33) add another dimension to living with mental illness. When I came off lithium (after a near-fatal toxicity scare), I could write with a pen again, could appreciate the intensity of colour and no longer had to live with the distressing diabetic thirst. Psychiatric medication is not benign (Slade et al., 2014).

The impact of living with the symptoms of mental illness was mollified by various forms of external drivers such as case-management from service providers. This was at times a lifesaver '*Jim is with me in this moment – in my distress*' (V.29). External drivers were also powerful agents of control, '*called duty psychiatrist – a 10 year old on her 6 month rotation*' (V.17) and often worked within an anti-recovery model '*medical model risk adverse*' (V.42) (Slade et al., 2014).

This external involvement in my care, my illness and my recovery brought with it issues such as agency, control, choice and conformity. Various professionals decided what I needed, '*There's nothing out there for people like you*' (V.22); '*You shouldn't*

*have another baby* (V.23); *'I think that you should take lithium'* (V.24). When discussing medication side-effects, I was told *'You have no choice'* (V.25). This continuing lack of control and agency allowed my infantilisation to grow, which had repercussions for my social connectedness, my roles of mother and wife. For many years I was encouraged to be a child. I did not have to make decisions, open the post or answer the phone. Going to 3rd Sector social or day groups exacerbated my decline into childhood, *'Hold out your hands'* in order to have my hands checked before I was allowed to eat (V.26).

A fundamental part of my recovery journey has been the movement away from and the reliance on other people to manage my illness, my recovery and my life – towards me becoming the central agent of my own destiny. Recovery can occur and progress without professional intervention (Repper and Perkins, 2003, Leamy et al., 2011, Bird et al., 2014).

#### **Reflections on mental illness and negativity**

In describing theme 3 - impact of my mental illness - there could be a tendency to concentrate on and emphasize only the negative aspects of the impact of mental illness. Mirroring the first draft of the vignettes as merely a deficit narrative (Ellis, 2009). This in itself can be seen as a characteristic of major depressive disorders (American Psychological Association, 2005, pp.349-350). It seemed more comfortable to become mired in the pity and 'naval gazing' (Sparkes, 2002, Lockford, 2002, Ellis, 2009) of the catastrophic and life changing entity that is mental illness. This raised a number of reflections on the process of writing the vignettes, which could have implications for the narrative workshop development in phase 3.

When writing the vignettes, it felt easier (although traumatic) to reminisce and reflect on my darker experiences. Writing the more positive vignettes required much more planning and were written with embarrassment: an inability to acknowledge a compliment or praise. In order of writing, the more positive vignettes were written last and were perhaps written more as reflections of what I have learnt – a review of the phases of my recovery journey (Leamy et al., 2011).

When I discussed the general content of the vignettes with Don, he noticed that there were no positive reflections (S.1) or any links, which showed a sense of my movement forward towards living a meaningful life. I added 5 vignettes: '*Life is too short – bring only the best wine*' (V.50), '*Sam you are so naughty*' (V.51), Getting Back on The Horse (V.52), '*That is why we are so attracted to you*' (V.53) and '*You are an inspiration*' (V.54).

The contextual description provided by the theme of Impact of my mental illness is only part of my story and my journey. There was little sense of recovery expressed. It reflected the sense of chaos, confusion, denial and lack of awareness that is a characteristic of the earliest pre-contemplation stage outlined in Table 1.2 the Recovery Stages in the Conceptual Recovery Framework (Leamy et al., 2011). It was not a recovery narrative but a horror story, which did not support the aim of this study, which is an exploration of what does the process of developing a personal narrative involve and how does it contribute to mental health recovery? This is the inherent danger of analysing themes in isolation, when the reality of a life lived is a complex interaction of temporal, multi-voiced social constructions, which are dependent on individual values and cultural practices (Martin, 2009). More recently: the knowledge and insight that I have gained; using the wellness tools that I have been taught; doing things differently (being more open and honest); thinking about things differently; the hard work that I have and continue to put in to my recovery; the hope of others and my own growing self-belief, have resulted in me living a more meaningful life with the more debilitating effects of the illness kept at bay (Anthony, 1993).

I needed support to consider the positive experiences of the impact of my mental illness. To acknowledge, express and be proud of my achievements. My need for scaffolding (Vygotsky, 1978) was considered in the personal narrative workshop programme in phase 3. What support might others need? There is a sense that people need to be heard (Deegan, 1987, Deegan, 1988, Slade, 2009), to tell their story (maybe repeatedly) (Frank, 1995, Frank, 2002), but may need support to look

towards the positives and to see a way forward (Moen, 2006, Gladding and Wallace, 2010, Mullet et al., 2013).

I was told that '*I was worth saving*'. As a result, I have benefitted from years of different therapeutic input (psychoanalytic, psychodynamic, art, Cognitive Behavioural Therapy (CBT) and Dialectical Behaviour Therapy (DBT) Skills for Life). These alongside my determination have supported me in my recovery journey. This therapeutic input is increasingly time-limited, CBT-based and only available to a minority. Hence the implication for the workshop development in phase 3 - how can the workshops provide the necessary framework to allow the individual to develop their personal narrative?

**Possible Focus Group discussion points:**

- At what stage would it be appropriate to undertake personal narrative development work? If it is appropriate for all?
- Is therapeutic input a necessity prior to my programme?
- What are the training needs for peer supporters?
- How can the workshops provide the necessary framework to allow the individual to develop their personal narrative?

**Theme 4: Identity**

**Sub-themes:** Sense of self, stigma and roles we play.

Slade (2012) suggested there were three central elements regarding an individual's construct of identity: a sense of commonality (sociological perspective); difference (psychological perspective); and permanence over time and space (philosophical perspective). Within Western culture, roles and social status have become increasingly important parts of one's definition of the self (Stevens and Wetherell, 1996). In essence, identity is a combination of an inner private world and an outer public world. Our outer world combines the roles that we play and the masks that we wear (Goffman, 1963, Goffman, 1971); whilst our inner world contains the parts that we keep to ourselves.

### **Sub-theme: Sense of self**

Developing and/or regaining a positive sense of identity and self is a key recovery process (Leamy et al., 2011, Slade, 2012, Bird et al., 2014). Large parts of my 'non-mad' identity were lost to me for many years: '*Sam was disappearing*' (V.14); '*Sam became nothingness*' (V.14); '*lifeless lump of shit*' (V.13); '*in shadows*' (V.19) and a '*failed human*' (V.37). '*I no longer know who I am*' (Vignette 23).

### **Sub-theme: Roles we play**

In personal narratives that I presented about my experiences of mental health and recovery (to a variety of audiences), I used the image of 'Wonder Woman' (Marston, 1941) as a metaphor for the many roles I juggled: fast-track teacher, wife, mum, sister, friend, colleague – someone who worked and played hard. It was my sense of identity of 'what I ought to be', what I had been programmed to achieve, '*a barrister, something special*' and '*anyone can be a teacher*' (V.11). The 'ought to be' characterised by pressure from my mother - a relationship that has had a profound effect on my mental health (V.4; V.6 and V.7).

In 1996, I had my first breakdown. The hopeless and catastrophic assault of mental illness on my sense of self (Anthony, 1993): a '*frightened unloved child*' (V.48), '*always waiting to be found out as an imposter*' (V.32) and '*I leave Sam at the door*' (V.26). I lacked awareness of what was happening to me, confused and hopeless (V.12, V.13 and V.14) - described as the pre-contemplation stage in the Conceptual Recovery Framework (Table 1.2, Leamy et al., 2011). My lack of awareness and understanding was compounded by professionals continually asking, '*tell me about yourself*' during assessments and treatment (V.22). They wanted a specific narrative that I was incapable of telling.

My breakdown and the subsequent disruption to my life (Frank, 1995, Frank, 2002), led to new roles being played. These roles profoundly influenced: how I saw myself; how others saw me; my physical demeanour; and the new language used. I became the mental patient, '*The destruction of a teacher, wife, friend and mother*' (V.14). I developed a service user persona and identity (Goffman, 1961, Kleinman, 1988)

which was based on being different from society. I was an insider in a new gang, whose members are considered as outsiders (Tajfel and Turner, 1979) and therefore stigmatised by society:

*'my thoughts noticeably dull. I leave Sam at the door. My language reboots to childhood. My step slows, shoulders hunch. A veil of infantilised unwellness descends. I become the part. I merge into the crowd'.... 'I become the part'* (V.26).

At the time, this was my world: *'all I needed was to sit in the same room with others who were like me'* (V.22). This sense of 'otherness' was further exacerbated by the traditional medical model of mental health services which accentuated difference and permanence of the mental health identity (Slade, 2012).

Over the course of my mental illness and recovery journey, there has been a sense of ever changing roles: Changes to the parts that I play in the wider world - from go-getter to mental health patient to reclaiming a meaningful place in the world, whilst still living with my mental health difficulties (Anthony, 1993). This has at times resulted in role conflict. A key part of my recovery and the regaining hope was to become involved in service user activism, to raise my head above the parapet, to be a *'voice piece of the ideal service users'* (V.47). As a service user activist with professional qualifications and experience, it was often the case that on paper I was wanted for both attributes. However in reality, I was often only required to play the service user role. Whilst working in an NHS Trust (2010-2013 as the Service User Involvement Co-ordinator) I was told by my manager (a fellow service user) *'you are a service user, not a professional'*, *'perform under the service user ticket'* or *'leave your service user hat at the door'* (V.38 and V.39). This feeling that one was not allowed to play more than one role at a time can be detrimental to recovery. It doesn't allow for authenticity or positive risk taking.

A similar point to the professional or service user roles is the duality of the public and private persona, *'the public Sam'*, *'the public mask'* and the *'private Sam'* (V.48). There was a sense of public *'role-modelling'* (V.39), playing something other than my self *'watching the performance'* (V.12), *'a façade'* (V.6). Often it is easier to maintain

the public mask at the expense of the private self, '*public face stronger, private person fading*' (V.40). Maintaining the public mask with an '*I'm fine*' (V.14) and '*Sam you are so naughty*' (V.51) takes a lot of energy and resources.

For years I hid behind my public mask. The only person who I allowed to know the full extent of my suffering was my husband Don. He lived it too. My mental illness was private and deeply shameful (Ellis, 2009). The fear of '*labels, disability, stigma, and stereotypes*' (V.39) drove me to push harder in public, until '*all the wheels fell off*' when my private and public persona morphed into one. In my mind, I became the '*total mental patient*' – '*I ate pre-chewed food*' (V.26). My public roles as a teacher and professional lost. As this shuffling, monosyllabic, insular service user, I was never fully accepted as one of them (service users). I self-stigmatised, '*labelled as a nutter*' (V.22), '*a junkie without the euphoria*' (V.33) and '*don't you know that I am borderline?*' (V.48). Professionals thought '*I was worth saving*' (V.28), '*that there is nothing out there for people like you*' (V.22) and '*it's alright for people like you*' (V.42). Perhaps this only partial acceptance in to the mental health world (Goffman, 1961, Kleinman, 1988) aided my recovery and allowed me to develop a more authentic sense of self. This is not true of many highly medicated service users who still inhabit an institutionalised, infantilised world of low expectations and little hope. I think that my pre-breakdown experiences of successful education, good career and happy marriage allowed me to be hopeful when I was able to be. I had been more than '*the diagnosis*' (V.52). For service users without success before the onset of illness (especially those with early onset psychosis) have little to draw upon.

The insight, the awareness and the reframing that I achieved on my long road to recovery (Leamy et al., 2011, Bird et al., 2014) has also resulted in me seeing others differently and sometimes more negatively. Maybe partly as a result of my psychology degree, psychotherapy training, years of therapy and the hard work that I have put in and continue to put in, I see people differently – especially my sisters, '*Older witch, role of disabled victim*', '*basks in her illness narrative*' (V.34) and '*stuck and sinking into her victimhood*' (V.36). They '*prefer me to be ill*' (V.37) because when I am unwell I am more like them and they understand me. This is abhorrent to

me, alien ideals, devoid of hope. Hope is a key factor in developing a more positive sense of self '*Never being the victim*' (V.53) (Leamy et al., 2011). At the first meeting with my care-coordinator (after months in hospital) she said '*There's nothing out there for people like you*' (V.22) confirming my change in role to a mental health patient and taking away any hope of returning to my former life. Equally, given my fragile sense of self, her judgement of who I was and what I needed was damning.

### **Sub-theme: Stigma**

Overcoming stigma is an important part in regaining a positive sense of identity (Leamy et al., 2011). Goffman (1963, p.13) stated that:

*'stigma will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed'.*

Mental health stigma is in essence about social identity. How do we view ourselves as service users? How do others' view us as service users? And how do we think that others view us as service users? 9 out of 10 people with mental health problems experience stigma and discrimination (Time to Change, 2015).

The stigma associated with mental illness influences social exclusion, employment and relationships. Stigma and the fear of the consequences of stigma can lead to people not seeking help resulting in increase in severity of symptoms and potentially a longer recovery time. I initially refused any formal psychiatric help from my GP:

*'I can give you a CPN, a psychiatric nurse... and I said, no because if they found out at school, I would never work again... and at the time was fast-tracked to headship' (S.2).*

My fear of being stigmatised as a 'nutter' (learned from the mass media and my family) outweighed my desire to be helped:

*'It wasn't until a few years later that it (stigma) became less and less important... I don't care about stigma anymore.... because until we hit it head-on, we will be kept in that silo' (S.2).*

A carer said to me '*that it is alright for people like you*' (S.1). She was referring to the idea that recovery was possible for me because of my skills, education and personality. She implied that I faced less stigma, because I didn't look like a service

user, that I was challenging stigma by being articulate and intelligent. Perhaps she was right. I don't look like one of the Hollywood masks (as examples of service users, Robert Gordon University, 2015), but I have had to go through my own internal battles of self-identity and my perceptions of what others may think. Also the reality was that I excluded myself and distanced myself from the world when I was particularly ill or in crisis. Nobody saw me apart from Don, John Doe and mental health workers. I became adept at wearing a public mask at huge private cost.

The role of labels, labelling and mental health diagnoses are important determining factors of Goffman's (1963) view of stigma as a language of relationships. The labels that we give ourselves and are given by others have huge effects on our self-identity, sense of self and our place in the world. For example whether we are part of in-groups and/or out-groups (Goffman, 1963). Mental health services historically have been set up to separate service users (institutionalisation and care in the community) from the rest of society. Service users used day services, social groups, lunch clubs, employment programmes and therapeutic programmes and treatment that have resulted in institutionalisation and infantilisation. This had and continues to have a stigmatising effect:

*'An individual diagnosed with diabetes would not be expected to live every moment of their lives with other diabetics, yet this is normal for mental health service users' (Shepherd, 2013).*

An effect of this is for service users to become the label, '*don't you know that I am borderline?*' (S.1) and the diagnosis – to see themselves as a depressive, as a nutter as a schizophrenic (Goffman, 1961, Goffman, 1963, Kleinman, 1988), which further perpetuates the sense of separateness:

*'As I enter, my thoughts noticeably dull. I leave Sam at the door. My language reboots to childhood. My step slows, shoulders hunch. A veil of infantilised unwellness descends. I become the part. I merge into the crowd. I walked through' (S.1).*

An important way to reduce stigma is by role-modelling and breaking stereotypes by creating awareness and understanding about mental health in others. I have

worked towards these goals by developing and sharing my recovery story with others:

*'I was asked to run a workshop around: *The Person behind the Diagnostic Label*, for the 2<sup>nd</sup> year Health Science students (November 2014). I have given a similar talk on many other occasions. Sometimes called 'My Story', 'My Journey' etc. – usually with the same component parts but tailored to the different audiences that I was talking to'* (S.3).

For me, it is important to show the person behind the label:

*'I may be a service user, but I am much more than that. I am not my diagnosis – well not all the time anyway'* (S.3).

In reality, an individual plays many roles (attributes and perceptions of the role) and labels (the name given to the role). Some roles and labels can compliment each other such as wife and mother. Some roles and labels co-exist in an acceptance that one can be both, such as sports fan and professional. Other roles and labels are regarded as oppositional with a sense that if an individual is one, then they cannot be the other e.g. a service user and a professional. Often in such cases the stigma surrounding the service user role takes precedence over all other roles – a sense that one is always a service user. This view doesn't support recovery, *'leave your service user hat at the door'* (when I joined an NHS Trust, S.1) and *'You are a service user, not a professional'* (when I had experience as both a peer trainer and as a teacher, a Recovery College, S.1):

*'The role wanted me to only focus on the 'disabled' part of myself and not the integrated whole that I had worked so hard to achieve' My recovery is about regaining all parts of my identity and to value all the parts that I can bring to the table. The emphasis of the peer and the AMH trainer re-enforces only the 'illness' part of me. I have worked hard not to be just a service user, but to use the whole of my lived experience within my teaching and training'* (S.3).

Across my recovery journey itself, learning and growth have contributed to the reinstatement of a more positive sense of self and the integration of the it/me persona (Leamy et al., 2011, Bird et al., 2014). This has occurred by regaining hope, developing relationships and beginning to challenge and change my core beliefs such as *'not good enough Mother'*. Recovery processes identified by Leamy et al. (2011) as likely to occur in the more advanced stages of an individual's recovery.

Essentially, from the '*old Sam*' to the new one (V.49): '*change old inauthentic Sam*' (V.48), '*old Sam behaviours*' and '*new Sam behaviours*' (V.49).

The 'old to the new' could leave the impression that changes in my sense of self were as a result of my mental illness and my subsequent recovery. In reality, even without these factors, sense of self is not a static concept – life happens, we experience it, incorporate the good and bad experiences, adapt and grow as people. It is likely that I would be a different Sam now anyway.

**Possible focus group discussion point:**

-Does writing a Personal Narrative (PN) or Recovery Narrative (RN) have any effect on sense of self?

## **Theme 5: Relationships**

**Sub-themes:** John Doe, Don, relationships, family and external drivers.

Relationships and the roles people play within the vignettes were essentially about dynamics, power, powerlessness, ambivalence and the influence that we have over each other – a sense of how we touch each others' lives. Our narratives are entwined (Ellis, 2007).

### **Sub-theme: Family**

My family split into two very separate groups of people, my core inner circle (Don, my son John Doe and me) and the 'other' – two sisters and a niece (V.34). There is also a wider family that has not been part of my recovery journey (including my in-laws). This wider family was barely present in the vignettes; '*I am alone in a large family*' (V.27) and '*Don's parents lack of help*' (V.23). My parents, two sisters and a brother are dead. My family, particularly my Mother had a profound effect on my sense of self, core values, my life choices and my mental health. Much of what I wrote about my family involved a deficit narrative – a sense that they were all flawed (Ellis, 2009) and I was effectively powerless and lacked agency. Without my subsequent reflection on all the vignettes, the overall deficit and fatalistic narrative could have dominated and impacted on my reframing process. It is likely that this

narrative would not support recovery. This had implications for phase 3 narrative workshop development.

**Possible Focus Group discussion point:**

-Is it important to support a more balanced approach to narrative development?

My mother was a central character in the vignettes:

*'As I grew up, the youngest of 7 (my nearest sister 8 years older), I was aware of mum's control and of the others subjugation to that control. The lying that we employed so as not to feel her anger, disapproval or her being cast off. The latter was the worse – mum is not talking to you. The lengths that people went to please her, yet nothing was ever enough. What was instructive was that when mum suddenly died – the family that had been held together by a grip of iron, disintegrated. Two long standing marriages collapsed within months – instigated by the son-in-laws that mum had no time for' (S.3).*

Dad was a non-entity, '*a weak father*' (V.1). He died when I was 10 (V.3). He had little influence alive but a significant impact when dead. His death changed my world - from a '*reluctant mother*' and I '*the child that ruined her life*' (V.6), to '*I became my mother's world*' (V.5). My mother became an '*all-consuming mother*', '*a toddler in aging woman's clothes*', and '*a master manipulator*' (V.6). She did not allow me friends or boyfriends, '*she doesn't like anyone*' (V.8) because it meant time away from her. As long as I was a '*living embodiment of what she wanted*' (V.6) things were fine. Often, we lived in silence – her disappointed in me, waiting for me to beg forgiveness. Still '*her influence lives on*' (V.27) with my '*Mother in my ear*' (V.23). My mother was equally adept at playing the '*victim role*'; she was all alone and unloved. The vignettes described the hugely destructive and long lasting influence that she had over her children. Now, '*what is worse for me is that one is morphing into my mother*' (S.3). I now lie to them. In a recent epiphany, I realized that a '*dead mother preferable*' (V.46) so might have had less of a toxic influence on my life.

Add to this dysfunctional scene: '*a bully brother*' (V.1) who terrorized the family and emasculated Dad; an elder sister who had undiagnosed Borderline Personality Disorder (BPD) who didn't want us to know that she had died (V.27); and a much-

loved sister and friend who died at 37. The two remaining sisters are forever asking 'what if it makes you ill?' (V.37):

*'a simple meet up for coffee as equals, as sisters – sharing a common womb, a common sociopathic mother – yet worlds apart' (V.34).*

In essence - '*black hole that is family*' (V.34).

### **Sub-theme: Don**

Don and I met in 1982 at Atlantic College. We '*grew up together*' (V.52). We have been married 30 years. Before my breakdown, we were partners. For years afterwards Don took on different roles, some reluctantly as carer and advocate. When my agency and autonomy were lost, he became my parent '*Don is Dad and Mum to me*' (V.23), '*longing for him to rescue me*' (V.10) and '*Don cleaning up my mess*' (V.33). He was a reluctant jailer too:

*'I can't be the one solely responsible because I have to sleep and all the rest of it' and 'there were a number of carers that did hide the meds, but were continuing to do that when they were well' (Don, S.1).*

He was always uncomfortable with this power imbalance and was always hopeful that our partnership would resume, '*he held my hope, when I couldn't hold it myself*' (S.3).

In the chaos and bewilderment, he was the only witness (V.48). We suffered together '*Don and I cling together*' (V.50) and '*both dying inside*' (V.14). He suffered alone, never sharing with his parents, '*you never let them in*' (V.31). He lost his wife, Mum to his son '*Don will find a better Mum*' (V.23) and a friend. He was equally bewildered and lost (V.13). He lost his career. He developed his own mental health issues (V.44), at times '*he is overwhelmed by the responsibility*' of caring for me (V.10). He became my nurse '*Don's insistent watchfulness*' (V.23); a voice of reason '*Don persuades me to wait for psychiatrist*' (V.17) and my ally '*come and get me*' (V.17).

When I couldn't speak for myself, he was my advocate '*banging on doors*' and '*got agreement that I could stay*' at a private psychiatric unit (V.20). In this role Don

operated outside his comfort zone and his 'acceptable middle class learnt behaviours'. He had to bang on doors and shout the loudest when negotiation and diplomacy failed, '*trying to keep me in [a private psychiatric unit]*' (S.3). I am lucky that Don advocated for me when I couldn't do it myself. Many service users are not in this fortunate position. With my continuing growth in resilience and agency, we are partners again.

#### **Sub-theme: John Doe**

My son chose John Doe as his pseudonym in the vignettes, '*yeah... you can include me (in your vignettes) but don't call me by my name*' (S.2). This may have been an unconscious reflection of the time he spent alone when I was unwell. John Doe has been affected by my illness, by what might have been and the many times that I was absent especially during his early years. He is an only child. We were fearful of having another (V.23). He never wanted to be labelled 'the son of a service user'. He wanted no special support. He did not want to be defined as a young carer. He just wanted to be my son. He did not have any formal role in my care or was part of the decision-making process around my mental illness. He chose John Doe to remain anonymous, however the use of this pseudonym has provoked interest in the readers of the vignettes. It stands out because of its anonymity.

Living with symptoms such as disconnection, emptiness, constant fatigue, non-existent motivation, medication side-effects (V.25) and punitive core beliefs of being a perfect Mum and wanting to be nothing like my Mother, I struggled with my relationship with him. I was '*overwhelmed with love and awe*' for him (V.23). I felt bereaved when I went back to work when he was only a few weeks old (V.12). His birth in 1996 emphasized the lack of family support that we had and the hammer blow that I had to my identity and the competing demands of motherhood and professional life. The 'ought, should and must' in my life became overwhelming. For many years, Don was both Dad and Mum to John Doe. He was '*too loud*', '*too vibrant*' and '*too demanding*' (V.23) for me.

John Doe's importance in my life and on my recovery is not reflected in any real presence in the vignettes. The vignettes described my mental health world, which John Doe was separate from. Yet, my role as Mum and trying to be a 'good enough mum' has and is fundamental to whom I am:

*'Much of the past 18 years have been mired in the cesspit of depression. It has in many ways shaped my experience of motherhood including only having John Doe. Yet at the same time, I have worked tirelessly to counteract these effects with John Doe. I promised to never be my mother, to love him unconditionally. Although at the same time, I battled the 'not good enough mother' whereas in reality my mother really was never good enough' (S.3).*

It wasn't a conscious decision to exclude him from the vignettes. I wondered if his shadowy presence in the vignettes was because I was still distressed by my inability to always be the Mum that he needed. John Doe and motherhood are largely absent from my public narrative presentations. It is a role so important to me and fundamental in both my illness and recovery yet it remained a part of my personal and internal world. It is perhaps still too raw - an unconscious act of protection. It may be because it is such a difficult and emotional issue for me that I have not felt able to discuss it in public – I might lose control and diminish my public mask:

*'and then maybe at some point, you might then decide that you are confident enough to make those things public' (Don, S.1).*

The timing and my willingness and ability to share aspects of my narrative needed to be determined by me. It does not mean that I will never revisit it or other more difficult aspects. My narrative is an ever-evolving piece-meal production of new material and revisions in the light of new life experiences, developing knowledge, understanding and insight (Ellis, 2009).

### **Sub-theme: Relationships**

In my Mother's eyes, possible friendships were direct competitors with her and her plans for me. She allowed no friends - *'No time for friends'* (V.5). Before my Dad died, I was 'a feral kid' *'running wild with the pack'* (V.1). After his death, I had enforced friendlessness. I won a scholarship at 16 to a college in Wales. I met Don and made friends (V.50). In recent years we have reconnected with those friends whose *'love and understanding that is real'* (V.51) and *'we walk towards each other'*

*and hold each other*' (of my reunion with my Chilean door-mate in 2014, V.50). My social isolation and disconnection is significantly lower. I am slowly reclaiming my place in the social world (V.50-54). These friends are my family (Leamy et al., 2011, Bird et al., 2014, Slade et al., 2014).

With my increased knowledge, I am aware of the affect my BPD traits of rejection and abandonment have on relationships. A therapist helped me realise that I had dealt with this fear by being the one who abandons (V.36). I work hard to maintain additional relationships (other than Don and John Doe). Over my recovery journey, a number of relationships have existed as a result of receiving services, '*she gives me time*' (V.24), '*you have no choice*' (V.26), '*18 months into a relationship not of our choosing*' and '*intimate strangers*' (V.30). These external drivers have at times been lifesavers, holders of my hope, agency and motivators. Professionals that were most effective were collaborative '*you've had your moan, now get to work*' (V.29), '*we worked out a plan together*' (V.36) and '*go away and do some research*' (V.35). They have been disproportionately important in my life, but as I have developed understanding, resilience and tools their influence has diminished. I am now the central agent in my life (Leamy et al., 2011, Bird et al., 2014).

#### **Sub-theme: External drivers**

The fact that Don and I '*walk this path alone*' (V.31) meant that we often '*told no one*' of our struggles, '*we shut others out*' and '*asked for no help*' (V.14). This led to a deepening of our difficulties, often beyond crisis point (which resulted in long recovery times). In the early years, we had little experience of asking for and being given help, especially from services. There was huge fear around the stigma of being labelled '*a nutter*' and never being able to teach again. I was concerned that Social Services would deem me an unfit mother. Services would be punitive and not helpful. At the time the '*catastrophe of the mental illness*' was preferable to admitting that I needed help. I didn't have the awareness at that time to understand what I needed and what we needed as a family. I think that this is quite common. In retrospect, I have realised that being honest with others is liberating,

*'raw honesty that you face yourself'* (V.53) and has helped in my peer relationships – where we support and inspire each other (V.54).

I am conflicted in my desire to be a recovery role model (Testimony narratives, Frank, 1995) and being told that I am inspirational, *'this is why we are so attracted to you'* (V.53). In the first draft of the vignettes, I omitted any reference to others' positive views of me. It has a dissociative effect because I find it uncomfortable to be praised. It is easier to acknowledge that *'I am challenging'* (V.15 and V.42), *'am trouble'* (V.17) and *'they think that I am a spoilt bitch'* (V.34). Others have posed questions that have had a positive influence on my recovery including *'you have a lot of anger'* (V.18) and *'you don't know the power you have other others'* (V.32). My Mother did not allow me to express emotions. I was an empty vessel although I did not know it. I was shocked to be told that I had a lot of anger. I was kicking a hospital wall at the time, but I didn't make the connection. It took a further 8 years of therapy before I was able to accept that it was okay to have emotions. The *'you don't know the power...'* was a negative statement said to me by my manager in the NHS Trust because she thought that I could be disruptive and lead others astray. It allowed me to reflect on the line between assertiveness and toeing the corporate line. I realised that I had lost my activist voice – a core value of who I am, so decided to leave the Trust (V.47).

In the early years of my recovery journey (when I would have never described it thus), mental health services (and the medical model) took over and dominated my life:

*'I remember during that time my weekly therapy or going to see the psych or whatever; they were very important parts of the week'* (S.1).

Like Don, professionals held my hope when I was hopeless:

*'when you're hopeless, you're nothing, and them coming in and rescuing and telling you what, they give you a diagnosis, they tell you what is wrong and they say, "you do this, you do that, you'll get better", the drive is external'* (S.1).

Within my recovery journey and the vignettes there was a sense a distancing and reduced reliance on external drivers and other people and of growing agency and

my own abilities to be a fully functioning and contributing adult in a social world (Leamy et al., 2011, Bird et al., 2014). Whilst describing the relationship that I had with my mother, the vignettes were also an acknowledgement of my growing awareness and understanding of the destructive power dynamics that I assumed to be normal. The vignettes reflected my growth and my experiences of doing things differently.

### **Theme 6: Emotions and Behaviours**

#### **Sub-themes: Emotional response and suicide.**

##### **Sub-theme: Emotional Response**

My difficulty with emotion and emotional response was reflected in the vignettes. Growing up, I was conditioned not to display emotions, keep behaviour neutral and do as my Mother wanted. I lived in my internal world - a black and white world of 'positive emotions' and 'good behaviour' and 'negative emotions' and 'bad behaviour' where the latter resulted in silence and displeasure. My emotional self was stunted. Whilst this behaviour served me well as a child, it was not fit for purpose as an adult. How I viewed both the world and myself was unbalanced and punitive (Table 4.5 the disparity in the number of positive and negative references in the vignettes).

**Table 4.5: The frequency of codes in the vignettes**

<b>Positive Emotions</b>	<b>Negative Emotions</b>
7 (2 codes reflected the emotional response of others e.g. ' <i>compassion appears</i> ', V.30)	46
<b>Good Behaviour</b>	<b>Bad Behaviour</b>
3	24

It was not a stretch to link my mental health diagnosis with the emphasis that I placed on the negative. A product of my up-bringing; my insecure and avoidant attachments (Bowlby, 1969, Bowlby, 1973); and my faulty thought processes (e.g. catastrophic thinking). The *positive emotions* in the vignettes described the '*relief*' (V.14) and '*freedom*' (V.15) that I felt when I decided to end my life. The '*euphoria*' (V.23) – a remembered feeling after the birth of John Doe. '*Resentment suppressed*' (V.36) used as an example of *good behaviour*. Contrast this paucity of good and

positive with the rich descriptions of the negative and bad in the vignettes. Three emotions (and shades of) dominated the vignettes: one, 'fear' (V.19-21), feeling 'frightened' (V.14) and 'scared' (V.21); two, a continuing sense of 'shame' (V.13, V.14, V.36 and V.47) – not understanding what was happening, but feeling appalled that it was. Three 'anger' and 'rage' (V.18 and V.21), a 'tower inferno' (V.36) and a 'raging inferno' (V.20). There was a physical, visceral quality to the anger and rage, 'white hot heat' (V.17) and 'red heat in back' (V.18). These emotions were experienced without the context of understanding, 'a cataclysmic implosion' (V.14). The 'bad behaviour' was a reflection of these inexcusable 'raw emotions' (V.36), behaviour I never believed that I was capable of, violent, aggressive behaviour that I disassociated from: 'emotions alien to me' (V.20), 'breakout aggression' (V.36), 'fists bunched' (V.18), 'kicking wall and door' (V.17), 'stamp my feet' (V.21), 'shouting' (V.49) and 'swearing' (V.18). The internal, locked down world no longer containable, 'he lights my litmus paper' (V.21). This breakdown in control further exacerbated the primary depression symptoms, thus added to the overall sense of confusion and despair.

Over time, as I gained awareness and reflected upon my emotional responses, I developed insight and understanding (Leamy et al., 2011). I learnt to acknowledge that all emotions have their place. I was able to reflect on this disparity of emphasis between negative and positive emotions and place them in the relevant learning context (the 'doing things differently' V.35 – 44).

**Possible focus groups discussion point:**

-How can individuals be supported to describe the trauma of their experiences (what they have come through) in order to reframe, contextualize and learn and move on in their recovery journey?

Leamy et al. (2011) described the recovery process as a struggle and a gradual process. The continuing difficulty I had with emotional responses could not all be linked to my recurrent bouts of severe clinical depression (did not match the diagnosis in DSM-IV (American Psychological Association, 2005)). Even during periods of wellness and living a meaningful life, I struggled with (and continue to do

so) feelings of '*abandonment*', desire to '*escape*', the need '*to punish myself*' and '*suicidal*' ideation – often leading to poor interactions with others, self-harm, lack of self-care and suicide attempts. All are BPD traits (American Psychological Association, 2005). The trigger, in 1996 was when Don said '*I don't know if I can do this anymore*' (about my deterioration in my mental health) (V.13). In hindsight, it was a feeling that I had every time my sisters left me alone with my Mother '*don't leave me with her*' and '*Sunday night bereavement*' (V.5). Added to this my Mother moved home without telling me. Although away at college, I still lived with her (V.9). I have been married since 1987, but I still have a regular sense of abandonment, especially if I get something wrong. This '*abandonment complex*' (V.27) has often resulted in a need or desire to be *alone* or to *escape*, '*need distance and space*' (V.30), '*lost and alone*' (V.6) and '*I merge into a crowd*' (V.26). I don't need to be alone to feel alone. The need to escape from my world, others and myself is a recurring sub-theme in the vignettes, '*hiding under my duvet*' (V.9), '*escape to my room*' and '*leaving this hellhole*' (V.17) and '*escaped together*' (V.51) from our home difficulties to the freedom of college.

Understanding that these emotions were as a result of significant and sustained traumatic experiences and loss (Bowlby, 1969, Bowlby, 1973), helped me rationalize them and work on my behavioural responses in a more appropriate and sustainable way. For example, one way that I dealt with possible abandonment was to be the one doing the leaving (unconsciously). When my therapist invited me '*to end the group properly*' (V.36), I finally understood what I had been doing. She wanted me '*to say goodbye*' and to be part of '*a group ending*' (V.36) and not just walk away.

### **Sub-theme: Suicide**

My suicide ideation was my ultimate abandonment of others, although I did not see it this way. My desire was always '*very rational*' and '*utterly focused*' (V.14). It was '*planned*' (V.12), the '*place chosen*' (V.14) and '*the means squirrelled away*' (V.14). For long periods of time, I was '*preoccupied with suicide*' (V.16). I needed Don to '*release me, let me go*' (V.44) because I believed that '*it would be better for everyone*' (V.14). Don could find a better wife and Mum for John Doe. Don carried

this burden of my suicidal intentions and attempts for many years. He made the decision not to '*hide my meds*' (V.44). He rationalized that we could not live in a ligature free, sanitized, 24-hour obs environment to keep me safe at all times – essentially an in-patient. During my periods as an in-patient, I learnt many ways around this – acquiring new knowledge and ingenious methods to self-harm in order to satisfy my need to '*punish myself*'. For example using a sharp twig '*arm a bloody mess*' (V.21).

Alongside developing insight and understanding, there is a sense that there needs to be a significant amount of 'retraining' for the individual who is on their recovery journey. Recovery requires continued work. A supportive and healing environment aids the multidimensional nature of the journey of recovery (Leamy et al., 2011, Bird et al., 2014, Slade et al., 2014).

### **Theme 7: Power and Control**

**Sub-themes:** Power and control and expectations.

#### **Sub-theme: Power and Control**

Within mental health, there is significant power imbalance between the service providers and service users. The exercise of power or perceived power comes in a number of forms including legislation e.g. Mental Health Act 1983 (HM Government, 1983 (amended 2014)) and the Mental Capacity Act (HM Government, 2005). These laws allow doctors and approved mental health practitioners (AMHP's) to forcibly detain an individual against their will for a varying length of time and/or make a particular treatment regime (including medication) compulsory.

Voluntary access to treatment in secondary services is made by referral and assessment. Professionals are '*omnipotent*' (V.21) the holders of knowledge, the gatekeepers to treatment, therapy and possible potential wellness. I was told that, '*You are worth saving*' (V.28), perhaps suggesting that others were not. Professionals have further power in their ability to make a diagnosis, with subsequent issues of labelling and stigma (Goffman, 1963), '*If you don't behave, I will change your diagnosis to BPD*' (V.21). Further, there is the possibility of a

service user becoming the diagnosis and inculcating social and cultural milieu, becoming '*the schizophrenic*' and '*the mental patient*' (Goffman, 1961, Kleinman, 1988).

Service users, on the other hand have been institutionalized and infantilized by the mental health system, grateful of receiving any care (given the scarcity of resources). Services have moved towards 'recovery focused', one-size-fits-all, evidence-based and time-limited interventions, where the uniqueness of the individual is often ignored (Slade, 2012, Slade et al., 2014):

*'I become the part. I merge into the crowd. Lunch is prepared for us. Cheap, pre-chewed crap. Mum shouldn't have gone to Iceland. Yet we wait in glorious anticipation. I've got out of bed for this. The highlight of my week'.* (V.26).

On the ward and in day groups, there were a number of ways of infantilizing, institutionalizing and reducing agency in an individual: '*no hot drinks after midnight*', '*unopening windows*' (V.15), '*look for sharps*' in belongings (V.21), '*open ward locked*', '*keys and alarm jangling on belt*' (V.17) '*being watched*' (V.26) and '*Hold Out your hands*' (V.26).

The exercise of power can be overt or more subtly applied. Relationships between staff and service users are unequal, and interactions tend to take place when people are most unwell, lack agency, motivation or cognitive skills. These relationships are unequal because they take place at locations, frequency and times of the professionals choosing (ward rounds, out-patient and therapy appointments), often involve multiple professionals present (some of which are unknown to the service user). Often decisions about care are made without the service user present. They keep service users waiting, '*How are you feeling today*' – *ward round*' (V.19); the service user usually sits on the lowest chair in the room; and professionals give little of themselves, '*Jan is power*', '*you make these decisions unilaterally, and this is not a democracy*' (V.30).

There are also possible power imbalances within other relationships, including between service user and carer. Often the carer is expected to take on the role of

professional when the professional is absent. For example holding and controlling medication, *'do you hide her meds?'* (V.44). This can result in the relationship dynamics changing within a relationship from partners to parent/carer and child. There is the perceived semblance of choice, e.g. when discussing the debilitating medication side effects *'that or death'* (V.25) and *'you shouldn't have another baby'* (V.23). There is the ever-present threat of sectioning if the 'correct choice is not made': *'informal – threat of formality'* (V.48), *'There's nothing that I can do for you'* (V.42), *'She's trouble – stay away from her'* (V.17) and *'Sam, you won't get into America again'* (V.20). During my involvement with secondary services, I seldom felt that I was treated as an adult who was allowed a real choice. One notable exception, when I was withdrawn from lithium (V.33), my consultant said *'these are your options, go away and do some research and then we will make a decision together'* (V.35). The duality between choice and conformity can lead to a sense of individuals *'playing the game'* and not being authentic, *'an agent under their control'* (V.47). It involved telling lies, saying what others want to hear, behaving, *'Play the game – stop being challenging'* (V.15) and *'act normal'* (V.14). I was regarded as challenging and difficult because *'I am not playing ball'* (V.33) and *'don't have to toe the party line'* (V.47).

#### **Sub-theme: Expectations**

Other's expectations of an individual are powerful too, especially when the power dynamics within a relationship are unequal (parent/child, manager/employee and professional/service user). My NHS work experience highlighted such a power imbalance. This had important implications on my sense of self, my identity as a service user role model and activist and the general status of services users working in professional environments. *'Leave your service user hat at the door'* (V.38), *'you are a service user not a professional'* (V.39) and *'your pay grade isn't high enough to support you in doing a PhD'* (V.41). My Mother's expectations were extremely high, *'all that I have invested in you'* (V.4, V.6, V.7 and V.11), *'expectations, dreams, hopes – hers not mine'* (V.5) and *'I am her star'* (V.6). Such expectations have been a tremendous burden.

‘*Low expectations*’ (V.26) can be equally damaging. Day services often acted as ‘holding pens’ and ‘silos’ for services users to attend. There was an expectation that service users will want to be with other service users. The sense of institutionalisation and infantalisation all pervasive, the future is more of the same. When a care-coordinator announced, ‘*there’s nothing out there for people like you*’ (V.22), she was partly right and in a way hopeful. She recognised that the ‘pre-chewed and lowest kind of denominator’ groups (V.26) for not for me. ‘*Getting involved*’ in ‘*mental health activism*’ (V.52) and ‘*leadership*’ (V.47) gave me a sense of empowerment and agency - important factors in recovery (Coleman, 2007, Slade, 2009, Leamy et al., 2011, Slade et al., 2014).

### **Theme 8: Communication and Voicing my Narrative**

**Sub-themes: Communication, voice and sharing my narrative.**

#### **Sub-theme: Communication**

Communication and the use of language may emphasise power differentials, separateness, stigmatization, opportunities and expectations. I used things that were said to me as the starting point of each vignette. Memories of events and experiences, reflections, interactions, actions, behaviours and conversations and my reactions were described (Ellis, 2009). The vignettes covered some of my life experiences to date, including my recovery journey. The vignettes emphasised the power of communication as a point of how we view the world, others and ourselves and how others view us. The vignettes are an example of my personal narrative. Moen (2009) suggested that it was a human process to develop narratives, because the narrative provides structure and order for life experiences. Narratives can be temporal, multi-voiced social constructions, which are dependent on individual values and cultural practices (Martin, 2009). Perhaps developing a personal narrative is even more important when a life is disrupted:

*‘those whose lives are disrupted fall outside others’ commonsense, reciprocal knowledge must use stories to establish new terms of common sense and new relations of reciprocity within a community that affords recognition’ (Frank, 2002, p.366).*

### **Sub-theme: Voice**

There is an emphasis on the importance of communication within a social world that is embedded within a particular culture. When unwell, my communication skills are poor. I disconnect and am isolated. My language-finding skills deteriorate. I become '*mute*' (V.13) and '*silenced*' (V.23). I have '*no language*' (V.17) to describe what I am feeling. This was especially true in the early stages when I had no awareness or understanding, felt only despair and blackness (V.12-14). My '*language reboots to childhood*' (V.26); thoughts oscillate between '*racing thoughts*' or '*no thoughts*' (V.12). It felt that I was unable to share what I was experiencing with others: '*when I am ill, I scream inside*' (V.37), '*I scream inside, I can't scream at them*' and '*I seethe inside. So much left unsaid*' (V.34). This may have been as a result of fear, shame, stigmatization or possible rejection. When I became an activist and openly voiced and shared my mental health experiences with others, I felt a huge sense of relief and liberation. My private and public personas became more in tune and authentic as a result.

I was aware that I used silence as a way to even out power imbalances with therapists. Given my psychotherapy training, I realized the power '*of silence*' and '*who will break the silence*' (V.30). Service users could also be powerful by withholding information or choosing not to take part. There can be a sense of power in the role of the victim too (Kleinman, 1988).

Given that narratives are social constructions that fulfill important functions, (a certain degree of communication and cognitive skills is required) in order for an individual to develop a personal narrative, I did not start to develop a coherent personal narrative until I joined an NHS Trust, when I attended training that required me to do so. I might have been developing my narrative unconsciously beforehand, but this was my first formal attempt. This needed to be considered in relation to the workshop development.

**Possible focus group discussion points:**

- What level of communication skill is required?
- Would non-verbal methods such as photography or art be more suitable especially at times when language skills are poor?

### **Sub-theme: Sharing my narrative**

I also needed to role model – show that recovery was possible, that I did not comply with common stereotypes and misconceptions of a ‘typical’ service user (Kleinman, 1988). To share my ‘disrupted yet hopeful’ quest/testimonial narrative (Frank, 1995) with others was/is about reducing the silence and stigma around mental illness too:

*‘I have used it myself (Anthony’s quote, 1993) as part of my own recovery talk delivered at conferences and staff induction. It has also been the basis of staff training courses’ (S.3).*

Equally important, was sharing the possibility that recovery is possible for all service users:

*‘.. planning to share some of my research on recovery models as well as share my own story... asked them (Carers) about ‘what they knew about recovery’ – I was immediately aware that I was in a room of skeptics and non-believers. There was little sense of hope. They didn’t believe recovery was possible or could happen to their caree’ (S.3).*

The importance that I placed on sharing my narrative with others in order to make a difference had an influence on the subject area of this research:

*‘I think that my research is impacting on what I think about my recovery especially in terms of moving forward’ (S.3).*

This highlighted the importance of knowledge and understanding in recovery – of being one’s own agent in recovery (Leamy et al., 2011).

Typically, I voiced and shared my narrative with others using a PowerPoint presentation approach. This served many purposes. *‘I like to use pictures, so that then allows me to gauge the reaction’ (S.2).* This allowed expansion, elaboration and analysis, *‘I can do this in ten minutes, I can do it in an hour...’ (S.2).* Sharing my narrative allowed me to paint a picture. I was aware that I self-censored and/or determined the content of my narrative that I was willing to share depending on the audience:

*‘And so it wasn’t all doom and gloom. So and that’s me there. So sometimes I would leave this kind of thing out, depends who I was talking to, but a sense of what was going on and so... And I would depend on who, you know, like being able to talk about anxious and avoidant and attachment, it would depend on*

*the audience'. (S.2)*

This could be due to a number of factors. I only shared what I felt able to share on any particular occasion. It was a defence mechanism. There was also an element of judging my audience (e.g. school children or mental health staff) and pre-judging their empathy. If I judged an audience to be disinterested, they would get the minimum factual account. A more empathetic audience would be given more emotional responses and 'thick descriptions' (Geertz, 1973). This is the main reason why I use pictures on my slides rather than text. It allows me the ability to decide how much I share and the audience is none the wiser. Sharing my narrative also provided evidence of my growing insight and understanding to others (Bird et al., 2014, Leamy et al., 2011):

*'I find that as I share my history with people, it allows them to open up about their own and helps develop the relationship beyond platitudes' (S.3).*

Sharing my meta-narrative (S.2) with my supervisors was a useful exercise in externalising my internal dialogue and of seeing things through another's view. This process helped our joint understanding. This was an important part of Autoethnography as method.

**Possible focus group discussion points:**

- Is it enough to develop a Personal Narrative for yourself or is a big part of the process in the sharing of it with others?
- How can individuals be supported to find their voice so that they can develop their PN?

**Theme 9: Lessons Learnt**

**Sub-themes:** Positive changes in me, on-going tensions and reflections.

**Sub-theme: Positive Change in Me**

Lessons learnt are important aspects of my recovery journey. The vignettes charted the recovery stages outlined in the Conceptual Recovery Framework (Table 1.2, Leamy et al., 2011). The stages reflected positive changes in me – a sense of what I needed to do to support my recovery and live a meaningful life.

There were a number of references in the earlier vignettes relating to a lack of understanding: '*can't explain what I am feeling*' (V.9), '*I know no better*' (V.12), '*descent into whatever*' (V.14) and '*no theories*' (V.14). '*No insight*' (V.14) and '*little experience*' (V.14) were all emotions and experiences characterised in the pre-contemplation stage of the conceptual recovery framework model (Table 1.2). The last reference to a lack of understanding was in V.22, which indicated a growing awareness of a more active self with a better sense of the mental illness. In a sense, mirroring the knowledge and understanding developed as an individual progresses through the different stages.

Whilst lack of insight characterised the earlier vignettes, the overall task of writing the vignettes allowed me to reflect on my journey, to take stock and consider what I had learnt. Writing clarified the underlying sense of my recovery journey throughout the vignettes in both a concrete, contextual sense and a subtler evolutionary sense evidenced by:

*'doing things differently... there are clear learning points and points that I do feel proud of. Yes, I felt crap and thoughts of self-harm crept in over the weekend. But they were just that, thoughts. These feelings have not been acted upon and have not derailed me'* (S.3).

The vignettes described '*growth*' too – '*the importance of being assertive*', and '*the endpoint, was above the game line*' (S.1). From deeply dark, destructive, chaotic descriptions of my experiences in the earlier vignettes, the vignettes gathered momentum towards recovery '*...towards the light*', (S.1). The latter reflective vignettes showcased a movement from hopelessness to hope and a reduction in my need for external support to the development of my internal drivers – a rediscovery of a sense of self, adulthood and agency. The reflective vignettes were less anchored to a particular time, place or incident but are more global points of learning, characterised in the later stages of the Conceptual Recovery Framework (Leamy et al., 2011). There was a growing sense of resilience: '*discharge is not a place of failure*' '*...discharge is a place of freedom, risk, ownership and agency*' (V.42), '*we are all survivors*' (V.50) and '*Getting back on the horse*' (V.52). There was a more positive sense of self, '*that is why we are so attracted to you*' (V.53), '*we are fully human again authentic and complex*' (V.50) and '*our time has come to be us again*'

(V.51). There appeared to be hope for the future, '*you are an inspiration*' (V.54) and '*I am making my path by walking it*' (V.54). The latter vignettes described epiphanies (Ellis, 2009) that were key moments of learning – light bulb moments rather than a more gradual realisation: '*I bet that you are borderline*' (V.45), '*I wished that she had just killed herself*' (V.46), '*Don't you know that I am borderline*' (V.48) and '*The old Sam*' (V.49). Epiphanies seemed to offer moments of clarity that helped my recovery.

Over the time-line of the vignettes (Fig 4.1-4.3), there was evidence of *positive changes in me*, '*discovered new me's*' (V.48), '*doing things differently*' (V.49) and '*breaking the cycle*' (V.13). There was a sense of taking stock, of growth, of being '*more human, compassionate*' (V.48). Gaining new knowledge and an understanding of my strengths and weaknesses, '*I acknowledge intolerance*' (V.49). There was a growing ability to take responsibility, '*I'm growing into an adult*' (V.49). There was increased connection with the world, '*Life is too short – bring only the best wine*' (V.50), '*reconnecting with lost friends*' (V.52); of '*taking risks*' (V.52), a growing '*confidence*' (V.52); and acceptance that recovery was really possible. Throughout the vignettes there was a noticeable change from hopeless to '*hopeful*' (V.22). '*Hope*' is vital in my recovery journey, '*you are worth saving*' (V.28), and '*wounded but not defeated*' (V.47).

A large part of the change in me, evidenced in the vignettes, was the reconnection with my core values (Vignette 54) and a refocusing on what I wanted to do and to be and not what others wanted me to be. This has been a powerful and liberating transformation. A part of my reconnection with the world and the development of valued social roles has been due to my desire to be '*making a difference in the lives of others*' (V.52), to '*forge ahead and inspire others*' (V.53) and to be '*contributing*' (V.49). These changes in me highlighted the multidimensional process of recovery (Slade, 2009, Leamy et al., 2011, Slade, 2012, Bird et al., 2014, Slade et al., 2014).

### **Sub-theme: On-going tensions**

Throughout my journey of recovery, there were considerable internal and external tensions that required on-going resolution. Given the inherent power differentials (including legislative power) and the fact that mental health services operate within the medical model, there was a continuous, yet unresolved battle between choice and compliance/conformity:

*'whilst I'd got the choice; I haven't really got the choice, so it's "play the game"' (S.1)*

*"You have no choice" again, and that around medication and when I used to say to the psychiatrist, "These are the side effects" and that's what you've got to live with because it's that' (S.3)*

*'I was told 'not to have another child because of how ill I had been with John Doe.... This decision, which I have always felt, wasn't really a decision for me or rather not a choice has left me with huge amounts of guilt. I sometimes watch John Doe. I grieve for the fact that he doesn't have siblings, will have no one to share loss' (S.3).*

Overcoming default thinking was another battle; 'yet still I had to go through all the default thinking of blaming myself and feeling inadequate!' (S.3). I have to work hard to accept being good enough – 'daily battles of being good enough' (V.52), especially around my role as a mother (V.23). Part of acceptance is about acknowledging all parts of who I am, including the good parts – the achievements. It is 'harder to acknowledge achievements' (V.52) probably due to my childhood experiences with my mother 'where's the other 2%' (V.5). I am left with the 'sentiments and attributes that leave me squirming' (V.54). Learning the value of acceptance (V.54) has been important but never easy:

*'acceptance of the loss and creating new meaning is what drives my recovery' (S.3).*

*'I suppose that there was no acceptance that the transition from illness and disability to wellness and ability could in itself be meaningful. It was an all or nothing position – a binary position, which in mental illness doesn't exist anyway. I feel that I have lost years to this illness, years of lost identity and meaning...' (S.3).*

*'I have accepted that I need to learn new skills and unlearn other skills, I will get huge amounts of feedback and critique and have to accept and work with it – and that this is all ok' (S.3).*

There was an on-going tension between my public and private worlds – through the process of sharing:

*'....I am presenting my authentic self – my private persona is made public. The possible reactions and therefore self-defense is ready – I am opening myself up to the possibility of rejection (a big one for me)' (S.3).*

This was particularly relevant to the autoethnographic process itself. It had the potential to raise further tensions regarding the impact of telling my narrative on those I have on-going intimate relationships with. There narratives are within mine (Ellis, 2009).

I have to '*work at my recovery*' (V.52); staying on an even keel '*takes effort and energy*' (V.49). I live with realities of medication, side effects and suicidal ideation. In order to maintain my wellness, I use my '*recovery tools*' (V.48):

*'So much has happened, major battles, small skirmishes, advances into enemy territory and ultimately new ground won. Even though the veneer of wellness, is just that, I have been able to use my tools, when I know that in the past, they would have been beyond me. Also new insight gained – wellness or my wellness is a veneer that I have to work hard at to keep buffed up' (S.3).*

Reflecting on the vignettes highlighted new skills that have become an important part of my wellness toolkit, such as mindfulness:

*'Yeah because I catch myself when we're walking down the beach. You know when I say, when we were walking along the shore and I said, "I can really smell the brine here"' (S.1).*

Reflecting on the vignettes highlighted the importance of being able to work as an indicator of my wellness and recovery. However work tended to be referred to indirectly and contextually rather than directly. This is similar to John Doe's coverage. Both are central to my core values yet I have subconsciously omitted or downplayed them in my vignettes. This may highlight the importance of timing (and narrative development and sharing) and creating a psychological distance in what is created and shared with others.

### **Sub-theme: Reflections**

The latter vignettes contained many realisations and learning points (determined because of the process of developing a narrative):

*'but also one of the things I have acknowledged while I was writing these last vignettes, was that when you learn something or you have a Eureka moment, that comes out of experiencing the shit. You know, it's not about having an insight; to get the insight you've got to go through the pain' (S.1).*

Reviewing the vignettes allowed for perspective taking and gaining a global picture from piece-meal experiences and individual events (Ellis, 2009):

*'But I think to me, it was really, doing these Skills for Life courses was a sense that it brought it all together in that, doing the psychoanalysis and CBT, the CBT was saying like, "You have the suicidal thoughts - Distract, do this, do that." Not actually thinking, well what is going on behind that thought? And from me, the Skills for Life and looking at all the emotional stuff was saying, "Actually, yeah, it's okay to be angry, it's okay to feel all the gambit of emotions'" (S.1).*

*'Then the last two [vignettes] was "The old Sam", now that's the phrase I used all the time; "The old Sam wouldn't do this, the old Sam would do it this way" and again it was my manager [in the NHS] who said, "You're always saying 'the old Sam', and actually it's a load of bollocks". When I was writing the vignette about it, what I decided I was doing there was reminding myself of the changes that I'd made' (S.1).*

When the vignettes were written, the ordering and labelling process and the grouping together into themes also allowed further insight to take place. The discussion with Don (S.1) about the vignette content was important, *'it's interesting because if you look at this you really do get a view'* (S.1). The importance of collaborating, sharing with others, and developing shared meaning with others was invaluable:

*'..if you'd been able to say, you know because one of the theories on depression is it's anger that you can't express to the person you're angry at, so you turn it on yourself, isn't it? So, that idea that if you'd been able to say to your mum, "I'm really angry with you", "I'm really pissed off with you" some of that stuff wouldn't hold the power that it holds' (Don, S.1).*

*'No but so, the antidote is what that told you, that flash of inspiration clarified that, that's how you felt, and we feel what we feel. And that, you know just what you've just been saying about it, you know it's okay to hate; it's okay to feel angry' (Don, S.1).*

*'It's that thing of, "Right, we'll go backwards, to go forwards" but I could say that probably you could go through all of those and say, each vignette, at the*

*end of the vignette, "Am I over that the game line or not?" (S.1)*

My recovery is not linear or straightforward but more of the spiral described by Slade (2009). There was and is 'ambivalence' regarding situations, relationships, emotions (V.44 and V.48) and how I feel about my recovery.

**Possible focus group discussion point:**

-Whether it is important that individuals are encouraged to think about the key recovery themes of hope, agency, resilience, evidence of growth, a positive sense of self etc. in their development of their PN/RN?

**Theme 10: Reflections on my Process of Writing Autoethnography**

**Sub-themes:** Revisiting trauma, creating distance and my writing process

Revisiting trauma and creating distance were two factors highlighted within the theme of reflections on my process of writing autoethnography.

**Sub-theme: Revisiting Trauma**

*'I am thinking about my recovery as an Autoethnographer. Over the past few days, I have been reading and reflecting on my process and how I will make my experiences worthy of writing about academically. I have been rereading [the] Ellis (2009) and Ellis et al. (2011) paper about doing ethnography and I am mindful of not being self-indulgent' (S.3).*

Writing and 'reliving torturous times' (V.52) was a difficult part of the process of creating the vignettes. In my process diary, I wrote about the emotional experience of writing the vignettes. When I wrote the vignettes, I viscerally relived each experience – telling it like it was (Wall, 2006). The vignettes were often written with little or no punctuation because the experience itself was often messy and unpunctuated (Ellis, 2009). The messy text of the earlier vignettes e.g. 'I don't know who you are anymore!' (V.12), 'I don't know if I can do this anymore' (V.13) and 'I can't let you leave' (V.14) described the chaotic and deeply distressing experiences and memories leading up to the catastrophic event of my breakdown. I made no attempt 'to pretty it up' (V.53).

### **Sub-theme: Creating Distance**

The process diary allowed a sense of distance (Short et al., 2007), an opportunity to question, reflect and ponder internally. It allowed me to understand the bigger picture, a sense of the direction of travel towards living a meaningful life. Writing the process diary gave me a degree of relief too. Naively, I thought that writing the vignettes would have been reasonably easy, as I had developed a number of recovery narratives that I have shared with many different audiences:

*'Did producing my narrative as a presentation – and a viral one at that – fulfill a defensive purpose? I think that it probably does as I can choose how far I want to expand on any one point at any time depending on how I perceive the audience is receiving my material' (S.3)*

*'I like the idea of thinking about the multiplicity of different identities. I remember using this in my earlier narratives for [the NHS Trust], but perhaps have moved away from this. I will need to revisit it. I am really struck by the multitude of narratives and the differences relating to the different audiences – I know that I do this and it is something that I can pick up in my autoethnography. The idea that I tell different narratives to different people and how the audience impacts on this' (S.3).*

I wondered whether developing my narrative in a different medium (presentation to written form), contributed to my emotional response to the vignettes? Writing allowed me to explore my lived experiences in different ways. I found the vignettes difficult to write and analyse:

*'I have found the whole process exhausting. It fills my head with white noise, with questions, memories and tangible memories of smell etc.' (S.3)*

The vignettes contained a significant amount of material, such as my childhood memories that I have never shared, written about, considered or processed in the light of my recovery. I hadn't rehearsed, reframed or retold them in any way before writing them as vignettes (Lahad, 1992, Parker and Wampler, 2006, King et al., 2012). Whilst writing each vignette, I allowed myself to be transported and immersed in each moment and experience. One vignette triggered another (Frank, 1995). I wrote with a stream of consciousness without the self-censorship that editing would usually provide. In the moment, I wasn't writing for an audience but for myself. This may have contributed to how much I relived the initial trauma:

*'I have been reflecting on my process and what I will be asking people to do – is it too much to ask people to relive their trauma? I thought back to the time*

*that I did my first storyboard. In reality, what I am doing now is very different. I am reliving specific moments rather than glossing over them as a statement of fact that the storyboard scenario wanted me to do. The storyboard is far more controlled and people are encouraged to look to the future and consider what they have learnt – is it a more manageable, less distressing task? I am not asking for a blow-by-blow account. It is an interesting thought that I hope to pick up in the focus group' (S.3)*

### **Sub-theme: My Writing Process**

The time I took to write and put the vignettes in order was relevant. Writing the vignettes took 3 months - in addition to the months of planning and years of thinking about it. At a particular point, I made the conscious decision to stop, that I had written enough – largely at the point when I had written the latter, positive vignettes. There was balance; the vignettes were not a series of pure misery. There was light too. Regarding my narrative truth, this felt appropriate.

#### **Possible focus group discussion points:**

- How much time would it be reasonable for an individual to take in developing their Personal Narrative (PN)?
- What are the implications on the development of the workshop programme?

I wrote the vignettes without any day-to-day support. I had any subsequent discussions about the vignettes and my emotional response with myself, in my head or in my process diary:

*'quite a bit of time to myself to process the process – escaping to the solitude in my head' (S.3).*

*'Don mentioned that after I have been writing, I appear very disconnected from the present and him in particular. I am in some far off place, lost in my own world, inhabiting the time of whatever I have been writing about' (S.3).*

Once I had completed the vignettes, I shared them at supervision and with a trusted friend, but this was after the fact – after my difficult emotional response:

*'we talked about how I had been feeling and I said that it had been a very cathartic experience especially after the learning that took place' (S.3)*

#### **Possible focus group discussion point:**

What support whilst writing the PN/RN should be factored into the workshops?

*'I believe that I am really growing as a result of this work – I am gaining a better insight into what has been happening to me over the past years' (S.3) and 'how*

*my research is informing my views of recovery and my own journey' (S.3).*

Writing the vignettes (V.1-54) and my process diary (S.3) along with the discussion with Don (S.1) and the meta-narrative discussion with my supervisors (S.2) has given me a better understanding of the reframing process (Ellis, 2009). In particular linking the time-line (Fig. 4.1-3) to the vignettes led to the realisation that initially there were no positive vignettes and that there was no balance or a sense of recovery. The earlier vignettes were a series of chaos narratives (Bruner, 1987, Kiesinger, 2002, Slade, 2009), with no unifying thread. The writing process and the reflection, which led to the additional 'epiphanies' and 'what I have learnt vignettes' highlighted the learning that had taken place, my growing sense of agency and empowerment - '*you are an inspiration*' (V.54). For example, the additional vignettes emphasised my growing role in my social world with the evidence of my growing connection to others, '*that is why we are so attracted to you*' (V.53) and '*Sam, you are so naughty*' (V.51). Frank (1995) suggested that the final stage of recovery was one of 'maintenance and growth' – a sense that the individual was able to live a full and meaningful life, where they are living beyond disability, are active agents in their own decision-making and are self-reliant. This is how I see myself now. This journey from passive, unknowing, chaotic, dependent on others to one of 'maintenance and growth' is documented in the vignettes. This autoethnographic process has allowed me to make the connection between the two.

### **Theme 11: Creating Vignettes**

**Sub-themes:** Writing the vignettes, collaborations and making connections.

#### **Sub-theme: Writing the Vignettes**

The vignettes were written over a period of time and developed from a number of personal narratives and recovery stories that I had written and presented to a variety of audiences. There was opportunity for refinement, reflection and further developing my narrative:

*'If you are looking at how you could do it, one of the things for me that I think is really important to do a bit, reflect, do a bit more; that it's not a once....' (S.1).*

Roe and Ben-Yishai (1999) added, 'people with severe mental illness may need to construct and then tell and continue to tell the story, deepening that story, re-positioning themselves as people who can narrate their own story while making efforts to successfully engage in daily life'. The act of writing the vignettes had an important impact on my sense of self. Developing and sharing a personal narrative could have therapeutic benefits such as a more positive sense of self and a growing sense that change is possible. Especially the latter vignettes (V.48 and V.52), which were reflections on what I had been through and what, I had learnt as a result. I was '*regaining a sense of self*' (V.52).

Reframing can allow sense to be made of what has, and is happening through the development of new meanings and insight. Integrating experience and new understanding can provide the necessary coherence and platform for further recovery. A significant consequence of reframing could be the development of a more positive identity, with the growing ability of the individual to distinguish between the 'me/it (from 'I am a depressive to I am an individual who has depression' – the illness is no longer the totality of the individual's identity' (Slade 2009). Over the course of writing the vignettes there was a feeling of a changing tone, a temporal and a positional shift - from the 'chaos narrative – to the quest and testimony narrative (Frank, 1995).

#### **Sub-theme: Collaborations**

There was the 'emerging', evolving, multi-voiced sense of what a narrative is (Moen, 2006) with the vignettes reflecting elements of co-construction of memories:

*'stuff with your mum; some of the things, and it may come into "Where is the other 2%" "Oh I thought you were going to be a lawyer and then I thought you were going to be a journalist" and there was a sense of "All I've invested in you with this and it's going to come to nothing' (Don, S.1).*

In the discussion with Don, there were examples of differing memories, some of which were contextual and temporal such as '*It was actually November*', (S.1). Other memories differed due to differences in viewpoint:

*'well my memory of it was just I was there and he was explaining about things and you were disagreeing' (Don, S.1).*

The development of shared meanings (S.1) as part of the process of developing the vignettes were important too:

#### **Discussion thread 4.2**

'I don't think you were trying to say that was a completely different person, which is what I think perhaps she was suggesting. The other day, you were saying, you said, "The old Sam", so it's still you. I suppose it's a shorthand for, "Two years ago, when I was at my lowest point, I would have done things differently". So you say, "The old Sam have done this"'

'.. and actually the "reclaiming" bit is about, it's almost recovering from the mental health services isn't it? It's about them no longer dominating your life'

'You know, some of these are hard places to be taken back to. I suppose what you're trying to do is bring out, and if I read the whole vignettes, that you know, the quote is often the start of the shitty bit, which then I presume you're bringing out some, you know, there is some lotus flower budding within the words, so kind of... The vignettes give the whole picture' (Don, S.1).

The discussion with Don (S.1) highlighted that I had omitted several influential experiences and relationships:

*'I've given titles and then within each part, there's a number of vignettes, and I just wanted to tell you the topic areas and see if you think I've missed anything out' (S.1)*

*'... and the OU being, the psychology being so important' (S.1).*

This allowed the opportunity to consider whether I actually wanted to include certain experiences or not – what I wanted to share:

*'Is there a vignette that is, "I'm glad I didn't kill myself"? (Don, S.1).*

There was not, and I did not write one to include in the second draft. This may reflect my on-going tension and ambivalence:

*'Do you know, I thought about it and I thought, I don't want to do it because I was thinking that people are going to read these and think, God, she is a negative person' (S.1).*

*'There was stuff that you mentioned, that I thought actually I wasn't going to go there, I couldn't go there and now I feel enough removed from it, that I'm ready to look at it again' (S.1).*

### **Sub-theme: Making Connections**

The vignettes (especially the first draft which contained much of the difficult material) were written as it was, rather than with a message or recovery learning point in mind. Once the first draft was written, I began the process of putting the vignettes into a coherent order that made sense to me and to provide a story line for others. Sorting the vignettes into a recognisable timeline, putting similar themes into sections by making connections and adding appropriate labels (E.g. '*thriving not surviving narratives*' S.1) moved the vignettes from a series of experiences into a recognisable story with the emphasis on the overall message of recovery:

*'... so the next set are the ones that I feel are about when I sort of hit rock bottom and start to move, so started to get some treatment etc. So "Beginning the Long Ascent"'* (S.1).

*'I think that needs to be one of the later vignettes as well'* (S.1).

This process of editing, the collaborative discussion with Don (S.1) and my journey reflections helped balance the material and gave it an overall sense of recovery, '*I had had to refocus and reframe in order to continue with this process*' (S.3). This subtle shifting of the vignettes from a personal narrative (telling my story) towards a recovery narrative (offering a message to others) '*I thought to end on a high*' (S.1). On rereading the vignettes, they seemed to have learning points that added to the overall sense of developing awareness and understanding of my life towards recovery:

### **Discussion thread 4.3**

S: 'I was saying about the quotes or the headlines; it's almost like they're the skeleton and you need to help people to be able to... Because people want to get it all down, but, "The Recovery Narrative" isn't it all, it's "What have I learnt?" So it's almost like the painful memories and the hopeless part is the below ground; it's almost like they are the roots. Then, "The Recovery Narrative" is about what happens above ground, in the light. So it's, you need to do some plotting of the roots, to be able to give it structure, but you need to focus on what happens from the ground up...' (S.1)

D: 'That's, what connects that kind of stuff, but that's not the recovery narrative is it? That's a timeline, but maybe it's an important step. In terms of the four tasks' (Slade's, 2009, Personal Recovery Framework)...

S: Yeah, the reframing, you need to get it in order before you can then start making some sense of it. I guess what you're looking for is, "What were the tipping points?" Were there tipping points where you suddenly, flashes of inspiration, "This is what moved me forward". You could almost do, if you did a line and said, "Right, for each one of these, did it take me below the line and then back up above the line? Or did it just take me below the

line?" (S.1).

## Theme 12: Methodology

**Sub-theme:** Autoethnography as method.

### Sub-theme: Autoethnography as Method

There was limited experience of using autoethnography as a research method in the Faculty of Health Sciences. Both my supervisors were unfamiliar with the method.

Using autoethnography within this study has been a journey of discovery for us all.

There were initial concerns about '*stepping outside mainstream academic practice*' (S.3). I made a case that provided a solid rationale for using this methodology. It was important that it would not just be an exercise in '*naval-gazing*' (Sparkes, 2002) (S.3):

*'I have reread a couple of articles that I read over the summer (Wall, 2006, Ellis et al., 2011) with more interest – I was reading them with an awareness that I had a little bit more knowledge. Ellis's article was an overview of the methodology whilst Wall's was about her journey of exploring the methodology and writing the article in an autoethnographic style. As I read and wrote my paper, I am increasingly excited about using this as my methodology' (S.3).*

In March 2014, I attended a Mental Health Qualitative Research Network (MHQRN) presentation on autoethnography (Grant, 2014):

*'Alec Grant (Brighton University) spoke my language – the importance of all the bits that are left out of traditional research – the body language, what is left unsaid, how the narrative evolves... He talked about 'hybrids' which is exactly what I am – a person of many identity's – can they be integrated and reconciled?' (S.3).*

Grant's presentation convinced me of the importance of including autoethnography within this study. It was crucial that I undertook my autoethnography and the subsequent thematic analysis. This was important given that the emergent data gave rise to factors to be considered when developing the phase 3 workshop. The data from my autoethnography was the building blocks for phase 2 and 3 focus group work. I have a much better understanding of my process as a result of developing and analysing the vignettes and an appreciation for the process of others. I have a clearer idea of my recovery journey too and the distinction between a personal narrative and a recovery narrative:

*'if you were just asked to write your story, would you be getting that (recovery narrative)? Or within a framework that I develop, would I be helping people to move beyond that (just writing about negative things)?' (S.2).*

I am not sure that I would have been able to develop the phase 2 focus group discussion points (that have emerged from phase 1) in any other way. The focus group discussion points have a greater depth and subtlety.

Writing my process diary (S.3) was an important part of phase 1. I started writing in October 2013, a full year before I wrote the first vignette. It charted my exploration of autoethnography as a methodology, building a case for autoethnography in this study and my process around writing and analysing the vignettes. It is a valuable supporting document giving an understanding of my process in developing my personal narrative and its effects on my recovery:

*'where to start or whether I wanted to. Where were my corners, my boundaries and the completed picture to work towards?' (S.3).*

*'Even though I talk the talk and walk the walk – I didn't allow myself to fully consciously acknowledge that shit is still happening – it is how I deal with that has changed – for example 'The teashop by the sea. The vignettes reflect the learning and the increased insight but this doesn't stop the initial experience of trauma when facing difficult experiences. This is really important because developing the narrative does not make everything better and make life rosy – it does allow reflection and perspective, but the trauma is still and continues to be experienced' (S.3).*

### **Theme 13: Reflections on the Process of Others**

**Sub-theme:** Reflections on the possible process of others'

#### **Sub-theme: Reflections on the Possible Process of Others'**

Before writing the vignettes and completing the analysis, what I expected others to do in terms of developing their personal narratives (and the possible effects on their mental health of doing so), was only partially thought through. Developing my own autoethnography helped me consider what the process might be like for others, *'it's already informing some of the questions I want to ask the focus groups'* (S.2). I had a growing awareness of the potential enormity of the task and a consideration of the possible ways to support individuals to navigate and therefore make the process of

developing a personal narrative more manageable. For example, I used quotations as 'coat hangers':

*'I'm just wondering, in terms of the eventual aim of this (to work with people), I'm thinking of stuff for myself as quotes or headlines; you could think of them as headlines from the tabloids.... tabloid headlines, and maybe that's an approach because if I wrote, each one of those quotes, you know instantly the whole situation that goes around it and as an aid to developing the narrative, doing those as, help people put them together and then work out which ones should be embellished as part of a recovery narrative and which ones should remain as just that's part of the pre-recovery narrative' (S.1).*

*'The storyboard is far more controlled and people are encouraged to look to the future and consider what they have learnt. Is it a more manageable, less distressing task? I am not asking for a blow-by-blow account....' (S.3).*

I have a better awareness of the need to support others through the process:

*'one of the things that's come out of it is thinking it's really hard, this stuff, because it's there and I'm going to be asking people to go to these places, how do I support them to look after themselves?' (S.2).*

My process raised a number of issues about:

*'the emotions that I had been feeling (in writing the vignettes), could be felt by participants writing their recovery story' and 'I was stuck in the crap – probably what many of the participants would be feeling and/or situated' (S.3).*

*'keeping people safe during the process of sharing', 'whether people are ready to do this work', 'whether it is right for everyone to do this work' (S.2).*

I wondered whether it is too much to ask people to relive their trauma:

*'What is included and what is left out – I am aware that I have concentrated on all the crap stuff to the detriment of the better – but this is where we ask people to begin their narrative, so they have to wade through the crap so might not be able to go any further and they are left with additional evidence of loss, distress and failure' (S.3).*

These concerns were explored in the focus groups in phases 2 and 3, based on my autoethnography.

#### **Theme 14 What I have learnt as a result of writing the vignettes?**

**Sub-theme:** What have I learnt?

### **Sub-theme: What Have I Learnt?**

At the start of my PhD journey I held the view that developing a personal narrative could only really be a positive experience and would naturally support recovery. I now have a greater appreciation of the complexity of the subject matter:

*'if anything, having done this work, I'm less of a "oh there's only one way to do this" and I'm probably more open now that I was a year ago' (S.2).*

Through my autoethnographic process I gained new insights into the process of developing a personal narrative. It provided an opportunity to reflect on my recovery journey including reliving past trauma and achievements. It highlighted areas of growth and new understanding. The overview provided evidence of reframing - the integration of the 'old Sam' and the 'new Sam' and the learning that has taken place over the course of the journey evidenced by the vignettes:

*'Yeah, the reframing, you know, you need to get it in order before you can then start making some sense of it. I guess what you're looking for is, "What were the tipping points?", were there tipping points where you suddenly, you know, flashes of inspiration, "This is what moved me forward' (S.1).*

I am mindful that the picture painted by vignettes was still one of my choosing. During the writing process, I chose what to write about, what to include, what I was ready and willing to share (whether consciously or not) and equally what not to include and to omit. I am also mindful of who I will share my vignettes with in their current form (Ellis, 2009):

*'If I gave people my vignettes, there is really no hiding – they see and feel all the blood and guts' (S.3).*

*'I realised that whilst I openly talk about my depression and anxiety, I rarely talk about my BPD traits diagnosis. At some level, I appreciate that this is another level of discrimination.... This is something that I need to reflect on... what happens in the sharing part – what is left unsaid?' (S.3).*

*'My story is still raw enough that I need to share it with people who will acknowledge rather than criticise it – with comments like 'it is easy for you to say', 'you are intelligent – this wouldn't work for my son' etc....' (S.3).*

Craig (2003) characterised this as 'bad faith narratives' but this detracts from the point of developing a personal narrative in this context – as a vehicle to develop self-understanding, shared meaning and ultimately recovery.

There was a huge emotional response in writing and analysing the vignettes. I wrote about difficult and traumatic experiences, '*suicide is very much part of my story and it needed to be in there*' (Source 3). I relived past trauma, '*writing about things brings up the triggers and all the unresolved hurt, again and again*' (Source 3). I needed support to work through my emotional responses. There was a sense of '*putting words to previously wordless emotions and experiences (Frank's chaos narratives)*' (Source 3):

*'I had been writing and reflecting retrospectively on very traumatic events and experiences, when at the time I had no language to express the emotion. I was able to do so now, but at the same time reliving the trauma. For me, understanding what went on is part of my learning and reframing – it is important for me to understand the chaos. To move forward I need to understand the past' (Source 3).*

In August 2017, I published '*From the Edge of the Abyss to the Foot of the Rainbow – Narrating a Journey of Mental Health Recovery: The Process of a Wounded Researcher*' (Robertson et al., 2017). As a process, this was traumatic too, because the vignettes and their analysis (50 years of lived experience) had to be edited and condensed into one paper. I had to choose what would go in and what would be cut. Also, the act of publishing left me feeling vulnerable. I was opening myself up to the wider-world and possible criticism.

#### 4.5 Discussion

##### **The Vignette Topics**

There were factors that I thought were important in my recovery, including reframing experiences and the role of stigma that were hardly mentioned (few codes) in the vignettes or in the process data sources. I do not think however that the small number of codes was a true reflection of their importance. It could be because they were not explicitly mentioned and therefore did not become a code to be counted. When the data sources were reread, there was significant evidence of reframing as a process, especially in the latter vignettes ('looking back on', reflections) and in the process discussions. Reframing did happen but it was not formally acknowledged. This is also true of the role of stigma. Little mentioned but influential in my behaviour, decision-making process and self-identity. Similarly the

concept of 'journey' (the dominant metaphor in recovery), and the underlying timeline, was not a key theme but is important in contextualising, understanding and making sense of mental health experiences and movement towards recovery.

### **Personal Narrative or Recovery Narrative**

Of particular interest was what was included and omitted from the vignettes. I did not include important relationships, which were pivotal to my recovery (e.g. Jim my Care-Coordinator). This possibly highlighted the difference between a personal narrative and a recovery narrative. It is not always the case that a personal narrative is a recovery narrative. The difference between the two may be the emphasis that is placed on evidence of working towards recovery and inclusion of reflections of learning, development and growth. A personal narrative does not necessarily have to contain any of these factors - a difference between Frank's (1995) 'quest' and 'testimony' narratives and the 'chaos' and 'restitution' narratives.

### **Timing**

Timing seemed to be a crucial factor in developing a personal narrative. This autoethnography and the analysis highlighted a number of questions such as:

- Is there a 'right' time to start the process?
- Is there a particular stage of recovery that developing a personal narrative is more suited for?
- Should developing a personal narrative be a one-off exercise or part of an on-going part of an individual's recovery process?

My analysis suggested that different aspects of the personal narrative could be tackled at different times. There were times when I couldn't 'write about a specific memory' but at another time I felt able to do so. I often need to 'do a bit', then reflect, and take time out and then 'do a bit more'. Writing the vignettes was achieved by building little blocks – it was not a one-off activity, especially as much of my processing was done when I was not actually writing.

#### **4.6 Methodological Reflections of using Autoethnography**

As the autoethnographer (phase 1) and the researcher (phases 2 and 3) of this study, I was interested in a combination of autoethnographic forms. Reflexive ethnographies document how the research changes whilst doing fieldwork. Having written my autoethnography, and on reflection, I realised the absence of positive experiences. This did not reflect my lived experience (reference my timeline Figs. 5.1-3). This reflective process enabled the writing of the 'what I have learnt' and the 'epiphanies' parts of my autoethnography. Ellis (1991) suggested that one could use introspection as a data source. The emergent themes of both the content and my process in writing the autoethnography informed the subsequent phases of this study. I realised that writing about positive aspects of my lived experience was much harder than writing about the difficulties. This may be true of others too and therefore was explored in phase 3 (workshop development). People may need to be supported to include positive as well as negative elements of their lived experience within their narratives.

There was an element of heuristic inquiry too – a sense of exploration and discovery within the research process (Kleining and Witt, 2000). Moustakas (1990 cited in Wall, 2006) stated that 'heuristic inquiry has arisen from the phenomenological tradition and began with a question that has been a personal challenge for the researcher'. In phase 1, I wrote and critically analysed my recovery narrative. I was mindful of the potential influences that affected this research, results and analysis including: my role within the culture that I intend to study (adult mental health recovery community in Hampshire, UK); my relational ties (Ellis, 2007, p.6) to my family; professionals that I worked with as a service user; other service users (co-researchers) with whom I worked with in this study (phase 2 and 3); and my own process in carrying out this study. The autoethnographic process has impacted on my life beyond this study. For example, I work as a mental health trainer and I am aware that I have made changes to what and how I deliver my training in the light of my research and my developing ideas around recovery.

Autoethnography can be a therapeutic process in itself, 'writing as a way of knowing, a method of inquiry' (Richardson, 2000 cited in Ellis et al, 2011, p.5). In this autoethnography, I analysed the underlying processes involved. As a result, I developed new understandings. In developing 'self-knowledge' autoethnography allows others to know too – making 'witnessing possible' (Denzin, 2004 cited in Ellis et al, 2011, p.6) and thus offers the potential for change. Witnessing and acceptance by others can validate one's own experiences. This is important when the subject is a difficult one, such as mental health.

#### **4.7 How Autoethnography Informed Next Phases of this Study**

The main reason for this autoethnography was to explore the process of developing, writing and analysing my mental health and recovery experiences in order to inform the focus group phases of this study. The data that emerged from the analysis of my autoethnography was the starting point for discussion within phase 2 focus groups (Table 4.6).

#### **Points to Consider in Phase 2 Focus Groups**

**Table 4.6: Phase 2 Focus Groups: Possible Topic Areas**

Possible Topic Areas	Comments
What is the difference between a personal narrative (PN) and a recovery narrative (RN)?	The process of developing and writing my autoethnography as the first phase of my research has helped clarify the subtle differences and the sense that we may label something as 'xxx', but the content may not actually match the label. As part of the focus group work, I think that it is crucial to discuss the interchangeable and indiscriminate use of 'personal narrative' and 'recovery narrative'.
Are the developmental processes similar/different in developing a PN or a RN?	Will processes such as reframing become more important?
What should a PN or a RN include?	Is this a matter for each individual?
Did factors such as stereotypes, stigma, relationships and roles affect your PN/RN?	Will individuals need to overtly consider these factors in their narrative development?
Do you need to revisit trauma or concentrate on the learning and personal development aspects?	If it is a RN, should the role of trauma be downplayed? If a PN contains more trauma material than a RN, will there be implications in terms of time needed, support in what to include/omit, emotional support etc?
How did the PN/RN that you developed represent a true reflection of yourselves?	In what ways is a PN/RN a mirror or a mask?
Did writing your PN/RN have any effect on	What is the impact on developing a narrative –

how you saw yourself?	including moving forward?
What were the effects on on-going relationships, sense of self as a result of developing your PN/RN?	Writing the vignettes had important consequences on my on-going relationships Relational ethics
What did it feel like whilst developing your PN/RN?	Emotional response
What did it feel like after completing your PN/RN?	Emotional response
Is it enough to develop a PN/RN for yourself or is the sharing of it with others important too?	The timing, willingness and ability to share needs to be determined by the individual, but that doesn't mean that it will never be revisited.
When is it appropriate to begin developing a PN/RN?	At what stage would it be appropriate to undertake PN/RN development work? If it is appropriate for all?
Is developing a PN/RN a one-off activity or an in-going activity?  What might this feel like?  Hopeful for the future?	This is an important consideration for the workshops. In developing their PN/RN, am I asking an individual to produce a snapshot of a never-ending process?  Can the workshops provide the tools for the individual to continue developing their narrative outside of the workshops?
Did developing a PN/RN contribute to your mental health recovery?	Reflections from focus group co-researchers
In what ways did developing a PN/RN contribute to your mental health recovery?	Reflections from focus group co-researchers

### Points to Consider in Phase 3 Focus Groups

Added to the points regarding narrative development that emerged from the analysis of my autoethnography in phase 1 and in the light of the phase 2 focus groups discussions, these points were considered and discussed in the phase 3 focus group (Table 4.8). At this stage this table was incomplete.

**Table 4.8: Phase 3 Focus Groups: Possible Topic Areas**

Possible Topic Areas	Comments
How can the workshops provide the necessary framework to support the individual to develop their PN/RN?	
Is it appropriate for all service users to have the opportunity to develop a RN/PN?	
How do we support people to include positive evidence?	Support whilst writing the PN/RN should be factored into the workshops.
How much do we encourage someone to include all aspects of their PN/RN?	An important consideration is whether it is important that individuals are encouraged to think about the key recovery themes of hope,

	agency, resilience, evidence of growth, a positive sense of self etc in their development of their PN/RN?
Should individuals include whatever they want to?	
How can individuals be supported to describe the trauma of their experiences (what they have come through) in order to reframe, contextualize and learn and move on in their recovery journey?	
Is therapeutic input a necessity prior to my programme?	
What might the training needs be for peer supporters?	
How much time would it be reasonable for an individual to take in developing their PN?	What are the implications on the development of the workshop programme?
Is developing a time line a useful first step?	
How can individuals be supported to find their voice so that they can develop their PN/RN?	
What level of communication skills is required?	
Would non-verbal methods such as photography or art be more suitable especially at times when language skills are poor or when a greater need for distance is required?	

#### 4.8 Chapter Summary

This chapter described how my autoethnography was conducted and the thematic analysis procedure followed, in order to develop the vignette content and process themes from the emergent data. Within the analysis, important narrative development points came to light. These points were carried forward as discussion points for the phase 2 focus groups (Table 4.4). In addition, some points, more relevant to the narrative workshop design and implementation were carried forward to phase 3 (Table 4.5).



## CHAPTER 5 PHASE 2 FOCUS GROUPS

### 5.1 Introduction

This chapter describes phase 2 of this study. This includes co-researcher recruitment and data collection for the two focus groups. As in phase 1 autoethnography, thematic analysis was used to analyse the emergent data (Braun and Clarke, 2006) . Having outlined this process in Chapter 4, its application to the focus group data is described here. The results from phase 2 focus groups informed the focus group for phase 3 workshop development. Emergent phase 3 focus group discussion points are highlighted within the text. These points were summarised (Table 5.5) and were taken forward into phase 3.

### 5.2 Method

#### Co-Researchers Recruitment

To undertake phase 2, two focus groups were established. Co-researcher recruitment was an important and sensitive undertaking given they were defined as 'vulnerable adults' (Tee and Lathlean, 2004, Lathlean et al., 2006, Tee et al., 2007) and the majority were known to the researcher (both factors were discussed in Chap 3 methodology). These factors were reflected in the sampling strategy and the recruitment process.

#### Sampling Strategy

Purposive sampling (the target population was small, with specific characteristics, experience and knowledge) was used (Goodman and Evans, 2010). The co-researchers for the focus groups were drawn from two sources:

1. A convenience strategy of contacting service users using existing service user networks was used. Service users from a NHS Trust (experts by experience) who had developed their personal narratives (recovery stories) using a storyboard media (the only option available). They were active in service user involvement activities. They were known to the researcher who had either facilitated the development of their narratives within 'Train the Trainer Programme' or 'Developing Your Recovery Story'

courses and/or facilitated focus groups that they had participated in (in my role as Service User Involvement Co-ordinator within an NHS Trust).

2. A poster (Appendix 5.1) was used to offer service users who had developed a personal narrative the opportunity to take part in the focus groups. The poster was displayed in Wellbeing Centres (Hampshire County Council), at the University of Southampton, Solent Recovery College (in another local NHS Trust) and existing peer networks in Hampshire. Further, gatekeepers were used to contact service users who accessed these organisations.

### **Inclusion/Exclusion Criteria**

The following inclusion/exclusion criteria were applied (Table 5.1) in recruiting:

**Table 5.1: Summary of Inclusion/Exclusion Criteria used to Select Co-Researchers for Focus Groups**

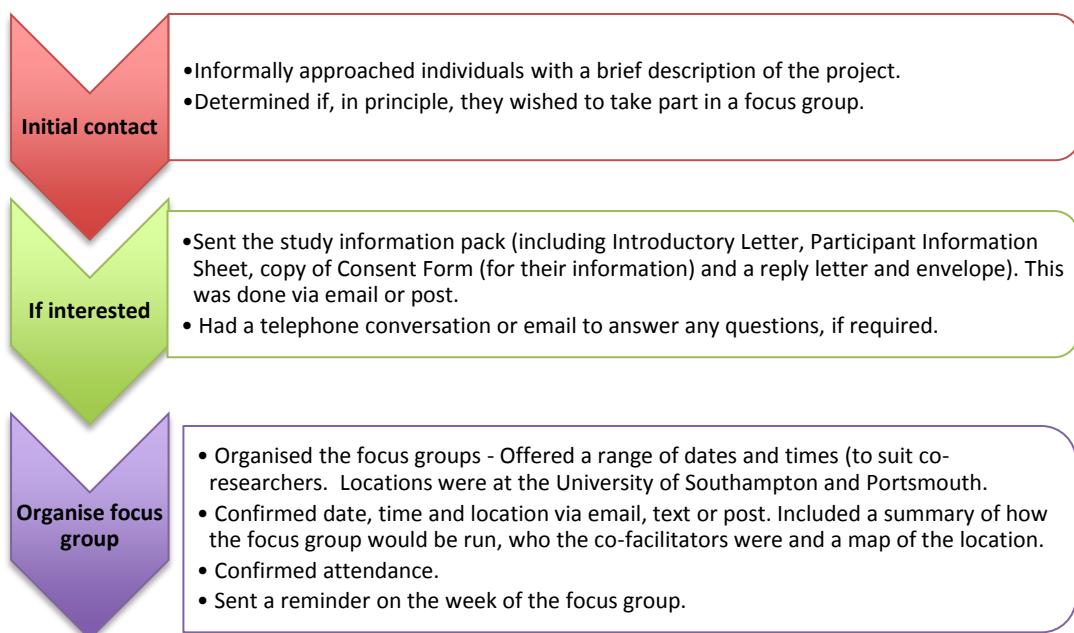
<b>Inclusion/exclusion criteria</b>	<b>Rationale</b>
Historical and/or current use of adult mental services (Age over 18)	Focus of study was the process of developing a personal narrative and mental health recovery.
Currently not in an acute phase of mental ill health or distress (e.g. an inpatient, subject to a Community Treatment Order [CTO], receiving Hospital at Home treatment or accessing a community crisis team).	To protect the co-researchers from harm and exploitation. It was hoped that participation in the focus group would be a worthwhile and meaningful experience.
Service Users who had previously developed a personal narrative (recovery story).	Focus Groups purpose was reflecting on whether and in what ways developing a personal narrative had supported their mental health recovery.

Four possible co-researchers were excluded, as they had not developed any form of personal narrative. They were offered the opportunity to participate in the narrative development workshops when they ran.

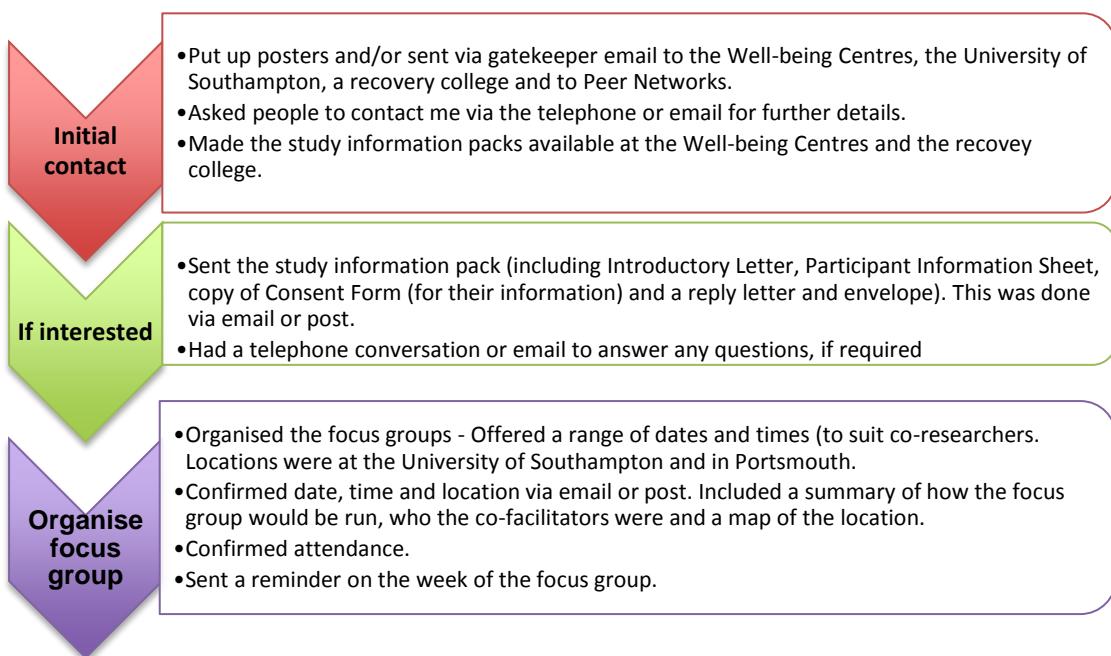
### **Recruitment Process**

Giving the sampling strategy, co-researchers were either recruited directly (Figure 5.1) or via the poster (Figure 5.2). Consent was taken at the start of each focus group.

**Fig 5.1: Recruitment Process for Co-Researchers Known to Researcher**



**Fig 5.2: Recruitment Process from Poster (Appendix 5.1)**



### **Focus Group Attendance**

The aim was to recruit up to six co-researchers for each focus group. There were 7 co-researchers in the Focus Group A and 4 in Focus Group B (7 were recruited via the poster). The researcher knew the majority of the focus groups co-researchers.

There could have been issues regarding boundaries and free consent to participate.

These were mitigated by (Box 5.1):

#### **Box 5.1 Focus Group Attendance Considerations**

##### **Box 5.1**

1. Adequate time given to the consent process at the start of each focus group.
2. An opportunity to discuss and reflect on boundaries and the experience of taking part at the start and end of each focus group.
3. The presence of independent co-facilitators (researcher's supervisors) at each focus group.
4. The recruitment process itself. If after being sent a recruitment pack, there was no response from an individual, no further contact was made.
5. The service users recruited were experienced in service user involvement (including research and service development work). Whilst respecting that they could be vulnerable, it was important to treat them as adults.

All phase 2 co-researchers expressed an interest in contributing to phase 3. At the appropriate time, they were contacted again and the same recruitment procedure (Fig 5.1) as in phase 2 was carried out.

### **5.3 Data Collection**

Both focus groups were conducted similarly. Box 3.9 outlined how the emotional wellbeing of the co-researchers was ensured. This included: receiving joining instructions; being properly greeted; offered refreshments; being briefed and debriefed; consent taken; group agreement developed; and the co-researchers being supported throughout (with three co-facilitators present).

### **Focus Group Discussion Topics**

As the research process and strategy of this study was emergent and formative, it was important that the focus group discussions were flexible. Themes generated from the autoethnography (phase 1), were used as prompts, if required. The researcher produced laminated cards (prior to the focus groups) with the topic themes and possible supplementary questions (neither was used). Box 5.2 outlines how data was collected from each group.

### Box 5.2: Data Collection from Focus groups

#### For each focus group:

- Cards with themes (developed from autoethnographic work of phase one) were prepared to generate initial discussion. Cards could also be used as prompts. The cards were placed on the table, but were not used.
- After the introductions, the researcher asked an opening question about 'how had people developed their personal narrative?' and the discussion began. Very little prompting was required. The facilitator did offer a break (midway), restarted the discussion after the break - with a summary of what had been discussed earlier. The facilitator asked for closing remarks at the end of the focus groups.
- On the table there was paper, post-its and pens for the co-researchers to use. Two co-researchers used this paper for doodling. They left this on the table at the end, but it was not used for the analysis, as the facilitator would have needed to ask the co-researchers what they meant by the doodles.
- It was planned that the group could use flip chart paper to make notes but this was not done.
- The co-facilitators (who sat outside the group) made notes, which were given at the end to the facilitator to help as field-notes. These notes were another record of what was said and by whom.
- The focus group was recorded using a good quality digital recorder (Olympus DM-670).
- The researcher produced detailed field notes immediately after the focus group co-researchers had left. These field notes included:
  - Impressions and reflections written by researcher.
  - Sketch of room layout
  - Notes from the co-facilitators

The recordings for both focus groups were transcribed verbatim by *Transcription City*. Each transcription was sent (via email or post) to the co-researchers, to allow them to check accuracy and to ensure continuing process consent. One co-researcher asked for some minor changes to be made to the text to add further clarity. This was done and the text was sent back to the co-researcher for their consent. After the researcher had completed the thematic analysis of the focus group data, this was sent to all co-researchers for comment. No one asked for any changes to be made. The thematic analysis and points to consider were carried forward to the phase 3 narrative development workshop focus group (Table 5.6).

### **Data Storage**

The facilitator and co-facilitators' field notes and any paper or post-its used by the co-researchers were collected and stored in a locked filing cabinet. The recording of each focus group was uploaded to a secure desktop at the University of Southampton and saved on a secure data stick. The data was uploaded to a transcription service (Transcription City, recommended by Student Finance England) for a verbatim transcription (including pauses, talk overs etc.). The transcription was stored on file (that only the researcher had access to) on a secure desktop at the University of Southampton. It was saved onto a password protected secure data stick, which was stored in a locked filing cabinet. Any hard copies of data, analysis and the data stick were stored in a locked filing cabinet.

### **5.4 Data Analysis Procedure**

Braun and Clarke's (2006) six-phase thematic analysis approach (Table 5.2) was used to analyse the data generated from the focus groups (phase 2).

**Table 5.2: Six-Phase Thematic Analysis Approach for Focus Group Thematic Analysis**

Phase	Procedure	For Each Focus Group (A and B)
1	Data familiarisation	<ul style="list-style-type: none"><li>• Listened to data recording of focus group discussion (checked that it was clear for transcription).</li><li>• Listened to the data recording whilst reading the completed transcriptions. Any third party names were redacted on the transcription. Any errors between what was said and the transcription were corrected.</li><li>• The transcription was sent via email or post to all co-researchers for checking and to see if they were happy with the transcription. One change was asked for (because the transcription did not reflect what she thought that she had said). The change was made and the transcription returned to the co-researcher for checking.</li><li>• The co-researchers were asked to choose a pseudonym or the researcher chose one. Only one co-researcher chose their own pseudonym.</li></ul>
2	Generating initial codes	<ul style="list-style-type: none"><li>• Printed the transcription with line numbers.</li><li>• Used an A3 sketch pad, glued one page of transcribed text per page.</li><li>• Highlighted text into units of code. Completed the whole transcript (Focus Group A - Appendix 5.2. Focus Group B – Appendix 5.3).</li></ul>
		<ul style="list-style-type: none"><li>• Reread each page of transcript as a whole.</li></ul>

3	Developing themes	<ul style="list-style-type: none"> <li>Added comments about the codes on each page.</li> <li>A 'code table' was produced'. Similar/same codes were placed in columns. Tentative theme headings (that seemed to match the codes) were added to each column. When a code did not match any of the existing sub-themes, a new column of codes was started and a tentative sub-theme name assigned. This was completed when all the codes were assigned. 57 initial sub-themes were developed for the FG A (Appendix 5.4) and 126 for the FG B (Appendix 5.3)</li> <li>Some codes appeared to meet the criteria for different sub-themes. These codes were added to each relevant column. When sub-themes were reviewed (stage 4), these codes were attached to the most relevant sub-theme (so they were not double-counted).</li> </ul>
4	Reviewing themes	<ul style="list-style-type: none"> <li>The 57 initial sub-themes (focus group A) and the 126 (focus group B) were reviewed. For focus group B, similar sub-themes were added together (62 sub-themes remained). These sub-themes were put together under themes (10 for focus group A and 9 (Appendix 5.5) for focus group B (Appendix 5.3 and Appendix 5.6)</li> <li>A further review was undertaken and some sub-themes were moved into more suitable themes.</li> </ul>
5	Defining and naming themes	<ul style="list-style-type: none"> <li>In the initial coding stage, comments were written around the text. These comments included ideas about theme generation and ethnographic comments about the codes themselves (e.g. links to phase 1, narrative and political/social/economic critique).</li> <li>These comments were added to a table that was then used to define and name the themes for the analysis. The comments were also used in the analysis.</li> <li>Focus group A: 10 themes were developed (Table 5.3)</li> <li>Focus Group B: 9 themes were developed (Table 5.4)</li> <li>The themes from Focus Group (A and B) were reviewed and combined to reflect the themes generated from both Focus Groups (Table 5.5). These themes formed the basis of the analysis in this chapter.</li> </ul>
6	Producing the analysis	<ul style="list-style-type: none"> <li>For each focus group, the themes was analysed and discussed in the current UK social, cultural and political and theoretical recovery model context (Leamy et al., 2011, Bird et al., 2014).</li> <li>The thematic analysis was used to develop questions, factors to be considered and discussed for the phase 3 narrative development workshops focus group (boxes within text).</li> </ul>

## 5.5 Findings

Table 5.3 is a summary of the themes and sub-themes that emerged from Focus Group A; table 5.4 the emergent themes and sub-themes from Focus Group B; and table 5.5 the combined themes of Focus Groups A and B which were used in this analysis.

**Table 5.3: Focus Group A: Themes and Sub-themes**

Themes	Sub-themes
Narrative Content	Definitions or name, content/story and context and content of narrative, language of recovery
Narrative Form	Media, structure and coherence
Timing	Before and after illness, recovery process and cycle, continuum of wellness, timing and time scale
Working with Others	Co-production, peers, part of a dialogue, agreeing/confirming/clarification, different opinions, external processes or drivers, the perceptions of others and outside perspective
Process of Sharing Narrative	Sharing story with others, audience, concerns for audience, incorporating mental health tools into narrative, telling our stories is a political act, who is the narrative for? and whose story is more valuable or significant?
Impact of Sharing Narrative	Value of sharing story, narrative contribution to recovery, identity, labelling, effects of sharing narrative, story heard and reaction of audience
Continuing Development of Narrative	Value of developing a narrative, editing narrative, having our own voice in our own narrative, becoming lost in our own narratives, constraints on developing/sharing story, piecemeal or one off, narrative, creating a narrative to fit an audience, other's using your story for their own purposes and language of recovery
Making Sense of the Narrative	Reflections, eureka moments, understanding, agency, internal processes, making sense of, negative emotions, positive emotions, it/me integration and reframing
Relationships in the Narrative	Others in our narratives and effects on family
Phase 3 Workshops	Where to locate workshops? Workshop development

**Table 5.4: Focus Group B: Themes and Sub-themes**

Meta-themes	Sub-themes
Recovery – Political, Social and Cultural Context	Social, political and cultural context; historical context of madness; external drivers; background to sharing recovery story; individualize mental illness; personal journey; causes of mental illness and distress; recovery doesn't exist and value of recovery as a concept
Narrative	Personal Narrative v Recovery Narrative; Name of Recovery Narrative; Language of Recovery and Narrative;
Developing Narrative	Process of Developing Story; Developing Narrative; Purpose of Recovery Stories; Use of Recovery Story; Recovery Story – who is it for?; Value of Developing Narrative; Value to Self; Good Enough; Story is for Me; Reframing; and Letting things go and moving forward; Context of Narrative
Narrative Form	Media; Value of Storyboard; and Piece-meal v one-off
Making Sense of...	Value of Wellness Tools; WRAP; Learning; Learning about Self; Growth; Agency; and Making Sense of
Sense of Self	Illness Identity; Regaining Identity; Sense of Self; and Label
Other Voices in Narratives	Working with Others; Relationships with Professionals; Family Impact on Mental Health; Impact of Family; and Peer Group using Examples of Others
Impact of Sharing Narrative	Value of Sharing Narrative; Contribution to Recovery; Being Heard; Finding a Voice; Being Believed; Audience; Purpose of Audience; How other People use our stories for their own Purposes; Sharing with Audience; and Beliefs – Yours and Others
Focus Group and Peer Working	Focus Group; Clarification, Differences and Agreements; Clarifying own Understanding using Perspective of Others; Using Comments of others to Solidify own Thoughts; Different Perspectives of Purpose of Recovery Narrative; Different Perspectives of Recovery; Similar Experiences of Developing Narrative; Given Voice; Commonality of Experience; and Sharing Information within Focus Group

**Table 5.5: Combined Focus Groups (A and B) Themes and Sub-themes (basis for analysis)**

	<b>Focus Group Themes</b>	<b>Sub-themes</b>
1	Recovery – Political, Social and Cultural Context	Social, political and cultural context; historical context of madness; external drivers; background to sharing recovery story; individualize mental illness; personal journey; causes of mental illness and distress; recovery doesn't exist and value of recovery as a concept.
2	Narrative Content	Definitions or name; content/story and context and content of narrative; personal narrative v recovery narrative; name of recovery narrative; language of recovery and narrative.
3	Narrative Form	Media; structure; coherence; value of storyboard; and piece-meal v one-off.
4	Timing	Before and after illness; recovery process and cycle; continuum of wellness; timing and time scale.
5	Developing Narrative	Process of developing story; developing narrative; purpose of recovery stories; use of recovery story; recovery story – who is it for? value of developing narrative; value to self; good enough; story is for me; reframing; letting things go and moving forward; context of narrative; editing narrative; having our own voice in our own narrative; becoming lost in our own narratives; constraints on developing/sharing story; piecemeal or one off; creating a narrative to fit an audience; other's using your story for their own purposes.
6	Process of Sharing Narrative	Sharing story with others; audience; concerns for audience; incorporating mental health tools into narrative; telling our stories is a political act; who is the narrative for? and whose story is more valuable or significant?
7	Impact of Sharing Narrative	Value of sharing narrative; narrative contribution to recovery; identity; labelling; effects of sharing narrative; story heard; reaction of audience; contribution to recovery; finding a voice; being believed; audience; purpose of audience; how other people use our stories for their own purposes; sharing with audience; and beliefs – yours and others.
8	Working with Others	Co-production; peers; part of a dialogue; agreeing/confirming/clarification; different opinions; external processes or drivers; the perceptions of others and outside perspective; working with others; clarifying own understanding using perspective of others; using comments of others to solidify own thoughts; different perspectives of purpose of recovery narrative; different perspectives of recovery; similar experiences of developing narrative; given voice; commonality of experience.
9	Sense of Self	Illness identity; regaining identity; sense of self; and label.
10	Making Sense of...	Value of wellness tools; WRAP; learning; learning about

		self; growth; agency; making sense of; reflections, eureka moments, understanding, agency, internal processes, making sense of, negative emotions, positive emotions, it/me integration and reframing.
11	Other Voices in Narratives	Relationships with professionals; family impact on mental health; impact of family; peer group; using examples of others in our narratives; and effects on family.
12	Phase 3 Workshops	Where to locate workshops? workshop development; focus group; and sharing information within focus group.

### Reflections

After further reflection and re-reading the analysis, some of the original sub-themes from Table 5.5 where not formally discussed within the analysis or discussed in relation to other subthemes as there seemed to be duplication and therefore a degree of redundancy. These sub-themes were amalgamated into Table 5.6. This was a truer reflection of the analysis.

**Table 5.6: Focus Groups (A and B) Themes and Sub-themes (basis for analysis)**

	Focus Group Themes	Sub-themes
1	Recovery – Political, Social and Cultural Context	Social, political and cultural context and value of recovery as a concept.
2	Narrative Content	Personal narrative v recovery narrative; language of recovery and narrative content.
3	Narrative Form	Media and value of storyboard.
4	Timing	Time as context; recovery cycle and continuum of wellness.
5	Developing Narrative	Process of developing a narrative; value of developing a narrative; value to self; constraints on developing narrative; reframing and editing narrative.
6	Process of Sharing Narrative	Sharing narrative with others; peer narratives and telling our narratives is a political act.
7	Impact of Sharing Narrative	Value of sharing narrative; being believed and contribution to recovery.
8	Working with Others	Commonality of experience; group dialogue and co-production.
9	Sense of Self	Sense of self.
10	Making Sense of...	Growing understanding.
11	Other Voices in Narratives	Family and peer group.
12	Phase 3 Workshops	Where to locate workshops?

(Full make-up of sub-themes that have been amalgamated in appendix 5.7)

As in phase 1, the emergent themes were interpreted within this researcher's experiential framework and the conceptual recovery framework: recovery processes (Table 1.1); recovery stages (Table 1.2) and the characteristics of the recovery journey (Table 1.3) (Leamy et al., 2011, Bird et al., 2014).

### **Theme 1: Recovery – Political, Social and Cultural Context**

**Sub-themes:** Social, political and cultural context and value of recovery as a concept

#### **Sub-theme: Social, political and cultural context**

Throughout the focus group, James introduced background information about mental illness and recovery, including an historical overview to madness - '*mad people seen as a challenge to natural order*' (583). James held very strong views regarding mental illness and the concept of recovery:

*'I am speaking for myself...having rejected the notion of recovery...[recovery has] been hijacked by services...way idea of recovery has been interpreted in government policy, enacted in organisations that work with people...' (James, 360-363)*

Whilst the concept of personal recovery underpins mental health policy and subsequent mental health system delivery in most English-speaking countries (Slade, 2012), it was important to acknowledge James's scepticism (Bird et al., 2014) . He felt that mental illness and recovery needed to be considered within a political, social and cultural context as an explanation of the causes of mental illness and distress (James, 146-7):

*'racism, classism or sexism... has an impact on peoples' mental health...can't just section off mental health' (162-3) ... recovery has been completely depoliticised and turned into something that is about a personal journey' (James, 140-2).*

Slade (2012) suggested that, locating problems within an individual (accentuating difference rather than commonality) was how mental health services were set up and operated. For example, clinical practice and outcomes (therapy and 'skills for life' training) focused on 'changing the individual' to fit in with society and to appear normal. A criticism of mental health services has been the focus on individual problems to the exclusion of individual strengths and environmental deficits and

strengths (e.g. poverty, unemployment and cultural resilience). Accentuating difference may in itself contribute and maintain a stigmatised identity (Slade, 2012):

*'you're the problem, there's something wrong with you, you need to work on yourself ...that's all you need to do' (147-9) and underplaying any external drivers by 'focusing on the personal journey... not looking at the wider issues... those things never get addressed' (James, 400-2)*

Further, '*the recovery agenda has become about shrinking services*' (609), adding to James's scepticism (Bird et al., 2014). Current government policy and statutory service provision's emphasis on the individual and their recovery journey has relegated more global concerns regarding mental illness and it's causes:

*'...until we address in society that cause distress... trauma, abuse, racism, sexism and classism ... we are having conversations about individual and the personal and fix yourself... we don't have conversations about fixing communities, societies and families.... don't think that personal recovery conversations [will help this]' (James, 366-74)*

*'recovery, whatever you think that is, always has to take place in a social, political, cultural context' (James, 142-4)*

James suggested, current implementation of recovery was in itself:

*'... unhelpful to a lot of people... doesn't necessarily reflect aspirations for themselves, aspirations for others and aspirations to change thing in wider society...' (James, 364-6)*

*'... you're [service users] the problem people... fix yourself, be quiet, don't complain, don't make a fuss, just sit there, be mindful, do a recovery story' (James, 415-7)*

James acknowledged:

*'how important [recovery] is to people and [the concept] had its uses for people... way of beginning conversation... using a different sort of non-medicalized language' (James, 356-9)*

Sandra agreed 'if a young person gets ... a recovery improvement... the potential there... don't know what they can achieve' (637-9).

However, there seems to have been a philosophical shift from recovery within the medical model towards an increasingly social model in recent years. Perkins (2012) said that recovery is about recovering a life worth living, which included taking part in all facets of life. Slade (2012) supported this view '*participation and inclusion do*

*not involve changing people to fit in, but changing the world' (P.14).* As a result of government policy: New Horizons (NHS Confederation, 2009) and No Health without Mental Health (Department of Health, 2011), and possibly as a result of the economic climate there has been, and will continue to be, significant systemic transformation. For example the ImROC initiative (Implementing Recovery through Organisational Change) (Shepherd et al., 2008, Slade, 2012, Shepherd et al., 2014) has involved setting up psycho-education recovery colleges (Perkins et al., 2012). The growth of peer support has also been an important recovery-focused initiative (Slade et al., 2014). Research suggested there are benefits to both the peer who is supported and those that carry out the support (Repper, 2013). Peer support has resulted in employment opportunities for service users, within statutory services and in 3<sup>rd</sup> sector provision (Alice is a senior peer support worker on an inpatient ward and Ellie is a well-being practitioner). There have been concerns regarding how peer support has been set up within organisations. These concerns include: dealing with existing dual relationships - being a service user within the organization as employer and the impact on existing social relationships with other service users; tokenism - peers becoming subsumed into the organisational culture; and status and power imbalances (peers are often employed on lower, non-professional grades) (Repper and Carter, 2010). Slade et al. (2014) said, it wasn't enough for organisations to employ peers if they were disrespected, marginalized or assimilated into existing clinical roles.

### **Sub-theme: Value of Recovery as a Concept**

James questioned the value of recovery as a concept and the rationale for individualising mental illness, when the existing implementation of services is embedded in existing power structures and the status quo:

*'handy for people who have a lot of power, invested interest... doing alright in society... way everything is organised is working out for you... don't want people upsetting the applecart' (James, 404-7)*

*'mental health services maintain the status quo' (James, 396-7)*

James's views raised two points. Firstly, his negating the concept of recovery as 'problemising the individual' may be seen as fatalistic. James said *'I reject the entire*

*notion of recovery' (355-6), which called into question the premise of this research. Yet, developing a narrative and its contribution to sense of self and agency may give one the ability to challenge society and mental health at a macro level. Having developed the conceptual framework for personal recovery, Leamy et al. (2011) concluded that there was a need for research for self-narrative development.*

Secondly, given James's strong opinion and willingness to share it, there was the danger that the focus of the group discussion could have been hijacked without discussing the topic (relevant to this research) of the process involved in developing a personal narrative, especially when he stated '*I wouldn't say that I have a recovery story' (354-5), (or one that he will share with others). However the themes and data that emerged from the focus group after this initial setting out of James's views on recovery and mental illness suggested that developing a personal narrative was very important to the other co-researchers. In this initial discussion there appeared to be little room available for other co-researchers who may have felt unable to voice different opinions or perspectives. However Sandra disagreed with the emphasis that James placed on the political and social context of the individual journey, '*It's a personal thing, it's a personal journey ... takes place in this much wider context'* (James, 144-5) and said that recovery needed to come from and be understood by the individual first:*

*'...put it in your own terms and on your own terms... the way you see it before you can start to do anything else ... how else can you see it – you can't see it from other people's point of view... or any of the political or ideological... have to see [recovery] the way you see it and how you experienced it' (Sandra, 151-5)*

It was a difference in degree, ideological standpoint and individual perspective:

*'How would I tell my personal story... don't see that it would be possible... without addressing some of those [contextual] issues' (Jodie, 168-70)*

*'You're telling your personal story... all sorts of other things come into it ... that's where you start from (Sandra, 173 -75)*

A person's narrative may contain context of wider social issues but not at the expense of their individual story. There were differences in how the co-researchers

viewed recovery and mental illness in terms of: global context, an individual's lived experience, recovering a sense of self and illness identity (Theme 9, Sense of Self).

**Phase 3 Focus Group: Issue to consider in workshop development**

– working with people who 'don't get recovery' or challenge it as a concept

**Theme 2: Narrative Content**

**Sub-themes:** Personal narrative v recovery narrative; language of recovery and narrative content.

**Sub-theme: Personal Narrative v Recovery Narrative**

Moen (2006) suggested it was a human process to develop narratives; that the narrative provides structure and order for life experiences. Narratives can be temporal, multi-voiced social constructions, which are dependent on individual values and cultural practices (Martin, 2009). Macias (2009) suggested sharing the narrative with others is a universal process of narrative development that can allow an individual to make meaning and provide structure to experiences. This is particularly relevant when the narrative is 'disrupted' in some way due to illness, bereavement or other life events.

Within the literature, the term narrative was described as a 'personal narrative', 'life story' and 'guided autobiography' (Alschuler, 1997). In mental health, 'recovery story' or 'recovery narrative' are terms used to describe individual accounts of lived experience focusing on recovery. In everyday discourse, these terms for narrative are used interchangeably and perhaps with the assumption that they are the same thing. There are potential challenges regarding this broad brush-stroke approach. Using the word 'story' can be contentious because it can imply 'something made up and not to be believed' (Jonker and Jonker-Bakker, 1991, Jones and Morris, 2007). Also the term 'recovery' can be contentious and nebulous (Leamy et al., 2011). 'Recovery has a multitude of meanings, being an idea, the movement, the philosophy, a set of values, paradigm, policy and the doctrine of change' (Turner, 2002, in Bonney and Strickley, 2008). Recovery can imply that 'things needed to be fixed' and/or that a return to the pre-existing life before the illness (the medical

model) was practical or desirable (Bellack and Drapalski, 2012). Within the medical model, recovery can be regarded as a static concept - a particular point in time – a before the illness and after. This is contrary to evidence in the literature that concluded that as a process, recovery is both active, non-linear and is without cure (Slade, 2009, Leamy et al., 2011). The co-researchers in the focus group could be described as service users who are on personal recovery journeys ‘... living a satisfying, hopeful, and contributing life even with limitations caused by the illness’ (Anthony, 1993). This raises the question of ‘what defines an individual’s recovery and who defines it?’ These are philosophical challenges beyond the scope of this study.

The focus groups considered the name given to their narrative: what this might mean to them; whether this had any implications for what was included in the narrative and potentially shared with others. The discussion focussed on the ‘personal narrative’ and the ‘recovery narrative’/‘recovery story’. Initially there was agreement that they were the same thing:

*‘personal narrative and recovery narrative are the same thing’ (142).... ‘it’s personal but it’s also about your... (144) ...a life view’ (Ellie,173)*

*‘It’s about life (143)...the two go together... the two are connected so much in my life, through life experiences.... makes me understand more...’ (Sunflower, 224-5)*

There was a sense of interconnectedness between a personal and a recovery narrative. The content and it’s meaning important (Macias, 2009) , rather than the title. Other co-researcher’s said that a personal and a recovery narrative were different:

*‘You’ve got two stories...the narrative of your life and then the recovery journey’ (Peter 459-60)*

*‘there’s my personal story... quite difficult to separate from my recovery story (205-6)...personal narrative would be more about telling story of my life’ (Jodie, 214)*

The discussion highlighted two important recovery characteristics. One, recovery, is a gradual process, which could include different stages and phases. Two, recovery is

a non-linear process (Baxter and Diehl, 1998, Young and Ensing, 1999, Lapsley et al., 2002, Spaniol et al., 2002, Andresen et al., 2003, Leamy et al., 2011). The co-researchers discussed time frame and position on the wellness/illness cycle:

*'my story would be different if I was writing my life story, but actually writing about illness [in relation to recovery] ... I can only take that on the last years'* (Alice, 170-2)

This appeared to be a common contextualisation used by the co-researchers to enable them to consider the difference between a personal and a recovery narrative. They located some of the difference in terms of wellness/illness (where on their journey and how well they felt – recovery could be seen as a struggle, (Leamy et al., 2011) and their level of understanding of illness and recovery at any particular time (Slade et al., 2014). A recovery narrative seemed to include less detail:

*'being her personal story...if I was to write my personal story, it would have... loads more detail about my childhood... my recovery story would involve some of that... I wouldn't go into great detail and I'd sort of concentrate on like the journey...'* (Tina 179-182)

It appeared that the co-researchers actively edited and reframed narrative content:

*'wouldn't get into it all necessarily in narrative'* (Sunflower, 225-6),

*'lots of its really dark when I was really struggling....a lot of positivity'* (Tina, 381) and *'its too miserable... too messed up'* (Tina 384)

Carl's explanation of the difference between personal and recovery narrative highlighted his reframing process, personal growth and increased social connectedness (key recovery processes, Leamy et al., 2011):

*'personal narrative more like autobiography... about what actually happened to you...what your thoughts and feelings were...sometimes quite negative...way to complain about things. Recovery Story or Recovery Narrative... what did actually happen... instead of focusing on the negative things...what I cannot do... stopped me doing things... I started thinking about what I can do... qualified WRAP [Wellness Recovery Action Plan] co-facilitator ...the focus was on what can I do'* (Carl, 240-50)

### **Sub-theme: The Language of Recovery**

It seemed that the use of the word 'recovery' within the title (recovery narrative or recovery story) was important:

*'I think that the word recovery is important... it expresses what the narrative is'*  
(Jodie, 271-2)

*'Recovery implies better' (Ellie, 200)*

It could change the content (what is included and what is left out) of the narrative; the emphasis placed on different experiences; and what an individual might do with their narrative (including sharing it with others). For Alice, a recovery narrative wasn't enough:

*'another aspect of telling my recovery story.... I wanted to explain my behaviour to my family... that's why the recovery story is not enough' (1125-6).... 'my narrative is what was needed' (Alice, 1131-2)*

Equally Tina '*had to do some form of recovery [Work]*' (184) which enabled her to develop her understanding of the process of her recovery and was then able to include this growth in her poetry:

*'I've understood more of like who I am... and I think I've got more to put into a recovery story...if I'd done this sort of thing five years ago, I wouldn't have understood it enough to write a recovery story' (Tina 185-88)*

There appeared little consensus regarding what to call their 'narrative', and whether there was actually any relevancy in labelling it, '*I have always written... I wouldn't call it a story*' (Mary 608). Whether it was called a personal or a recovery narrative was a label (often determined by someone else, including the researcher in this instance), '*I don't like the term journey because its been X-Factored to the max*' (Peter, 461). This could raise the question of whose narrative is it? And what is its purpose? What constitutes a personal narrative and/or a recovery story is a question of individual needs, language and semantics. Like recovery itself, one's narrative can be unique to the individual. The important point was what the co-researcher's lived experience meant to them; and what they wanted it to include and exclude; what they felt able acknowledge to themselves; and/or to share with others.

There was also difficulty with the term 'recovery' – what it describes and for whose purpose? James stated that:

*Some people don't relate to recovery at all... I'm an unrecovered person, and*

*that is a valid identity (200-1) ... personally, reject the entire notion of recovery'*  
(James, 355)

Leamy et al. (2011) concluded, a characteristic of recovery is the idea of a journey:

*'I think that the word recovery's quite new... everyone would have talked about things in a different way...its just feeling better... I've never talked about it as my recovery' (159-60)...I will have called it my journey... just realisation and change'*  
(Ellie, 164-5)

Sunflower agreed, '*I struggle with the word recovery...wrong word*' (203-4). There seemed to be a consensus that the concept of recovery was firmly located within the medical model; implying that recovery equated to being fixed. Recovery as a concept originated within the service user movement (Chamberlin, 1978). Given the concept of recovery within mental health systems and providers, there can often be a sense that the theory and desire to become recovery-focused does not match operational reality (add service cuts to this). As a result, the word recovery (as opposed to the actual lived experience of being in recovery) can be viewed by the individual (James, Sunflower and Ellie) as an 'externalized concept', defined by others 'that recovery will happen to the individual'.

#### **Sub-theme: Narrative Content**

Although the purpose of the focus group was to discuss the process of developing a personal narrative, co-researchers used elements of their narratives to provide some context to the points that they wanted to make about their process:

Sunflower - film making (236-56)
Carl - service user involvement (725-42)
Peter - work on statutory service provision initiatives (565-80)
Alice - work as an in-patient Peer Support Worker (626-44)
Mary - creative writing group (609-10)
Tina - involvement with a service user group (420-2)
Ellie - work in the 3 <sup>rd</sup> sector (1236-44)
Jodie - family (871-96)
Harri - work with medical students (550)

This in turn supported their growing sense of identity beyond that of a service user (Leamy et al., 2011), '*I am more than my diagnosis*' (Sunflower, 222).

Timescale and wellness were also used to provide context - supporting their own understanding of their narrative and enabling the audience (the other co-researchers) to make greater sense of what was being shared. This highlighted an important potential constraint of lack of time when sharing a narrative. There needs to be enough time available for the narrative to be contextualised and coherently shared (Pennebaker and Seagal, 1999), especially if the narrative is shared for a purpose (e.g. at a conference, in the training room or in a support group). In reality, adequate time is not always available and further editing and reframing may be required. This is an acquired skill that could be off-putting to many service users.

**Phase 3 Focus Group: Issues to consider in workshop development**

- adequate time to develop and share narrative
- some work on editing narrative for different purposes
- support to develop these skills

**Theme 3: Narrative Form**

**Sub-themes:** Media and value of storyboard

The use of media was central to this theme of narrative form. How the co-researchers developed their narrative was explored in the sub-themes of media and the value storyboard. This medium, in particular, had been used by a number of the co-researchers to initially develop their narratives.

**Sub-theme: Media**

Other than James<sup>2</sup>, the co-researchers developed their narrative using a range of (and multiple) media. Sandra used a journal (309) and wrote poetry (306). Jodie and Carl developed presentations as part of service user involvement activities and training peers:

*'can't imagine a recovery where there isn't some element of recording... in whatever form, one's own experiences' (Jodie, 323-4)*

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<sup>2</sup> James stated that he did not have a personal or recovery narrative that he was willing to share. He had taken part in the Train the Trainer Programme and had had the opportunity to develop a narrative using a storyboard.

Alice began developing her narrative through a service user involvement group (339) and presented her narrative to peer groups and at '*a conference with about 100 people*' (346). Sharing aspects of her narrative with peers was fundamental to her work as a Senior Peer Support Worker on an in-patient ward. Sharing narrative as a peer could help to acknowledge lived experience (Deegan, 1987, Deegan, 1988, Glover, 2013), amplify commonality (Slade, 2012) and offer hope to others (Leamy et al., 2011). Tina had '*written poetry since I was little*' (377) and was exploring how '*to figure out how to put [her narrative] all together* (394-5) in order to add coherence and potentially greater understanding. She did not elaborate whether this desire for coherence was for herself and/or to make her poetry more accessible to others, although she hoped that through her work with a service user involvement group, she would be able to share her narrative with peers on an in-patient ward:

*'chat to the residents about the group and recovery... different sort of positive aspects of recovery... offer them some hope' (420-22). 'I talk and talking's the thing that I am good at' (Tina, 464)*

Peter developed his narrative as a result of '*hearing the personal stories of peer support workers... a real inspiration for me*' (432-4) and now used his narrative as part of his role as a peer trainer at a recovery college. This may fulfil similar functions as Alice in her peer support role. Within Peter's role, there appeared to be a more formal requirement to share his narrative within a training course as a form of testimonial presentation (Frank, 1995). This meant that his narrative had to comply with training aims, objectives and timing limitations (which could impact on what he shared). Mary used creative writing:

*'has always written ... I wrote things, articles, everything.... an article about my recovery story' (607-610)...I drew something to illustrate it' (621)*

Mary also participated in a Human Library (Human Library, 2015) where she shared her lived experience with and connected with the public. Whilst James had attended the same training (NHS peer training programme – Train the Trainer) as Carl and Jodie, he was clear that:

*'I won't share my recovery story... I don't have a ... I've done the training... I wouldn't say that I have a recovery story' (James, 352-5)*

After the initial narrative development, many of the co-researchers began to share their narratives with others. In doing so, other media was explored and used. This moved the narrative beyond something that they did for themselves but a narrative to share with others. The choice of using different media may be due to how the narrative was to be shared and with whom (e.g. peer one to one or at a conference of professionals). Harri initially wrote parts of her narrative as notes to her therapist:

*'mine started in therapy with my writing because I couldn't talk to my therapist'*  
(357-8)

These notes subsequently became a book (368). Harri also shared her narrative orally as part of a Human Library and in Forum Theatre (Cardboard Citizens) where she used her lived experience to challenge, educate and train medical students.

Sunflower used a range of different media including sharing her narrative as part of a social work Masters project:

*'I'd written stuff.... kind of creative so I've either stitched or written... and written poetry'* (308-9).

*'[the students] produced a film ... through black and white images, [it] would reflect my diagnosis or myself or my experience'* (264-6)...it's been used in the recovery college... in different places (268)... on a website' (Sunflower, 299)

For some co-researchers there seemed to be a subtle shift from the narrative being for personal use and understanding to becoming more of a public entity, with a greater willingness to share with others. There was a greater sense of connectedness with others. As the co-researchers used a range of media, there was a sense that different media be was used to explore and further develop and adapt the narrative for differing purposes and audiences. It was clear that some of the co-researchers were at a much earlier stage in developing their narratives both for themselves and in order to share with others. This difference between co-researchers, was probably a reflection of people also being at different stages of their recovery journey (Leamy et al., 2011). Tina and Mary had written a number of poems and articles about their mental health but had not yet organised them into a structured, complete, or coherent narrative (if this is even necessary). Sunflower said:

*'I've written a lot and written poetry... but that [film] was the first kind of*

*organised...' (309-10)*

Tina wanted help to put the poems together and to make them more accessible to others, (another possible function of the workshops):

*'I've never actually made a story out of it... I've wanted to for a long time' (389-90)*

*'some people say, I don't get that! ...because I use a lot of imagery ... how am I going to write a book of poetry about recovery and my journey if people don't even get what I am saying? (Tina, 396-399)*

Developing structure and coherence seemed to be important parts of narrative development and was possibly something that individual's needed help with.

**Phase 3 Focus Group: Issue to Consider in Workshop Development**

- How to support peers to develop a coherent narrative out of what they might have already produced.

**Sub-theme: Value of Storyboard**

Some co-researchers used the storyboard technique (Lahad, 1992) and the 'six-piece story-making technique (Dent-Brown, 1998, Dent-Brown and Wang, 2004) as a medium for their initial narrative development. Carl, Jodie and Sandra found it useful:

*'a recovery story... storyboard... found extremely helpful' (Jodie, 215-6)*

The storyboard technique appeared to support narrative development in a number of ways, including the way it helped some of the co-researcher's navigate an initial path through their lived experience:

*'personal story board... just like a comic book... this happened, how do I react, what did I do...asks you various questions... got a beginning, a middle and an end... five or six questions...' (Jodie, 220-2)*

The storyboard is made up of six elements (Table 5.7):

**Table 5.7: 'Six-Piece Story-Making' (6PSM), Lahad (1992)**

1. A main character in some setting	2. A task for the main character	3. Obstacles in the main character's way
4. Things that help the main character	5. The climax or main action in the story	6. The consequences or aftermath of the story

The storyboard could be used in a visual way to support the process of exploring mental health experience and what a meaningful life might be for the individual. It could be a visual representation of a life being rebuilt – offer optimism about the future. All are key recovery processes (Leamy et al., 2011). Breaking the narrative development down into the six elements '*helped me focus at a time when I didn't have focus*' (Jodie, 223). Importantly it:

*'helped me get started on telling my story... remembering my story...remembering who I was and telling myself what had happened to me... existing in a form of avoidance... I doubt that I could have told you, at that stage, what had happened to me... I couldn't speak...[no voice] didn't have it clear in my mind' (Jodie, 225-9)*

As part of an NHS peer-training programme, Carl, James and Jodie developed their storyboard with the support of peers who had previously developed their narrative using the same technique. This environment allowed on-going discussion, clarification, affirmation and the opportunity to share their storyboard with their peers. There was emotional and practical support as well as potential social connectedness. These factors would be key to the phase 3 workshop development – the potential importance of developing narrative within a supportive and healing peer group setting (Leamy et al., 2011).

As a process, these co-researchers felt that there were a number of advantages to developing their narrative through a storyboard:

*'very simple tool.. to help you tell your story...you can flesh it out from there (Jodie, 230-1)*

The ability to reflect, edit and develop the narrative in 'bite-size chunks' is particularly useful when individuals may be having difficulty with focusing, concentration and use of language (possible side-effects of mental illness and medication):

*'talking to some one... emotive thing... to relate...you can go as far as you want... what you feel people are interested to hear... each picture... aide memoire... I would do a picture thing... different way of doing it... you can lengthen it, shorten it... depending on yourself and whoever is listening' (Sandra, 314-7)*

Like the recovery journey itself (Leamy et al., 2011), developing the narrative through a storyboard can be an on-going process, which can use a combination of words and images. Equally it could be used to create a narrative through metaphor (Mills and Crowley, 1986, King et al., 2012), thus allowing greater distance between narrative and narrator (Scofield, 2005, Rubin, 2009, Thompson, 2012). This may be particularly important in the initial stages of narrative or when the content is difficult. These benefits may be equally true of other media too. For example:

*'had an absolute phobia or terror of public speaking quite personal...write poetry ...isn't so personal' (Sandra, 304-6)*

*'developing, however you do it, even if its just thinking, it depends what people like to do, how well they are and where they are at' (Jodie, 388-9)*

Timing, the wellness continuum (including levels of concentration, fatigue, medication effects) and the interests of the individual are all important aspects regarding narrative development and the media to use. Having documentary evidence to refer back to can also be useful in the continuing development of narrative *'I've still got my storyboard'* (Carl, 238); and perhaps as evidence of progress through the recovery stages described by Leamy et al. (2011) in Table 1.2. Other factors such as: access to equipment (camera or IT equipment); local opportunities (e.g. Forum Theatre or drama groups); cost implications and literacy difficulties were not explored in the focus groups but may be relevant to other individuals and therefore were considered in phase 3.

**Phase 3 Focus Group: Issues to Consider in Workshop Development**

- On-going peer support whilst developing narrative
- Working with peers to choose a suitable media – art/photography – less explanation and more interpretation?
- Practical issues regarding media – cost, availability, local opportunities

**Theme 4: Timing**

**Sub-themes: Time as context; recovery cycle and continuum of wellness**

**Sub-theme: Time as Context**

The co-researchers used time-lines and time-scales to contextualise their narrative development. Using time (usually measured in years) as anchor points, allowed

them to clarify how long they had experienced mental health difficulties and the length of their recovery journeys. Time was used to contextualise their narrative development in a number of ways including: making sense of lived experience over a substantial length of time (including elements of before and after the illness); and making sense of those experiences both for themselves and their audience (Deegan, 1987, Deegan, 1988, Alschuler, 1997, Deegan, 2001, Macias, 2009, Saavedra, 2010):

*'it's only thirteen, fourteen years for my illness... my story would be different if I was writing my life story, but actually writing about my illness, I can only take that on the last thirteen, fourteen years' (Harri, 168-72)*

#### **Sub-theme: Recovery Cycle and Continuum of Wellness**

Recovery is non-linear, gradual and can be viewed as a struggle (Slade, 2009, Leamy et al., 2011). Such aspects of the recovery process seem to be described and contextualized as a cycle or continuum of wellness/illness by the co-researchers. This continuum used time-line/scale to explain parts of their narrative:

*'the first forty years of my life as travelling down the hill, whereas in the past ten years.. going up a hill... going back down.. getting myself back up again... all downward spiral' (Ellie, 173-6)*

*'I was at the point in the middle probably or at the tail-end of... the down bit working on the way up again the Recovery College has become my recovery' (Peter, 448-50)*

The co-researcher's described their cycles of recovery, with a picture of ups and downs (often over many years) but within their narratives there was a sense of forward trajectory:

*'it all started bad, the bad points and then you are coming up' (Peter, 458-9)*

*'a mental health MOT... is it going to be like this all the time? Is there a chance I'm going to get worse? Is there a chance that I'm going to get better? Starting point of recovery and I didn't realise that' (Peter, 471-75)*

*'the last years of my crisis, numerous crisis...when I thought that it would be some kind of relief... I've always written' (Mary 606-7)*

This sense of moving forward (even during periods of crisis) included regaining a sense of connectedness, hope, and empowerment. The co-researcher's descriptions appeared to mirror the recovery stages outlined in the Conceptual Recovery Framework (Leamy et al., 2011). They described being at different points of their

continuing journey within their narrative, which they explained as part of their narrative development process.

As Leamy et al. (2011) concluded, the gradual trial and error process of recovery can be a struggle. Co-researchers discussed the effects on their narrative development of different periods of illness/wellness, which could act as constraints and/or drivers to further narrative development:

*'it is my recovery journey... over the last couple of years... got the whole emphasis was on recovery.... then I had a relapse big time' (Sunflower, 208-12)*  
*'Whereas I'm at the stage now where I am an open book' (Alice, 324)*

*'I don't consider me having a recovery story until the past six, seven years. I didn't know what recovery was or didn't do anything to try and recover and so my past six years would be very different which I would call a recovery story to my life story' (Alice, 148-151)*

*'Because I was still in all those negative patterns... and even when I was relatively well [it would be difficult to develop a recovery story] (Tina, 188-9)*

This raised a question of whether an individual needed to be in a positive place to begin to develop their narrative. And when was the right time to start developing their narrative:

*'if I'd done this sort of thing [recovery work] maybe five years ago, I wouldn't have understood it enough to write a recovery story' (Tina, 186-7)*

On the other hand, Harri:

*'started mine when I was at my lowest because I was writing through therapy'*  
*(Harri, 769)*

*'I think that it can start at any time' (Alice 776)*

Ellie suggested 'its sort of being ready' (804). The right time to develop a narrative is different for each individual. This may reflect the stage of their recovery journey. It is important to recognise that individuals may have contemplated and mentally began to development their narrative as preparation (whether consciously or not) before more formal action began.

Peter summarised this issue of timing using a petrol station metaphor (how different people use petrol stations (Mills and Crowley, 1986, Parker and Wampler, 2006).

Some only think of a petrol station when they realise that they need fuel and then hope that they can get to one in time. Other people plan ahead:

*'Petrol station analogy... same thing for your story... if you get access to it ... people giving stories... showing you how to do a story... you might not need it then... down the line... when I am ready... there are [people and opportunities] randomly there ready and waiting for you to like click into it' (Peter 837-44)*

**Phase 3 Focus Group: Issues to Consider in Workshop Development:**

-The issue for phase 3 workshop development is how to allow individuals the opportunity with support and resources to begin the process of developing their narrative when they are ready.

**Theme 5: Developing Narrative**

**Sub-themes:** Process of developing a narrative; value of developing a narrative; value to self; constraints on developing narrative; reframing and editing narrative

This theme explored the process of and value to the individual of developing a narrative. Important process elements such as reframing, sharing, editing and constraints on developing narrative are described.

**Sub-theme: Process of Developing a Narrative**

Bruner (1987) suggested narratives were 'world making' and were the only way to interpret life's experiences. The process of narrative developing seemed to be closely linked to the value that the individual placed on its development - the narrative development (and possible reframing) was an important part of an individual's growing self-understanding:

*'...the creation and growth of the recovery story 'lifts the rug' and deflates the huge avoidance techniques I have developed around unpleasant memories... huge need to understand... lot of thinking around the event – not ruminating and marinating in it – much clearer and constructive line of thought... takes me forward – reached a comfortable level of understanding around it I can let go'* (Jodie, 1089-95)

*'In addictions recovery, part of the recovery process is writing your story' (Ellie, 709-10)*

*'even if you don't share it, getting things off your chest (365-7)... started at my lowest... writing through therapy... used all of my experiences' (Harri, 769-70)*

Ellie suggested that the:

*'process of writing, something goes from one side of the brain to the other... the process is very important' (Ellie, 786-7)*

What was written appeared less important than the actual process of writing. As a process, the value of developing a narrative seemed difficult to both describe and quantify:

*'Some things change and I can't quantify it...realisation not quite sure how I got there... not always a conscious process... maybe the environment that I am in [peer support in the 3<sup>rd</sup> sector], maybe some of the things that I am doing that helped me move forward... couldn't tell you how I did it... not always measurable... I haven't worked out what it was... maybe I don't know' (Ellie, 804-11)*

However it happened, tangible change occurred for Ellie, which impacted on her sense of self and empowerment:

*'found myself behaving differently... me being responsible for the changes... different mind-set... some of it was therapy, some of it was unconscious...' (Ellie, 813-22)*

James was clear that he saw little personal value in developing a narrative, although other co-researchers did not support his view:

*'I don't have a [recovery story]... I've done the training ...I wouldn't say that I have a recovery story' (353-4)*

The value in developing the narrative could be similar to the value of sharing the narrative with others, in terms of the co-researcher's feeling a '*release... its out there*' (Harri, 364-5). Sharing the narrative could also contribute to connectedness and a further sense of action and progress in the recovery journey (Leamy et al., 2011, Bird et al., 2014).

Narrative development seemed to make a difference to the other co-researchers and those that they shared their narratives with (Alschuler, 1997). Sandra used a range of media over a great period of time:

*'Waiting for a recovery narrative course ...absolute phobia of public standing up.. thought it might help... this thing quite personal...write poetry which isn't so personal... just an interesting exercise.. kept journals for 21 years... appreciate the sort of argument you have with the blank page and tunnels you can sort out ... once written something... different perspective and calmer look... work*

*through it and come out the other end... feeling a bit more down to earth about things... I would do a picture thing... different way of doing it... you can lengthen it, shorten it... depending on yourself and whoever is listening' (Sandra, 303-17)*

### **Sub-theme: Value of Developing a Narrative**

Sandra discussed a variety of media that she had used: poetry (Gustavson, 2000, McArdle and Byrt, 2001, Tolton, 2004); creative writing (King et al., 2012, Pert, 2013); and a journal (Laitinen and Ettorre, 2007, Lent, 2009, Bartlett, 2012). Using this range of media highlighted the opportunity for varying degrees of emotional distance (Scofield, 2005, Parker and Wampler, 2006, Rubin, 2009, King et al., 2012, Pert, 2013). It appeared that Sandra edited and adapted her narrative to suit how she felt and whom she shared with. This seemed as important to her as being heard by others (Burnell et al., 2009, Saavedra, 2010). Before starting to develop her narrative, Sandra explained that she focussed on living:

*'I didn't talk about what was going on inside... it was about taking on responsibilities... trying to keep your life together... keep you relationship together...I do think that it may come in useful – recovery narratives' (Sandra, 552-6)*

A further characteristic of the recovery journey is that recovery can be a life-changing experience. This could partly explain the movement through the different stages (Table 1.2: pre-contemplation, contemplation, preparation, action, maintenance and growth) (Leamy et al., 2011, Bird et al., 2014). This was reflected in the co-researchers continuing to develop their narrative over time (to include new lived experience, insight and understanding). They also continued to edit their narrative (for different audiences and purposes):

*'my worker said...speak as though there's nothing that you want to hide... to be an open book... to be secure... that is part of your life but be aware of your audience as well' (Sunflower, 1145-9).*

*'the nuts and bolts are the same... the process the same... you tailor it in different ways... how much you leave out... when your audience' (Sunflower, 801-3)*

Like the recovery process itself (Slade, 2009, Leamy et al., 2011), developing a narrative did not appear to be a static concept. The co-researchers described how their narrative changed over time and had the potential to change as their

understanding and insight grew. Due to the film made about her narrative, Sunflower felt able to challenge her diagnosis with her psychiatrist:

*'...eventually I was able to go back to my psychiatrist and I didn't meet any of the criteria for borderline personality disorder... it was wonderful...brilliant but difficult...because I was perceived in that way for a long time and treated in that way afterwards' (Sunflower, 301-5)*

With greater understanding, it appeared that there was potential for greater personal agency and empowerment too (evidenced by Sunflower being able to challenge her diagnosis) (Leamy et al., 2011, Bird et al., 2014). Whether a narrative is a one-off production or is continually developed in a piece-meal fashion seems to be dependent on each individual:

*[narrative] changes over time... changes with growing understanding... as you grow and move on and life... it would be very different [now] to what I had done with the students' (Sunflower, 226-8)*

*'my narrative was so different when I first started telling it... because some of the stuff... I hadn't addressed some of the painful stuff... even though I wanted to, I couldn't until I had worked on those issues' (Alice 319-23).*

There was evidence of self-editing and managing content to self-protect through creating different degrees of distance (from both content and audience) (King et al., 2012, Pert, 2013). With practice and growing self-esteem, the co-researchers suggested what they were able to share had changed over time (Roe and Ben-Yishai, 1999).

When an individual began their process of narrative development, they may not have been aware of this from the outset. Harri began by writing notes to her therapist, *'I was writing but not realising that eventually it was going to turn into a book'* (845); Mary – a collection of articles (608) and Tina – her poems. For them, it had taken time to develop (and was an on-going process): Putting the pieces together to move towards a body of work - a collection of artefacts, poems, stories, articles, art and photos that are parts of a picture. For Tina this was still a work in progress:

*'written poems since little... kept all poems since puberty... never made a story out of it but wanted to' (377-90)...'still in early those of narrative development'* (Tina, 394)

### **Sub-theme: Value to Self**

Whilst it may be important to share with others, the value of narrative development for growing sense of self may be as (or more) important for the individual. Jodie equated developing her narrative with the start of her process of getting well '*its part of getting well... I don't think I could have gotten well*' (750). Carl added:

*'Looking at recovery story... not just about what happened in my life, its about believing and the value of myself as more than what I'm able to do for other people ...I'm not just... my value is not only what I can do in society for other people. My value is that I'm actually, I'm a person and I have value...part of the world... I have rights... I have good friends' (Carl, 847-56)*

A key aspect of narrative development was regaining their voice within their narrative (Deegan, 1987, Deegan, 1988, Deegan, 1995, Deegan, 2001, Moen, 2006, Coleman, 2007, Martin, 2009, Slade, 2009):

*'... you said about the individual becoming much more important in their own story.... because it wasn't my story... I didn't have a story... I wasn't important... accepted my position... something about being a victim...victim is somebody who's suffered whatever it was... through no fault of their own... I wasn't completely fault free...inviting what was happening to me... didn't know what I was doing or how to be different... I knew there were things that I needed to change' (Jodie, 752-63)*

*'What does matter to me...because I don't matter but what matters to me... is about having it in the conversation... because it's reintroducing ourselves to the idea that I'm actually a person in my own right' (Jodie, 774-777)*

Through her narrative development, Jodie described her growing sense of self, greater agency and responsibility (Leamy et al., 2011, Bird et al., 2014) – narrative's transformative effect (Atkinson and Delamont, 2006b). Importantly she said developing her narrative enabled her to have a 'conversation with ourselves' - to begin to see value in herself:

*'...most about the narrative is who am I, what am I gonna say about my story that's just for me...but I am listening to myself, I'm listening to my own narrative and that can give me understanding... address things that I may have been to frightened to address before important thing... Its about doing more sooner... the narrative is about talking to me and listening... biggest challenge is when I am negative about myself, which I try no longer to be my default position... it makes me rephrase it into a positive thing...extremely difficult to do...doesn't come naturally' (918-30)*

Developing a personal narrative can contribute to a growing sense of agency and an increased social connectedness (Leamy et al., 2011, Bird et al., 2014) if shared with

the right active and authentic audience (Slade, 2009) - highlighting the importance of being heard. James was however, concerned that in '*focusing on the development of the story and how it benefits the person* [this research]' (132-4), there could be a danger of not considering how other people use these narratives for their own purposes (both positive and negative):

*'organisations will take our recovery stories and use them for their own purposes... or even academics (135-6)... its not just a story that you write for yourself so that you can recover... deliver it at a conference... for organisation to say... there's a recovered person, aren't we wonderful, didn't we do a good job' (James, 190-4)*

Jodie suggested that narrative could be used (and is used) within the NHS to train staff:

*'from a training point of view... for people to be aware... how blasé they can be... how busy... [how professionals treat service users] impacts on people' (294-7)*

### **Sub-theme: Constraints on Developing Narrative**

The co-researchers highlighted a number of possible constraints, which affected both their narrative development and sharing it with others. Some constraints were emotional:

*'hiding shame...fear of sharing it in public' (Alice 341-4)*

*'ashamed...embarrassed' (Hari, 358)*

*'isolation... feeling that you're the only one going through it... guilt... cross with myself... same things cropping up...same mistakes... round in circles' (Peter, 1000-11)*

The co-researchers described being unable to hold their emotions in check at times.

This affected what they were able to share at a particular time:

*'depends on where you are [emotionally] ...when you are going through [cycle of wellness]' (Tina, 391-2)*

'Trust' (Tina, 409) and 'others perceptions around mental health' (Sunflower, 494) and 'fear of being judged' (Sunflower, 1015) were important issues regarding whether and how much to share. Sunflower was 'shunned' (1035) and 'ostracised by family' (1046-7) for trying to talk about her lived experience (an example of the importance and impact of relational ethics within our narratives).

Other constraints were more practical (although emotional and practical constraints seemed to be interlinked). Getting started can be difficult 'some things very difficult... seems very easy now' (Mary, 611) and 'time is a big constraint as to what can be shared... there's not enough' (Alice, 328). When the co-researchers were invited to share their narrative they were usually given a time slot and a theme that was relevant to the audience (reflecting the needs of the organiser and the audience).

Developing narrative through different media may be beneficial. For example, photography (Stewart, 1979, Gauntlett and Holzwarth, 2006, Glover-Graf and Miller, 2006, Dennett, 2009, Dennett, 2011, Erdner and Magnusson, 2011, Bartlett, 2012, Dennett, 2013, Prag and Vogel, 2013, DeCoster and Dickerson, 2014) and art (Heenan, 2007, Stickley et al., 2007, Caddy et al., 2012) could be used as self-expressions that provide a safe (creating distance), non-verbal way to deal with difficult emotions. As media, they have the advantage of transcending potential language barriers. Given that the 'right time to begin' narrative development can be different for individuals and that language ability can be affected by mental health, this was an important consideration for future workshop development.

There were possible political constraints in developing and sharing narrative. Ellie said (1234-6) that mental health and recovery was located within the medical model, which brings with it resource constraints. In this model, recovery was described as a return to a former life prior to the illness (Whitwell, 2001). This is at odds with recovery models, conceptual recovery frameworks and recent literature (Slade, 2009, Leamy et al., 2011, Bird et al., 2014). However, most service users still receive mental health services dominated by the medical model (Slade, 2012), which can impact on an individual's recovery. For example:

*'we hear about people's experiences [in her peer support role]... they've never really actually shared their story... if they had been working with people with an understanding from a personal perspective and were able to share because they are told not to disclose... in this setting you keep yourself to yourself' (Ellie, 1236-44)*

Disclosure and its consequences is an important constraint regarding what to share (especially with professionals). Sunflower said '*I still didn't disclose*' (1037).

Disclosure can have legal (and social and economic) ramifications e.g. under the Mental Health Act (1983) and could potentially result in loss of liberty.

### **Sub-theme: Reframing**

Other than James, the co-researchers used context (Macias, 2009) and some narrative content to anchor, add coherence (Saavedra, 2010) and support their explanations of their narrative development process. Carl talked about relationships with professionals (451-62), his education (858-65) and his service user involvement (725-40). Sandra discussed her involvement with a poetry group (936-7). Jodie talked about her family (707-15), living abroad and the education system (633-46). Using context in this way helped them and their audience to make sense of their growing understanding. This provided important examples of their reframing process.

Reframing could allow sense to be made of what has, and is, happening through the development of new meanings and insight – continually interpreting and reinterpreting one's experiences (Bruner, 1987). Reframing could provide an opportunity to reflect on an individual's experience of mental illness including: possible causes; help and constraints; support needed; and lessons learnt (Lahad, 1992). Reframing may support the development of a more integrated and positive sense of self. Integrating experience and new understanding can provide the necessary coherence and platform for further recovery (Slade, 2009, Leamy et al., 2011, Bird et al., 2014):

*'If I do what I can do, instead of complaining about what I cannot do...maybe life isn't as bad as I thought... recovery...is not going back to the person I was before I was ill. Its about accepting the fact that I am ill that life happened to me, bad things happened... way of thinking about I get something good out of this...not being a negative person...its self-improvement, thinking about the future ... I thought about what I could do, and how I could recover... the recovery model idea of looking at things' (Carl, 254-65)*

Potentially the role and meaning of reframing may be important to the individual.

Reframing may be a key process in developing sense of self and 'being good enough':

*'when you get branded as not good enough by society... I started to believe that I was no good ...I felt that I was less than other people... but even though I've been pushed down so many times, it's not just about being pushed down, it's about believing that life isn't all about success... that being a person is good enough (Carl, 858-65)*

Carl described a degree of acceptance, making sense of his lived experience and creating new meaning in order to move on with his life (Roe and Ben-Yishai, 1999, Leamy et al., 2011, Bird et al., 2014):

*'I couldn't do...getting up in front of people and talking... actually did stand up and talked to them... I actually believed that for many years, I said to myself I'm too shy, and my illness is too severe...just can't do that' (Carl, 279-82)*

*'Rather than being a victim (722)... I felt like a victim... still felt as though I was a victim, I could use that personal knowledge as a good thing... rather than being another victim which was 100% bad and negative, I started thinking, well I can help other people who have had similar experiences... being a victim is not 100% bad... actually something good there' (Carl, 730-5)*

Carl's sense of self and his belief system were tied up in an 'it/me identity' of illness (Kleinman, 1988). An individual's illness becomes the individual's identity, such that they are indistinguishable and the individual becomes the illness. For example, 'the schizophrenic' or the lived experience is so chaotic that there is little coherence or insight within the narrative (Frank, 1995). For many years, Carl's illness identity limited what he did and how he felt about himself. A consequence of reframing could be the development of a more positive identity, with the growing ability of the individual to distinguish between the 'me/it (illness)' (Slade 2009), such that the illness is not all pervasive.

Reframing through narrative development supported increased insight and a feeling that Carl could help others through his peer work within his community. Like Carl, Jodie was similarly impacted by her illness identity (which negated any belief in herself):

*'You're standing on one side, then you go to the other side... seeing the same thing from completely different perspectives ...very busy being ill... wasn't room, or space, or energy, to do anything about becoming well... wasn't aware of that [realisation], but the illness itself ... my focus was down and inward...it's a shift in focus ... what WRAP does... gives me space, and the focus, the perspective to look at the wellness side of it, not just being unwell' (Jodie, 325-357)*

For both, reframing involved considerable internal processing (Leamy et al., 2011, Bird et al., 2014). They both identified WRAP (Wellness Recovery Action Plan) (Copeland, 2013)), as a tool that helped them in this process. There was a shift in the language they used and a subtle distancing from the illness/victim identity. The co-researchers seemed to be using their narrative development to reframe their lived experience (Roe and Ben-Yishai, 1999) which in turn contributed to their mental health recovery in many different ways: (Deegan, 1987, Deegan, 1988, Deegan, 1995, Deegan, 2001, Leamy et al., 2011, Bird et al., 2014):

*'got a job... actually managed to do something that I told myself every day that I couldn't do, for many, many years' (Carl, 269-70)*

#### **Sub-theme: Editing Narrative**

Editing appeared to be an important element in both narrative development and sharing with others. The literature seemed divided as to whether narrative editing was acceptable. Bruner (1987) suggested that there were external and internal criteria for narrative construction: of rightness; of how one felt or what one intended and of coverage. Criticisms of this view included the role of omissions and commissions - what is left unsaid and intentions (the narrative may not be true) (Craib, 2003, Atkinson and Delamont, 2006a). Hyvarinen (2008) commented that 'narrativity always carries with it some sort of tendency to revision' (p.266). Moen said the reframing process in the development of narratives could have different purposes. It allowed flexibility – the narrative could differ depending on time and audience. It could evolve as new experiences and insights are added. Moen (2006) added there is no single, static or dominant narrative – human knowledge of the world is relative. The co-researchers continued to make choices as to what to include especially if they were focused on their recovery narrative as opposed to their personal narrative:

*'wouldn't get into all necessarily in narrative' (Sunflower, 225-6)*

*'recovery story would involve some of that... I'd concentrate on the journey' (Tina, 181-2)*

*'other things... about other areas...something that you don't want people to know (Sunflower, 998-9)*

Some editing involved 'toning down' the content in order to protect the co-researcher:

*'made an agreement ... not to include dark stuff' (311-2)... 'its about what you give' (Sunflower, 316)*

*'I did leave lots of bits out' (Alice, 350)*

*'had to tailor [the narrative] for one of the courses [Recovery College]' (479-80)... 'tailored as I have gone along' (Peter, 664)*

Also there seemed to be an influence of others in determining what and how the narrative was shared. Alice talked about:

*'for us to give our story to a professional... story is very different to the real one... very different story to what is actually on their [the service users on the ward] notes' (Alice, 858-60)*

Alice was asked to share her story at a conference '*by a very strong psychologist*' even though she was unsure (349). Sunflower was asked to share her experience of crisis care because '*it would make a good learning point* [for the team]' (601-2). In these examples it appeared that the needs of the co-researcher were trumped by the needs of others. Some editing seemed to be enforced by others - being told to change the way the narrative was presented - other people used the co-researcher's narrative for their own purposes. For example, Sunflower's film project:

*'[the students] ticking the boxes as far as social work is concerned' (Sunflower, 276)*

*'[the students] got out of it what they needed to' (Sunflower, 313-4)*

Peter's experience about telling the 'right narrative' for the Recovery College (479-87) and his sharing elements of his story with professionals with a specific goal (565-80):

*'what Peter said is very valid, is what we want to hear' [his former manager]' (588)*

Further, Peter added dramatic production when sharing (he felt that his story wasn't 'juicy' enough):

*'extended it after the break... I didn't need to give them [the students] a cliff-hanger' (658-60)*

Sometimes compromise may be necessary for the narrative to be heard and understood (Bruner, 1987):

*'some people don't get imagery in poems... will need to add where I was at, what I was feeling' (Tina, 400)*

There could be an element of second-guessing what the audience would want to hear. Narratives are edited to fit the audience and to support what the co-researcher wants to tell the audience (Bruner, 1987):

*'trying to use the story in different ways...break it down into its constituent parts... this fits what I am delivering on that day' (Peter, 691-3)*

Having to edit or change their narrative for others can result in the co-researcher becoming lost in their own narratives. The social work filmmakers and the Recovery College were examples of external drivers interpreting, using their language and to a degree taking ownership of the narrative. This could have an impact on sense of self:

*'seeking permission ... I don't even know if I am allowed to do this [provide her own commentary to her film]' (179-80)... 'this is all that I've got...it's their project but my voice' (Sunflower, 279-81)*

The students were making decisions about Sunflower's narrative:

*'I'll write a poem for you about your life...' [A student filmmaker, 272]... other people's voices (271)... how can this represent me and my life' (Sunflower, 275-6)*

Sunflower found it '*really hard asking for own voice in own narrative*' (280-1).

Having been asked to tone down his narrative, Peter decided that '*elements [about his wife and children] weren't necessary totally*' (653). The feedback he received from the professional caused Peter to further reflect on his narrative and alter it. Alice responded to a similar request not to mention alcohol or suicide (although these were important parts of her lived experience):

*'it's a huge part of my story' (734)... 'I've gone along with professional... only tool really is my story... my story is all I've got really' (739-43)*

Equally narrative development could allow the voice of the co-researcher to be heard. For Sunflower, writing in the third person '*...this happened to her...she said this*' (795-6) and the distance that this created allowed her to write about her lived

experience (King et al., 2012, Pert, 2013). With the confidence gained by the experience of sharing her narrative with her peers and in public, Alice found her voice within her family and a renewed connectedness (Burnell et al., 2009, Leamy et al., 2011, Bird et al., 2014):

*'if I need to say something about my mental health, I will say it... release to be able to talk to other people, tell my story... I wanted to explain my behaviour to my family' (Alice, 1025-27)*

For the co-researchers, their narrative and their continual development appeared to: be a tool to support their recovery; to take account of growing awareness; understanding (both their own and their audiences); agency (taking control and responsibility for own life); and social connectedness (Leamy et al., 2011, Bird et al., 2014). Their narratives seemed to support the reframing process - finding their new place in the world and their changing identity. Frank (1995, p.55) concluded, 'the way out of a train wreck is telling stories'.

**Phase 3 Focus Group: Issues to Consider in Workshop Development**

- Supporting people to get started
- Is it possible to address difficult life experiences through the development of the narrative itself or do you need to have done the therapeutic work before developing the narrative so that the narrative is essentially 'giving voice' to the lived experiences?

**Theme 6: Process of Sharing Narrative**

**Sub-themes:** Sharing narrative with others; peer narratives and telling our narratives is a political act

### **Sub-theme: Sharing Narrative with Others**

The co-researchers shared their narrative with a range of audiences:

Peter - peers and carers in a Recovery College  
Sunflower - a film (developed social work setting) shared online and in a Recovery College  
Harri - within therapy, in a book and interactive theatre with medical students  
Alice - at conferences (mental health and other), peer support groups and on acute in-patient wards  
Mary - involvement in a human library  
Ellie – peer support as part of her work  
Tina - informally with friends and service user/peer support group  
Sandra – informal poetry group  
Jodie – service user/peer support groups, WRAP facilitator and in a Recovery College  
Carl - service user/peer support groups and a WRAP facilitator

What is shared can be dependent on who the audience is ‘who you’re talking to’ (Sunflower, 318) and on ‘where you are [on personal journey]’ (Alice 319). Mary and Tina described being at the start of their narrative development journey with much of what they had developed (in the form of articles and poems) only used for personal purposes (understanding and reframing their lived experiences). Initially very private thoughts could in time be shared with others, ‘not shared but it is less personal now’ (Mary, 623) and ‘recently ...sharing my poems’ (Tina, 396).

James would not be willing to share his narrative. For other co-researchers, the process of sharing their narrative had gathered momentum as the narrative and their confidence developed. Sharing their narrative seemed to allow the co-researchers to make meaning and provide structure to their experiences (Macias, 2009). From sharing their narrative informally with people known to the co-researchers (such as friends, family and within the therapeutic process) to larger and more formal settings with unknown audiences. For Alice, sharing with friends and family was harder than sharing with peers. In her peer support role, she was comfortable in sharing her narrative:

*‘I’m an open book and I can talk about anything in public without breaking down’ (Alice, 324-5)*

The co-researchers appeared to tell different narratives depending on who the audience was and what the purpose of the narrative was (Slade, 2009):

*'For us to give our story to a professional [as a case history] ... story is very different to the real one... very different story to what is actually on their notes'*  
(Alice, 858-60)

Peter considered how he could share elements of his narrative with professionals for the purpose of developing a mental health-training programme:

*'from personal experience of such a thing... well I felt that when I went through such a thing'* (581-2)

Sunflower was asked to talk to her local care team about her experience of care:

*'they feel it would be a good learning point... I think how amazing... from your experience, normalise it and make it into a situation that people can relate to'*  
(601-4)

Sunflower wanted to demonstrate 'being unique... and it's like you maybe come out with advice' (951-2).

The audience and its purpose can affect what is shared (Slade, 2009). Editing the narrative for an audience was an important part of the sharing process:

*'if I'm telling my recovery narrative, then it is focused at who I'm speaking to and why I'm speaking to them... I would share things with one group that I would deem inappropriate with another group... I don't feel the relation of that experience, that recovery story was any less for fact'* (Jodie, 207-11)

Choosing what to share helps to: maintain relevancy; audience interest 'what you feel people are interested to hear' (Sandra, 235); and can also act as protection for the narrator:

*'what I share is not really my recovery story... I share aspects of being unwell... how I overcame them... probably only told recovery story two times... talk a lot to various people and groups... difficulties in communicating with me when I'm not well... describe how that manifests itself... what that process is to me... a quite convoluted difficult process'* (Jodie, 532-9)

*'rather than tell a narrative... [facilitating a course] at the end of it people will know very little about my life or my history'* (544-9)

*'I don't talk about what's going on inside'* (Sandra, 552)

Whilst choosing what to share with an audience, Jodie felt that it was important to be honest:

*'it helps me now to be able to say to people, I'm struggling today gets us back on an even keel... share a lot of things...'* (541-2)

Timing and wellness were important considerations on what and whether to share. Jodie believed that audience reaction to her narrative, was not her responsibility, authenticity was crucial for her:

*'...I only share what I am comfortable with in that situation... and sometimes you share more than you thought that you would and other times not as much... not about withholding... I am not the listener's responsibility... its ok to get upset' (557-66)*

Although Jodie acknowledged that she could not get it wrong because it was her story (Bruner, 1987, Polkinghorne, 1988, Frank, 1995, Atkinson and Delamont, 2006b), audience reaction to her narrative was outside her control. Being heard and being believed (Jonker and Jonker-Bakker, 1991) appeared to be key elements in the co-researchers' sharing their narrative with others:

*'One needs a certain amount of wellness ... in all self-awareness, nobody can tell me that I am wrong. Its my story, so I cant get it wrong when I share what I share can't say you missed out a bit or was that bit true or that's hard to believe' (Jodie, 557-60)*

In sharing their narrative with others, the right time, place and understanding (of their own process and of the audience) was important for the co-researchers. Developing and sharing the narrative aided their process of recovery and the growing sense of who they were (the integration of the it/me persona) (Leamy et al., 2011, Bird et al., 2014):

*'[the] process of the recovery story and how it aids recovery – its benefits to others is apparent through their narration of how hearing them has helped them in their own progress but subjectively. It actively erodes the shame one feels... past experiences and simply being mentally unwell... I had a responsibility [in her illness] – I could have reacted differently (Jodie, 1074-82)*

Sunflower described how the process of sharing her narrative had allowed her to develop a sense of who she was in terms of rebuilding and redefining a positive sense of identity:

*'what makes sharing your narrative, having your narrative powerful... you get affirmed by people in different ways' (510-11)*

From the co-researcher perspective, sharing their narrative allowed a greater degree of honesty, truth and a slipping of the public persona into a more authentic self:

*'living a lie... perfect life at the inner turmoil... nobody would have guessed... then it all burst...so good to be yourself, to be who you are warts and all, every aspect of you out in the open... such a relief... you don't have to make the effort to be someone else' (Alice, 543-49)*

There were a number of important elements to sharing the narrative, including the importance of being heard and listened too (Frank, 1995, Slade, 2009, Saavedra, 2010):

*'it's really good, what you've shared and what you've said (Academic Tutor to Sunflower, 283-4)...*

*'really important that story was heard' (Sunflower, 289-90)*

*'being able to say it out loud yesterday [in the focus group]... belief of the effect of our thoughts and words in our own mind – they are listening and listening well – saying these things out loud in the presence of (appropriate) others is like popping a water balloon – it takes the weight out of the event and the shame surrounding it' (Jodie, 1085-9)*

Sharing their narrative introduced the perspective of others. It may support building social connectedness (Leamy et al., 2011, Bird et al., 2014). Sharing could have a normalising effect (e.g. when Harri's medical students thought that she was not a service user because she looked normal). One wonders whether we need the perspective of others to understand our own story. Sharing the narrative can aid meaning and provide structure to experiences (Macias, 2009). Sharing can support the development of a coherent narrative that can be more readily understood by others (Pennebaker and Seagal, 1999, Kempson and Murdock, 2010). In ensuring the narrative made sense to others (especially in adding contextual and timescale references), further aspects of self can be, or may need to be, revealed. For example, in trying to get professionals to understand what it might be like to be restrained, Alice 'told them when I was restrained...' (645).

If it is important to share the narrative, it is 'really important that the story is heard' (Sunflower, 289-90). The students in Harri's interactive theatre wanted to 'hear more...we don't get that in the textbook' (562-3). Sharing and being heard offered a

connection and an opportunity for reflection. Further, the listener could then use the narrative to aid their understanding and for their own purposes:

*'someone will be in the group [Recovery College]... that resonating with people...she's [a student] saying to the group something I'd already said in another group... wow someone is actually listening to me... someone whose heard' (Peter, 689-700)*

*'they've heard my story... actually impacted on them... they want to relate and use it themselves in helping somebody (Peter, 700-03)*

Sometimes there is a mismatch between what is shared and what is heard. As a result the audience may not react in the way the narrator hoped:

*'the story that the [professionals] have heard may not be the story told' (Alice, 873-5)*

*'not being listened to by professionals... [has implications] ... incorrect diagnosis, incorrect medication, being sectioned, restrained because somebody didn't listen to what you say' (Ellie, 899-901)*

*'I don't believe you' (423)... when you are telling your recovery story, it's not what some people want to hear... certainly in my role as a peer (625-6)... some people in to hospital find it hard believe that I was at such a low point' (Alice 736)*

Jodie expressed further concern about the narrative becoming about what the audience wants to hear rather than what the narrator wants to share:

*'[sharing] can be damaging (521)... speaking with peers...depends on how well person is... if your sharing with a group, some people get really fixated on one aspect' (Jodie, 525-7)*

A further possible issue regarded how others (individuals, academics and organisations) used the co-researchers narratives for their own purposes. For example being asked to present at conferences for mental health organisations on specific aspects of their recovery or to provide role models to others (James, 191-2). James commented that this research was doing a similar thing!

### **Sub-theme: Peer Narratives**

The support of peers (others with lived experience of mental health problems) was valuable in terms of offering hope, practical and coping strategies (Chamberlin, 1978, Repper and Carter, 2010, Leamy et al., 2011, Repper, 2013, Bird et al., 2014). One form of peer support is acknowledging lived experience through sharing peer

narratives (Deegan, 1987, Deegan, 1988, Tillmann-Healy, 1996, Coleman, 2007).

Listening to peer narratives was very important to the co-researcher's:

*'[asked by others] what is your story?' (Peter 453)*

*'I feel so grateful, inspired when others share their story with me' (Tina, 435-6)*

*'the value that's in people's stories in mental health' (Ellie, 707-8)*

*and*

*'The power for me [of sharing my narrative] delivering it and then students [Recovery College] saying thank you' (Peter, 477-79)*

Sharing peer stories can, however, raise the issue of whether a narrative is perceived by others or by the co-researcher themselves as good enough:

*'it's common [Peter's story] ... I feel self doubt... I feel like I've got a very lightweight story... not got the more fruity or juicy diagnosis' (Peter, 668-700)*

There appears to be an unwritten hierarchy within the medical model and the mental health world: Physical health is seen as more important than mental health and within mental health there is a further hierarchy. Secondary care service users are 'proper' service users and those with diagnosis of schizophrenia and bipolar disorder 'trump' depression and anxiety (often affirmed by service users themselves). This can be evidenced by the continued focus of government policy of achieving parity between physical and mental health (Department of Health, 2014) and the degree of mental health stigma (Mind, 2013a):

*'if you had breast cancer... multiple sclerosis, there's every support group under the sun and people flood to it because its seen as a good thing. And yet, all of the value that's in people's stories in mental health, they are just as important, but its just so sneered at still (705-9) ... still have to justify things... constantly having to work harder than anyone else has to, to talk about how they have struggled' (Ellie, 712-4)*

These feelings of inadequacy may impact on the perception of self and the value of individual narratives to others:

*'I didn't feel that I had anything massive... I felt that my story was so insignificant compared to...' (527-9)*

*...'I'm still struggling with the bit that it didn't feel significant compared to...' (Ellie, 533)*

*'you're almost trying.... to trump this one at times' (Sunflower, 672-4)*

Peter was asked, ' who's it for, what is the purpose of your story?' (565). This may be a key point in the rationale for developing and sharing the narrative - a consideration of who it is shared with and how the narrative may change as a result:

*'for me initially... sounds a bit selfish...I do want to give it out to show other people that there is recovery... once you find a few people that open a few doors or just one person share a bit that you can trust' (Tina, 404 -8)*

*'they've heard my story... actually impacted on them... they want to relate and use it themselves in helping somebody' (Peter, 700-3)*

These are examples of co-researchers narratives being used by another to help others.

Ellie supported Alice's view 'doesn't make the tools any more powerful really' (744). The narrative is the tool that co-researchers have used and continue to use to make sense of their lived experience and to be transformative for others (Frank, 1995, Macias, 2009). This is relevant when the narrative has been disrupted by illness (e.g. the co-researchers) (Deegan, 1987, Deegan, 1988, Roe and Ben-Yishai, 1999, Lysaker et al., 2006, Coleman, 2007).

Many of the co-researchers incorporated the value of recovery tools into their narratives, in order to teach others or better understand their own journeys:

*'I've started to learn mindfulness... appreciating the space between each thought... I find it really helps' (Tina, 386-89)*

The co-researcher's narrative seemed to be a powerful tool to support their own recovery process and the recovery of others.

#### **Sub-theme: Telling our Stories is a Political Act**

The act of sharing a narrative (or not as in the case of James) could be a political or a transformative act (Frank, 1995) at an individual and at a macro level (e.g. Deegan and Coleman whose lived experience is widely published). The roots of service user involvement, consumer activism (Chamberlin, 1978) and sharing lived experience has related to a desire to promote systemic and/or organisational change:

*'The wrong people are listening to the story sometimes... this isn't just about*

*'being peers this is about educating' (Ellie, 909-11)*

Many of the co-researchers were involved in making an organisational and systemic difference by sharing their lived experience: Ellie's work with her local GP care commissioning group (715-20); Peter's work with crisis care system changes (570-72); and Harri's work with medical students (944-6). It could also be about changing other's (peers, family, professionals and the public) perceptions and behaviours:

*'its all compartmentalised, I want to be able to express when I do go and speak is how much would you feel if it were your colleague experiencing that?' (912-4)... we do stick it in a box...we've got to change that... somehow speaking out... people can identify... I've experienced that in a different way [normalising effects] ...you've got them nodding, you've got them crying...it makes a difference hopefully to other people' (Sunflower, 921-8)*

Sharing can make lived experience narratives more human, more personal and less voyeuristic. This could allow the audience to consider their own position and understanding within their own narrative - influencing the behaviour of others by telling narratives. Alice suggested that:

*'huge difference in the mental health nurse that are trained now, they are so much better... the older ones are more difficult [the younger ones have benefitted from lived experience narrative in training]' (929-31)*

Sharing the narrative is not always a positive experience. Recovery as a process and developing a narrative is not for everyone:

*'we don't want to hear people's stories [a peer at a conference] ... there is a negative backlash from some people in mental health areas who are service users... there is an anti-recovery movement... they don't see it as a positive' (Sunflower, 958-61)*

Although the co-researchers did not hold this view, there was a sense that the audience may not always positively view their narratives or may be detrimentally affected by the narrative. There was a concern for the welfare of the audience:

*'that's not going to help anyone...that's going to make them really depressed' (Tina, 392-3)*

*'being told off several times to tone down my story and maybe they're right' (Peter, 727)*

Alice weighed the potential harm of sharing her suicide attempt with her peers on the ward:

*'I feel it's a huge part of my story.... because some of the people now find it hard to believe that I was at such a low point... in some ways it is necessary' (Alice, 734-7)*

Alice discussed this dilemma with the professionals on the ward, 'I've gone along with the professionals' (739). Yet not to include this experience, reduced the potential impact and value of her story:

*'only tool really is my story. That's all I've got...you've got your theories, your training... your tools... my story is all I've got' (Alice, 741-2)*

**Phase 3 Focus Group: Issue to Consider in Workshop Development:**

– other's perspective may aid individual understanding and normalizing of lived experience

**Theme 7: Impact of Sharing Narrative**

**Sub-themes:** Value of sharing narrative; being believed and contribution to recovery

**Sub-theme: Value of Sharing Narrative**

James suggested an explanation of why people shared their 'recovery stories or what's come to be known as a recovery story' (181-2):

*'enabled groups of people... common understanding about what had happened to them... wasn't about something being wrong with them... injustice in society... why people who experienced services share with each other... conscious raising and now peer support...bigger context... not just the individual personal recovery story' (James, 183-94)*

Unlike James, 'I wont share my recovery story' (352-3), the other co-researchers suggested sharing their narrative was an important part of the process of narrative development (Burnell et al., 2009, Saavedra, 2010):

*'probably very good to share it and quite good to do it as well' (Sandra, 321-2)*

*'tell your story, you connect better with people, because they open up...everybody has a story' (Alice, 1131-2)*

Sharing their narrative appeared to have a cathartic effect on the co-researchers:

*'...and a narrative is about talking to ourselves and we're listening... my first opportunity to talk to myself' (Jodie, 869-70)*

*'therapeutic (330) ... huge amount of positive feedback (351)...relief... with secrets out in the open (353-4) and 'exposing the real self, the real person... getting over the shame' (Alice 974)*

Alice wanted to use her story because 'I wanted to explain my behaviour to my family (1125-6) (Frank, 1995, p.xii). Sharing the narrative seemed to reduce the sense of isolation and feeling different:

*'just to know you're not on your own' (506)... you speak out and often its not just the people who got mental health stuff, it's the other people' (Sunflower, 500-1)*

There was a sense of reaching out to others. Sharing their narrative showed the co-researchers that whilst they were unique, there was some commonality of experience (Leamy et al., 2011, Bird et al., 2014):

*'huge difference to me.. I think realising that I wasn't on my own... felt like my story was different... core kind of strands...' (Sunflower, 986-991)*

*'the thing is going on in same their world' (Peter, 1013)*

The emotional effects of sharing their narratives were mixed, with fear and anxiety being common emotions when the co-researchers were just starting to share or were sharing their narrative in a different environment to a strange audience:

*'[first conference]... nerve-wracking... haunting memories.... never forget it' (Alice, 347-50)*

*'reduced shame and feelings of isolation... start to normalise stuff... realise that everybody experiences stress... can empower people... honest' (Sunflower, 507-21)*

There was a sense of growing agency and understanding in individuals suggesting a further connectedness (Leamy et al., 2011, Bird et al., 2014):

*'I realise that all the things that I share with people now, I feel a responsibility (Ellie, 535-6)*

In sharing his story, Peter realised that the value of sharing was less about the content of the narrative and more about:

*'recognition ...it's the emotions that you've gone through... frustration or anxiety or anger... whichever shape of form... resonates with people' (Peter, 686-8)*

There were feelings of relief about 'being genuine' (Ellie, 539). Harri acknowledge that sharing her narrative was 'amazing, fantastic experience that helps me too' (563):

*'warts and all, every aspect of you out in the open. A relief life is so much easier you don't have to be making the effort to be someone else' (Alice, 546-9)*

Through narrative development, an individual's growing sense of authenticity, agency, normalisation, social connectedness and reduced isolation could have a positive impact on identity and labelling (Leamy et al., 2011, Bird et al., 2014). After taking part on her film project, Sunflower realised that 'I am not my diagnosis' (222).

There seemed less need to maintain the public persona:

*'living a lie, this mask... perfect life and inner turmoil... you don't have to be making the effort to be someone else' (Alice 542-49)*

In the Conceptual Recovery Framework, Leamy et al. (2011) suggested recovery could occur without professional intervention and that recovery is aided by a supportive and healing environment. Peer support through sharing narrative seemed to be a powerful motivation for the co-researchers:

*'I realised that I do have a story that could be positive to someone... I want others to know that they can have it too' (Tina, 409-4)*

*'we've given hope... something could come of this...you touch people in ways that you don't expect' (Peter, 488-92)*

*'there could be somebody else like me who is embarrassed and frightened and didn't want to see a doctor. That is what made me write about my experiences, to help myself but also to help other people' (Harri, 372-4)*

*'others [in-patients] need to hear stories... they are hopeless... they don't see people who are recovered – they need role models' (Alice, 416-8)*

The value of sharing may be about offering a testimonial example to others, that recovery is possible (Frank, 1995), 'I was ... a flagship' (Sunflower, 211). The value of sharing their narrative is not always for an immediate benefit, but may just sow the seeds in others, when the time is right for them to begin to develop their own narrative (Peter's petrol station analogy, 837-842).

### **Sub-theme: Being Believed**

There can be a difference between what an individual believes and what others believe (Jonker and Jonker-Bakker, 1991, Jones and Morris, 2007). Carl recalled his experience of not being believed by a professional working with him:

*'I told the locum what had happened, but he didn't believe me ... [locum said] not possible for something like that to happen... some things are hard to explain... just be honest...actually happened ... didn't have any explanations' (Carl, 451-68)*

James added that not being believed by professionals could also lead to further medical investigation and can contribute to an individual's illness identity (Kleinman, 1988) and reduced sense of agency:

*'if you told [psychiatrists] that you had certain beliefs... a belief that something that they might need to take an interest in, drag out of you or talk out of you...'* (James, 473-475)

*'people who work in statutory mental health services... like members of a cult... particular a very fixed view of things ... and if you don't share that particular set of beliefs with them, then they think that there is something wrong...that's my own belief' (James, 505-9)*

Through her narrative development and her service user involvement work, Jodie acknowledged that she had an increasing sense of empowerment (Leamy et al., 2011, Bird et al., 2014):

*'my belief systems have changed... from accepting everything others told me, to thinking for myself, albeit 30 years later' (Jodie, 714-5)*

It was important to accept that some people will 'not get' or have no interest in another's narrative. Slade (2009) acknowledged the importance of the authentic listener. Audience reaction to a co-researcher narrative was not always positive: 'shocked look' (Peter, 482) and:

*'sneered at still [mental health story]' (709) ... [from a service user] 'we don't want to hear peoples' stories' (Ellie 958-61)*

*'I was shunned so I never talked about it (1035)...certain people just didn't want to know' (1038) and 'some stuff... is going to be trashed by somebody or be offensive to somebody...but saying it in such a way that you're open'* (Sunflower, 1151-3)

The audience questioning and asking questions about the narrative can also be difficult and can cause co-researchers to question themselves:

*'people with things they find really difficult to change say how can you accept that that happens then? How can you manage that thing? (Ellie, 1115-9)*

Co-researchers also had positive responses when they shared their narrative. Audience questions can support growth and encourage co-researcher reflection:

*'the students said thank you...feedback – oh wow ...what you have said inspired me... given me hope... asked questions' (Peter, 477-84)*

*'how others ask questions can change our responses – what has happened to you not what is wrong with you? (Sunflower, 885)*

The resultant sense of an emotional connection with the audience supported the co-researchers growing sense of self:

*'psychologist... crying... you are so brave' (Alice 504)*

*'something that I shared with them enabled them to laugh' (Sunflower, 525-6)*

*'you know that you are hitting the mark when you see people nodding' (Peter, 682-3)*

*'nodding, you've got them crying... it makes a difference to other people' (Sunflower, 926-8)*

### **Sub-theme: Contribution to Recovery**

The process of recovery can be a life changing experience (Leamy et al., 2011).

Through sharing their narrative, there was the opportunity for the co-researchers to gain further insight, growth and understanding regarding their own recovery:

*'key thing... the word challenge yourself... I've had to do that... more accepting yourself and approaching the stuff that I find difficult in a way that I had never done before... I do that from learning from other people [who have shared their narrative] (1015-21)...sharing my story with other people was huge (1022).... it's a release to be able to talk to other people. Tell my story...' (Peter, 1025-7)*

The co-researchers confirmed that their narrative development had contributed to their recovery:

*'it's a key element' (Ellie, 1213)*

*'I think that it is crucial, whether people have to be open to it... huge therapeutic effect on people... I know what it has done for me...when you reflect back on the therapeutic effect it is strong' (Alice 1217-26)*

*'it really boosted my confidence... I've been able to be so open and talk... feel much more confident in myself... I want to go forward... I want to learn new things... I don't just want to be that person with OCD... I want to challenge OCD (Harri, 1127-33)*

Given that James had rejected the concept of recovery in its current interpretation and implementation, did not have a recovery narrative and would not share it if he had; it was unsurprising that he saw no value in the link between narrative development and recovery:

*'I'd say no... my own belief is that recovery is a concept corrupted by services... I don't relate to and I won't... I don't... notion of personal journey... depoliticised something that's recovery... its reduced to something about identity politics and recovering identity... decontextualized' (James, 985-993)*

Ellie balanced James's view:

*[narrative and recovery] more a social model...difficulty of constraints and power of medical model...fighting all this time over resistance [of medical model]' (1234-7)... 'lack of narrative work done in medical model and acute settings (Ellie, 1236-44)*

Discovering or rediscovering their internal and external voice within their own narrative (from sharing it with themselves and others) appeared to be an important factor in mental health recovery (Frank, 1995), because it allowed sense to be made of lived experience:

*'part of the value of the narrative, whether its related to others or how its related or how much its related...I never had an opinion... certainly couldn't voice it...believe what I was told... and a narrative is about talking to ourselves and were listening...my first opportunity to talk to myself' (Jodie, 866-70)*

Sandra emphasised the internal work that had occurred for her:

*[my recovery narrative] been very useful to me... not just way I did recently but writing through years... been a godsend...what you think about politics and what's going on in the world... still have your own internal business to deal with' (Sandra, 996-1000)*

Jodie linked the contribution to her recovery in terms of action, hearing the stories of others and knowing that there may be a positive impact of your story on another. Sharing her story with others was about making a difference and in doing so, helped her growing agency, responsibility and social connectedness:

*'my definition of recovery is action... I have to do action...physical...so my recovery story is not about what happened to me, to get me there but its how I moved on... the action I take that's given me a recovery story... intertwined. Simple things and somebody I've run into 9 months later will say you changed my life... how much it helped me to hear and I believe if A helps B, A gets better... to share... don't need to know who its helping but at least I'm giving the opportunity' (Jodie, 1001-11)*

Carl also saw the contribution to his recovery in terms of making a difference to others:

*'writing [my] recovery story definitely helped me... made me think more about my life... I've presented my recovery story to other people ... it's given me the opportunity to say things... what are the messages that you want to tell people... time to improve, no miracle cure... need to keep going and not give in... don't give up, there is hope. Accept help from others ask for help from others... don't be ashamed of your illness' (Carl, 1019-27)*

Whilst Carl identified himself within an illness narrative (Kleinman, 1988), there were elements of reframing which highlighted improvement to Carl's sense of self as well as providing testimony to others.

**Phase 3 Focus Group: Issues to Consider in Workshop Development:**

- implications for where workshops are held
- need to consider safe environment to support all workshop participants (reactions to the narrative of others)

**Theme 8: Working with Others**

**Sub-themes:** Commonality of experience; group dialogue and co-production

**Sub-theme: Commonality of Experience**

The focus group highlighted the value of working with, sharing lived experience and narrative with peers (Repper and Carter, 2010, Repper, 2013):

**Discussion thread 5.1**

**James:** 'Yeah ... your recovery story, that is a question, who's it for? Is it just for you, is it for your family, is it for your colleagues? I mean, typically, recovery stories, or what's been come to be known as a recovery story, are something that service users shared with each other... enabled groups of people to come to a common understanding about what had happened to them, and that it wasn't just about them being something wrong with them... also a lot to do with things ... injustice in society... that's a lot to do with why people who have experienced services share with other... just like in the women's movement, it can be about consciousness raising, and now peer support. So it's not pure, so there's that dimension to it. It's not just a story that you write for yourself so that you can recover, and then deliver, say, at a conference somewhere, for the organisation to say, look, there's a recovered person, aren't we wonderful, didn't we do a good job. There's that other...so yeah, I guess, I'm just pointing to that bigger context, I suppose. Not just the individual, personal recovery story, I guess'.

**Sandra:** 'Is that where your interests...is that where you operate, in that area, at conferences, do you work in that way?'

**James:** 'Well...'

**Sandra:** 'Because I don't see it that way at all. I see it as a group of people sharing, rather than somebody standing up in a conference and telling your story, so, you know'.

**James:** 'Yes, I mean, some people don't relate to recovery at all, and say that, you

know, I'm an unrecovered person, and that's a valid identity'.

**Sandra:** 'I think it is, I think, you don't recover, do you, properly. You learn to manage, I think. And learn, also, a lot from it as well'.

**Jodie:** 'I mean, correct me, 'cause I'm not sure I'm really understanding what we're trying to clarify. But for me ... there's my personal story. Which would be quite difficult to separate from my recovery story. If, all this time ... if I'm telling my recovery narrative, then it's very much focused at who I'm speaking to, and why I'm speaking to them. So I would share things with one group that I would deem to be inappropriate with another group. However, I wouldn't feel that my, the relation of that experience, that recovery story, was any less for that fact'.

**James:** 'I agree'.

**Jodie:** 'And I think we all have developed, also, our about me telling the story of my life. Whereas a recovery story has, if we go back to the storyboard analogy, which I personally found extremely helpful' (180-216). own terminology. So for me, I suppose, personal narrative, would be more...'.

There was considerable difference between the philosophical, practical and personal view of developing narrative and its contribution to individual recovery between James and the other co-researchers: 'healthy debate is where we discuss our differences' (Jodie, 510-11). Co-researchers seemed to be working together to make sense of their own narrative, their understanding of other's narratives and the role of narrative within a wider political and social context. There was acknowledgement of shared understanding and lived experience - a potential source of support in the process of narrative development:

*'I think that a lot of people use that term [journey]' (Harri, 162)*

*'well I felt that when I went through such a thing, xxx probably says the same'*  
(Peter, 582-3)

*'you shouldn't feel bad about that at all' (Ellie, 663)*

*'does that resonate with anybody else?' (James, 150)*

### **Sub-theme: Group Dialogue**

The focus group appeared to be used to clarify understanding of different perspectives. For example, Jodie clarified her own understanding based on James's perspective:

*'I'm not sure I'm really understanding what we're trying to clarify' (204-5); 'I really like your distinction... and for that reason...' (Jodie, 271)*

*'but your saying... recovery story... whether its personal one or one that is shared... at the wrong end... issue is not here, issue back there, and its got a much broader base... its in schools, its in families ...local policy... lack of responsibility further back' (Jodie, 378-8)*

*'I could take your [James's] argument and make it much smaller...if you speak up if you challenge... offer an opinion that differs... [professionals] I thought that you were becoming unwell' (Jodie, 423-6)*

*'... I think that I completely agree with you... mad people are the last bastions of free speech... you can say anything... already negated as a person and nobody is gonna listen to you' (James, 431-4)*

Co-researchers appeared confident to express different opinions, regarding the discussion about the similarities and differences between a personal and a recovery narrative, or acknowledging differences in their lived experience or perspective:

*'recovery wrong word... it doesn't fit but having a life that I want to live, that I'm choosing and making most of...' (Sunflower, 203-7)*

*'isolation more debilitating than shame' (Peter, 995-7)*

*'I'm not hearing that, I'm not understanding that' (177); 'I don't see it that way at all. I see a group of people sharing rather than somebody standing up in a conference and telling your story' (198-9); and ...you were saying people should challenge what's going on in society, rather than the story of their own recovery narrative' (Sandra, 587-9)*

The focus group was used to gain agreement, confirmation, clarification and explore differences of opinion. The group of peers seemed to allow the discussion to deepen, questions were asked of fellow co-researchers and more was shared, 'I've not shared this before, it's for this room' (Jodie, 870-1). The focus group seemed to be a safe space to share. This was an important point regarding phase 3 workshop development.

### **Sub-theme: Co-Production**

Co-production (Slay and Stephens, 2013) has been adopted by mental health services to describe partnership working in the planning and delivery of mental health services. As a result, power is shared between service users, carers, families, citizens and employed professionals. Co-production involves making use of all assets, resources and contributions to achieve better outcomes and/or improved efficiency. Examples of co-production are Peter's involvement in a recovery college

(Perkins et al., 2012) and Alice's peer support role (Repper and Carter, 2010, Repper, 2013).

Co-production can be an important element of narrative development too. Working with others to make sense of a peer's narrative and using the experience of another to further develop the narrative. Peter worked with a peer trainer colleague who had shared her experience of developing her narrative with him (455-59), which he used to help develop his own narrative. As a result of the focus group, Alice said:

*'this is something that I can start in my peer support group... starting them sorting their life stories... never revealed to anyone.. it might be very therapeutic for them' (777-81)*

Narrative development (and the support needed to do it) may become reciprocal and exponential. The process of co-production introduced another's perspective into the co-researcher's narrative development. This can be supportive, surprising and at times overpowering. Harri's medical students were surprised that she was a service user 'oooh...I must look normal then... they were so surprised' (557-9). Harri could be both a service user and appear normal. There can also be less positive consequence of the process of co-production:

*'I'll write a poem for you [one of the Masters students].... And this will be the background to it [Sunflower's film] ...he's using social work terms; he's using concepts and its not me, it doesn't make sense. How can this kind of represent me and my life? (Sunflower, 271-76)*

In response, Sunflower wrote her own commentary, which she discussed with the student's academic tutor:

*'a lot of it [her commentary] was around things that I'd either been spoken to me or about me, good and bad, and how I was perceived...their perception and their reflection was maybe different from how I felt...it was only through collaboration... through dialogue... came to realise that what you sometimes perceive is different from what you experience' (Sunflower, 285-94)*

In this initially over-whelming experience of co-production, Sunflower gained an understanding of the process and the importance of collaboration:

*'I'd made an agreement with [her care co-ordinator] ... I was not going to go into the dark stuff' (311-2)*

The students used the film for their academic purposes and Sunflower developed her narrative through film, 'it was a two-way thing and it was really good' (267).

Working with others (whether peers, professionals or other 3<sup>rd</sup> parties) has other possible implications. Their perception of your lived experience and your narrative may be different from yours (as was the case with Sunflower). This may lead to the narrator being asked to edit or tone down the narrative:

*'you may want to ease off a bit when you say the dark side of your story... did you not see the shocked look on their faces?' [a Recovery College Trainer to Peter] (Peter, 481-2)*

*'I used to go around and give talks... in DBT groups and I wasn't allowed to tell them how I had tried to end my life ... I wasn't allowed to mention alcohol' (Alice, 729-32)*

In essence, another decided what was pertinent to the co-researchers story. Professional opinion seemed to add weight to the narrative (or it was perceived that it did):

*'What Peter said is very valid, is what we want to hear, this is the point' (Peter's former manager, 588)*

Professionals can act as drivers – supporting the co-researcher (either directly or indirectly) to start their narrative development and suggest the medium to do it in:

*'if you asked me to write my recovery story... going back maybe 10 years since... I got involved with the mental health services.... had no contact and there was nothing about me ever trying to change my life or do things differently or know anything about it really' (Alice, 153-157)*

*'I was thrown in at the deep end at a conference with 100 people stand up on stage.... I had this very strong psychologist who had been my therapist and wouldn't take no for an answer and I felt compelled' (Alice, 346-9)*

*'you could write a book' (Harri's therapist, 363)*

*'my doctor, after I came out of hospital, asked me to write about my life and my life story and tell me about my life' (791-2)... 'in that process he encouraged me to write the first thing that I could remember' (Sunflower, 794-5)*

*'the way he put this forward [Mary's creative writing teacher asked her to write about her worst experiences] was a bit shocking... but it worked...a way of expressing' (Mary, 616-8)*

*'[My worker] said speak as though there's nothing that you want to hide' (Sunflower 1145-6)*

A possible issue here is the balance between being supportive and/or directive. This was considered relative to workshop development, especially around choice of

media. It may be easier in a group setting for the facilitator to encourage language based narratives rather than art, photography or even quilting.

Leamy et al. (2011) suggested recovery could occur without professional intervention. Peers appeared to be very important in supporting the co-researchers to develop their own narrative. Peer support (Repper and Carter, 2010, Repper, 2013); sharing and listening to peer narratives (Slade, 2009); and learning from peers were factors important to the co-researchers. James found 'Julie Boyd [poet] ... very helpful to read' (974-7) and reading about service user and anti-psychiatry activists valuable. Carl and Jodie used their lived experience and narrative development to work with peers and to support them on their own recovery journeys:

*'great believer in doing things within mental health by stealth... achieved by asking a simple question or talking about themselves...not always receptive to questions but things become apparent to us.... In asking the question the seed is planted' (Jodie, 767-4)*

Peer stories seemed to be important (including in the recovery college and in acute settings). The testimony of others was a spur to action in the co-researchers (Frank, 1995):

*'found hope... a little bit of back bone from other people who were doing it... hearing personal stories... inspiration for me... [Other peers].. you've come from that and now you are in a Peer Support role helping other people sharing your story' (Tina, 430-35)*

Information about: recovery tools, such as WRAP (Copeland, 2013) (Jodie and Carl); anti-psychiatry and anti-recovery background (Goffman, 1961, Szasz, 1961, Goffman, 1963, Laing, 1967) (James); and different service user groups that showcased poetry (Sandra and James, 953-66) was shared within the group. Sandra suggested that she was going to follow it up after the group '*I can look it up*' (969).

**Phase 3 Focus Group: Issues to Consider in Workshop Development:**

- Using group to make sense of own lived experience
- Creating a safe sharing space and to be heard
- Peer support elements
- Commonality of Experience
- Support in developing narrative and getting started.

## Theme 9: Sense of Self

### Sub-themes: Sense of self

#### Sub-theme: Sense of Self

Mental illness can have a profound effect on how an individual perceives themselves, others and the world (Slade, 2012). Various stage models of recovery described this challenge to identity: moratorium (Andresen et al., 2003); overwhelmed by disability (Spaniol et al., 2002); crisis (Baxter and Diehl, 1998); and initiating recovery (Young and Ensing, 1999). These models were mapped on to Conceptual Recovery Framework (Table 1.2: stage 1 pre-contemplation) (Leamy et al., 2011). Regaining identity and a sense of self appeared to be a fundamental aspect of narrative development (Frank, 1995, Roe and Ben-Yishai, 1999, Lysaker et al., 2010) and contribution to recovery (Leamy et al., 2011, Bird et al., 2014):

*'[narrative development] ... reintroducing ourselves to the idea that I'm actually a person in my own right ... before I thought that I only existed to serve other people' (Jodie, 776-8)*

*'coming to know oneself again, is an essential part of becoming well... it doesn't matter how... as you become to know yourself... become more well, develop more awareness, do things... mindfulness, stepping back...' (Jodie, 344-8)*

Society, statutory organisations (including service provision) and individual professionals can have significant influence on an individual's lived experience and their sense of self. This can determine the narrative developed. Jodie suggested early intervention (especially within schools) with appropriate support could mean that '[early mental illness] doesn't become someone's narrative or not really having one' (898-91). When mental health services (usually dominated by the medical model) treat 'patients in their best interests' rather than being strengths based and goal orientated, a sense of institutionalisation, infantilisation (Slade, 2012), and an illness identity (Kleinman, 1988) can be created and maintained – the individual becomes their diagnosis:

*'when talking to...professional people... some degree making service users.. some reason that they might not be able to achieve some of the things that they want to... there can be that effect as well' (James, 285-88)*

*'extraordinary experiences with professionals... spoken to me, treated me or talked to me...I want to be treated in the same way you would be' (Jodie 290-2)*

An important indicators of individual recovery may be a reduction in the reliance of external influences and drivers (such as professionals) to determine an individual's lived experience and a growth in internal decision-making, agency and autonomy (Leamy et al., 2011, Bird et al., 2014). Prior to reframing, Jodie and Carl appeared to have little sense of self other than within an illness and victim identity (Kleinman, 1988):

*'You lose all sense of self... who one is... no perception of who I was or what I liked' (Jodie, 340-43) and 'very busy being ill... wasn't room, or space, or energy, to do anything about becoming well...wasn't aware of that, but the illness itself... my focus was down and inward...' (Jodie, 325-35)*

Carl continued to identify himself in terms of illness:

*'it's about accepting the fact that I am ill' (257-8), 'I felt like a victim... still felt though I was a victim' (730-2), 'society given you a brand... massive effect on someone's mental health' (830-2)*

He acknowledged that he was different before he became unwell, 'one thing that I always felt, even before I became unwell' (790). Through reframing (Bruner, 1987, Anthony, 1993, Frank, 1995, Roe and Ben-Yishai, 1999), Carl developed a stronger sense of self and a increasing separation between his illness and his identity (Slade, 2009). He began to value himself as a member of society:

*'you have to judge yourself – do I think the person specification, do I believe that I am up to standard (840-1)... I'm not just ... my value is not what I can do in society for other people. My value is...I'm a person and I have value... part of the world... I have rights... I have good friends (Carl, 852-6)*

Reframing his lived experience enabled Carl to make sense of and develop new meanings. Whilst he used some of the language of illness and victimhood to describe himself, there was a sense that there was movement from a binary position of illness to wellness, which resulted in him building a more rounded identity and persona. James rejected the possibility of a growing sense of self through regaining identity, 'unrecovered person and that is a valid identity' (201). This highlighted the point that narrative development work will not be suitable or wanted by all services users.

## Theme 10: Making Sense of the Narrative

### Sub-themes: Growing understanding

#### Sub-theme: Growing Understanding

James's view was contrary to the other co-researchers who benefited from the process of reframing their lived experiences through developing a narrative:

*'not necessary to make sense of everything... some things will make sense and some won't... I don't feel it necessary to explain everything... vast majority of life and what happens is explainable... come up with explanations that make sense to themselves that won't necessarily make sense to anybody else it isn't necessary to be able to explain things... some things are just mysterious' (James, 443-7)*

*'I've had to do some form of recovery... each time I've done it I've understood more of like who I am...' (Tina, 184-5)*

On being asked to present his recovery story at the recovery college, Peter:

*what my story was... made me look at what was my recovery (Peter, 453-'didn't know 4')*

Understanding, making sense of, and reflecting on their lived experience were important aspects of recovery supported by developing a narrative. There appeared to be increased agency and growth - with a sense of doing more and therefore greater social connectedness. Sunflower described a reframing process:

*'got the whole emphasis was on recovery... I just went for it (209-10)... I started to understand and make sense of the earlier stuff' (213-4) and 'made sense of how I behaved or reacted or understood things (Sunflower, 217)*

Her diagnosis made:

*'so much sense of my life experiences (262)... when I said that I didn't believe in recovery... it didn't describe cycle [wellness and crisis]... making sense of it for me... incorporating [cycle] and saying anybody else would feel that' (Sunflower, 962-69)*

For Sunflower, part of making sense of her experiences was accepting and normalising them.

Carl's reframing from a 'can't do to can do' resulted in his becoming a 'buddy co-ordinator... chairing meetings and taking minutes (738-9), sharing his story with professionals (274-5) and getting a job (269-70). Making sense of her lived

experience through narrative development also helped Jodie learn more about herself:

*'they've learnt how to evaluate things and how to handle knocks [people on the TV] ... that's something I never learned to do' (65-6)*

Sandra agreed 'you learn to manage' (202).

For Carl and Jodie, WRAP (Copeland, 2013) was important in helping them make sense of their lived experiences, 'WRAP fills those gaps in my knowledge and learning' (Jodie 66-7). Jodie described WRAP as:

*'not a therapy... its not treatment...works by osmosis... it works because of the way that it is put together... it is what gets my feet on the floor in the morning' (Jodie, 59-68)*

Peer facilitation is used to support people to develop their WRAPs. In order to facilitate this process, facilitators share their narrative with the group (to role model and offer hope to others at the start).

Developing understanding and insight are 'not always a conscious process' (Ellie, 805) or easy process:

*'I'm the one who's got to know... find out what it means and I think that stops me from dealing, moving forward and addressing things... always trying to understand...' (Ellie, 1107-10)*

It can involve 'working your way through pain' (Tina, 198). Ellie was aware that things had changed and that she was acting differently 'I am doing [things] that has helped me move forward' (804-11). The narratives shared by her peers helped Ellie's understanding:

*'by you telling me about your Mum made me realise that I can change it [Ellie's behaviour towards her mum]' (530-1)*

Peter described:

*'how do I write this about myself? ... started to realise that what was happening and realising that my story was longer' (Peter, 466-8)*

Like Peter, Harri and Tina used developing their narratives to help make sense of their lived experience:

*'coming to terms with things that have happened to you... discovering the causes of your condition... once I fully understood it... I'm going to write about*

*this' (Harri, 368-71)*

*'Mindfulness... [writing] poetry helps her understand her voices (Tina, 368-9)*

Reflecting on lived experience appeared to be an important aspect to developing understanding, reframing experience and recovery:

*'I'm in a different place now... look at it in a different way... maybe verbalise it in a different way (Sunflower, 799-800)*

It can support the it/me differentiation and strengthen identity 'recovery its part of the whole' (207-8) and 'I am not my diagnosis' (Sunflower, 222). Developing their narrative and sharing not only the narrative itself but also their process of developing their narrative appeared to solidify understanding and provided eureka moments too:

*'you get to the point... realisation ... I can talk about this... and maybe I can help somebody' (Hari, 854-56)*

*'start talking to people... the same thing is going on in their world' (Peter, 1011-13)*

This enabled the co-researchers to reflect on narrative development and its contribution to their mental health recovery:

*'its very interesting... because when you reflect back on the therapeutic effect [of developing your narrative] it is strong' (Alice, 1224-6)*

With growing understanding and reflection, there appeared to be increased agency, ownership and emotional responsibility in the co-researchers. There may be a point of recognition or realisation that recovery is more an internal and less an external process (where professionals and/or government policy are the directors):

*'it is my narrative is also my recovery journey' (208)... I could change or challenge [my behaviour]... less fatalistic... to be able to question that and challenge that and then make up my own mind... my own decisions was so amazing...wonderful (217-21) ... 'this is my experience from my life from what happened and how it shaped me... that's part of the narrative as well' (Sunflower, 1156-8)*

With growing agency, there was a desire to help others 'this isn't just about peers this is about educating' (Ellie, 909-11). Reframing lived experience through narrative development may be a key process in making sense of those experiences:

*'you know this is what it is, this is where I am, what I am going to do about it now' (Ellie, 1123-4)*

*'I don't want just to be that person with OCD... I want to challenge the OCD'*  
(*Harri*, 1127-33)

*'started to understand and make sense of the earlier stuff... where those connections were made [between earlier pain and behaviour] were actually more part of my recovery' (*Sunflower*, 214-5)*

## **Theme 11: Other Voices in the Narratives**

### **Sub-themes:** Family and peer group

There was evidence that the co-researchers used their narratives and the lived experience of others: to make a point more forcibly in their own analysis (especially when discussing their process of their narrative development); to highlight commonalities and differences (Leamy et al., 2011, Slade, 2012); and to show empathy. For example Peter talked about his grandfather's illness and his family's reaction to it (1055-1106); Alice talked about the narratives of those she worked with on the ward (adding a political dimension) (874-80); and Sunflower talked about her brother and niece (521-24). Although the co-researchers' narratives were about their lived experience and their own growth and learning, their narratives were/are intertwined with the narratives of others. There were other voices within.

### **Sub-theme: Family**

Family and other close relationships can have a powerful influence on distress, lived experience, sense of self and recovery. This was reflected in a co-researcher's narrative content:

*'... the determinacy of people's stress isn't just about things that are happening broadly in communities, but they are also things that happen between people that are very close to you (903-5)... stress can be caused by intergenerational... passed down through families... attitudes and value systems... impact on people's lives' (*James*, 907-11)*

Through developing her narrative, Jodie was made sense of her familial relationships:

*'biggest threat was my father...wait till they find out what you're really like... they won't like you, you won't be so cocky then... I knew that I was no good... always told you're not as good as other people... that is your framework... you don't have thoughts and opinions because you have no validity...I remember my mother saying I'll never understand you ... and part of my narrative was about getting an understanding around all sorts of things...' (*Jodie*, 881-95)*

There were continuing constraints and tension between: meeting one's own needs through narrative sharing and development and meeting the needs of others (including their right to not share); and the potential impact of our narrative on others (which in turn connects with effects on ourselves). There can be a moral dilemma too. In explaining our narrative to others, there was an element of needing to share the narratives of others, which were embedded in our own narratives. Peter had been asked to think about whether his children and his ex-partner needed to be in his narrative (654). Ellie suggested that it could be very difficult to leave out the voice of others within a narrative:

*'I work with people... child protection issues... going on as part of their stories... related to partners... hugely relevant' (Ellie, 661-3)*

Sharing others' narratives whilst sharing our own, may give rise to theorising about their motivations and behaviours etc. Peter described and rationalised his grandfather's experience and the family's reaction to it:

*'it's their shame, their guilt that they're hiding... shame of family rather than help family member [his grandfather]... the outside is more important... we can't let them [outsiders] see what's going on' (1093-5)*

*'people are scared of change... they want people to be the person who they used to be, not the person who's now quite often [changed] when we go through recovery (1088-90)... some people have had an impact on our past don't want to be reminded of the fact, (Peter, 1090-92)*

The co-researchers considered whether it was important to edit or not share their narrative in order to protect their children. Alice said her children did not want her to talk about her mental health experiences to their friends:

*'they're not in a place where they can feel comfortable with me being open to some person they bring home' (Alice, 1169-70)*

There was an element of 'our guilt in what we have put them [our children] through' (Alice, 1165) constraining what we shared with them and about them. In protecting others, there was also a sense of protecting ourselves.

Recovery is a life-changing, multi-dimensional experience (Leamy et al., 2011). Changes to the individual may impact on all those involved (close family, friends and

wider social contacts). Sharing their narrative with family seemed to lead to greater authenticity, honesty, greater understanding and better relationships (important recovery processes):

*'I talk to them... we have a good dialogue... watch TV together... I don't feel that I overload them with worries but more likely to say that I am having a shit day... its alright to get things wrong' (Ellie, 1197-1202)*

For many years, Alice was not able to share her narrative with her family in Ireland (1023). As a result of sharing her narrative:

*'sister in law have a great relationship with her... she admires me... she's opened herself up' (Alice, 1134-5)*

It appeared that sharing their narrative and being open and authentic had positive effects on the understanding and acceptance of others closest to them:

*'my kids have deliberately went down the path of learning psychology' (1171-2) and 'other family members have mental health issues... [the children] are comfortable sharing with some people... they pick who... using it to help drive them forward' (Peter, 1178-80)*

*'daughter is a mental health nurse' (Alice, 1181)*

*'same relationship with my children [as Ellie] ... gone into mental health jobs... they're very open... very open house... talk to me about anything... as their friends can... friends ask questions' (Harri, 1203-9)*

### **Sub-theme: Peer Group**

There was a potential multiplier effect that could have wider societal implications in terms of reduced isolation and stigma. However, this was not the case for all of the co-researchers. For some, their lived experience seemed different from that of the other co-researchers that they were unable to share their experiences within the focus group. Even with awareness and understanding, the trajectory of an individual's recovery journey and narrative are not always in their control. Parts of the journey and therefore the narrative can be dependent on the other people within their narratives (e.g. their families). This can leave them with a sense of powerlessness. Also, some parts of their life are more 'recovered, accepted and resolved' than other parts. Being aware of peer difference can make these discrepancies more difficult to accept.

**Phase 3 Focus Group: Issues to Consider in Workshop Development:**

– level of support within and outside of the workshops

**Theme 12: Phase 3 Workshops**

**Sub-themes: Where to locate workshops?**

As well as discussing the research question of this study, the focus groups fulfilled other functions that were important - factors considered in phase 3 development work (the issues raised are highlighted in boxes at the end of individual theme sections and considered in Table 5.7). The focus groups offered an opportunity for peer support, to share similar experiences and acknowledge commonality of experience (Leamy et al., 2011, Slade, 2012, Slade et al., 2014):

*'we've all got our own way of saying things... seems to be common experiences that everybody's had...invalidated by services' (James, 782-4)*

*'my voice goes when I am tired or stressed... quality of the voice doesn't matter as long as you can make a sound' (946-7)... I should just go for it (Jodie, 952)*

**Sub-theme: Where to Locate Workshops?**

In terms of where to locate the narrative development workshops (for phase 3 and beyond), the co-researchers were clear that it should be:

*'on a service user level... it will be really widely accepted in a peer support role' (Ellie, 1251-2)*

*'if you had any group of psychologists, they would love this idea as using it as a therapeutic tool' (Alice, 1254-5)*

*'don't give it to the NHS' (Ellie, 1260)*

Potential difficulties in locating the narrative development workshops within the NHS were discussed. If the workshops become a therapeutic intervention, access to them becomes rationed (secondary sector formal needs assessment, resource and time constraints). The workshops would not be available to all. Also within a statutory therapeutic setting there could be a power imbalance – the therapist directing the time, place, length of intervention, the media used and potentially owning the narrative output. An individual's narrative could be primarily used for diagnostic purposes and as evidence-based assessment. Narrative development could become another tool to be used within the medical model.

It seemed that where different co-researcher's wanted the workshops located reflected to a degree where they were located in terms of their work roles. Peter suggested the recovery college:

*'look at an education facility, you'd get more people participating because that barrier is not there' (Peter, 1269-71)*

Peter also suggested 'workshops for staff within the NHS... helps them to understand' (Peter, 1290-92).

The philosophical location and underpinning model was fully discussed and agreed upon in phase 3.

## 5.6 Discussion

### Reflections on the Focus Groups

James expressed a strong anti-recovery view. His primary focus was the political, social context of mental health and the issue of locating the problem firmly within the individual (Repper and Perkins, 2003, Slade et al., 2014). In his opinion, the concept of recovery had been hijacked by organisations for their own purposes (Department of Health, 2011). This did not reflect the original and unique meaning of recovery for the individual (Anthony, 1993, Scottish Recovery Network, 2013). Slade et al. (2014) suggested that recovery, as the latest model, did not apply to everyone. James said developing a narrative supported this status quo, and as such, rejected the use and value of a narrative for himself (although he did accept that others may find it useful). Whilst acknowledging his perspective, the other co-researchers were keen to discuss the process of developing a narrative and its value to them as individuals. James saw the focus group as another example of an external entity wanting to discuss the individual rather than the global, macro context of recovery and mental health.

Unlike James, the other co-researchers focussed more on the 'nuts and bolts' of the process of developing a narrative, including recording it in some form and sharing it with others. They described how they had developed their narratives in the context

of their own lived experience (Chase, 2013). Contextual anchors such as time and the wellness/illness cycle were discussed and compared. Acknowledging common shared experience appeared to be an important secondary consequence of the dynamics of the focus group itself. This feature of the group setting had implications for the phase 3 workshop development.

It was clear that there were subtle differences between the importance and emphasis that the co-researchers placed on different aspects of their narrative development process. This could have been partly due to where individuals were on their own journeys and what they were willing to share within the focus group. There was a different emphasis and value placed on internal or external aspects of narrative development, which seemed to highlight a distinction of the narrative being developed for personal use and/or for public sharing. For example sharing their narrative (which involved processes such as editing), being heard by others through providing testimony and potentially making a difference to others appeared to be more important for some. Sharing seemed to involve aspects of explaining behaviour to others (including close family) and being heard and believed. Besides being transformative (Frank, 1995), sharing their narrative could also be seen as a political act by some co-researchers – to contribute to systemic change and those who work within (Ellis, 2009). For others, narrative development was felt to be more of an internal process – making sense of and reframing their own lived experience and starting to ‘have conversations with ourselves’. For these co-researchers, sharing their narrative with others was less important; developing their narrative seemed to be about providing testimony to themselves.

Another difference between co-researchers was the relative importance given to the inclusion of other people’s voices (especially close family) within their narratives. To share their narrative involved sharing parts of the narratives of others (Ellis, 2007, Ellis, 2009). This potential moral and privacy dilemma was linked to the co-researcher’s willingness to share their narrative with 3<sup>rd</sup> parties. Given the interconnectedness of social relations, this issue was not easily rectified, but

mollified by continual editing of the narrative depending on the situation and the audience.

Similarly, there appeared to be different degrees of co-production within narrative development. There seemed to be a clear distinction between professional or peer input. Professional input appeared to take place within a clinical, medical model setting (with its inherent power dynamics and imbalances) often as part of a therapeutic alliance. Peer input which was very important to some of the co-researchers, was described as sharing common lived experience that was felt to be empowering (as examples of testimony) and reduced an individual's feelings of isolation and other negative feelings about themselves. For others, the development of their narrative appeared to be a very individual and internal process, with little professional or peer input. It seemed more about the individual making sense of their lived experience, changes to their identity and finding their own voice (Leamy et al., 2011). It may also be a reflection of where they were on their personal journey too.

The dynamics of the focus group appeared to be very important in providing a supportive and safe environment: to share aspects of their lived experience; to reflect on their own narrative and process; and to discuss and at times challenge different perspectives. There was a sense that 'things did not need to be explained as people intuitively got it' and that there was much commonality of experience. Although some of the co-researchers were meeting each other for the first time, the focus groups seemed to allow very difficult subjects to be openly discussed with humour and matter-of-factness.

Given James's strong divergent views of recovery and narrative development (which could have nullified any meaningful discussion of alternative perspectives), it was interesting how readily others were willing to acknowledge his view but also to challenge him and offer their own perspectives. This may not have occurred if the group had included professionals. There was a sense of equality and the fact that the focus group facilitator was also a peer (and had an insider perspective) may have

supported the honesty and depth of the discussion. This had important implications for phase 3 workshop development.

### **Researcher Reflections**

Given my insider perspective, conducting and analysing the phase 2 focus groups was challenging for a number of reasons. The emergent data and themes were not just academic data. There was an emotional connection and response, which linked to my lived experience and phase 1 autoethnography. This required significant processing and additional support.

Facilitating the focus groups was complex. They were held to hear the co-researcher's voices and to explore their perspectives. There was a tension between maintaining objectivity and neutrality as the researcher whilst at the same time knowing and having on-going relationships with a number of the co-researchers. There were times when I wanted to input my comments (what had emerged from my autoethnography), agree or disagree - to essentially become a focus group member rather than the facilitator. I did not - but I was aware of the urge.

I was aware that James held strong 'anti-recovery' views, which could have impacted on the other co-researchers. I did not want to exclude him from participating, but I knew that it could change the dynamics and affect what might emerge from his group. James expressed his opinions strongly and at length from the start. I was concerned about available space for the other co-researcher's that might wish to speak. It became clear though, that the other co-researchers were able to offer different perspectives too. In particular, Jodie was adept at bringing the discussion back to the focus of the group when necessary. This enabled me to remain neutral and not intervene excessively. The group negotiated a way through themselves.

I was aware of an emotional reaction that I had to some of the language used in both the groups themselves and in the analysis stage. In particular the group discussion around the 'illness persona' (Kleinman, 1988). Carl continued to identify

himself in terms of illness but acknowledged that he was different before he became unwell '*one thing that I always felt, even before I became unwell*' (790):

*'it's about accepting the fact that I am ill' (257-8), 'I felt like a victim... still felt though I was a victim' (730-2), 'society given you a brand... massive effect on someone's mental health' (Carl, 830-2)*

It was a difficult process writing this part up objectively, without adding my own comments.

Analysing the data from the transcripts caused a further emotional response and tension. I have on-going relationships with some of the co-researchers and I was aware that they could potentially read my analysis – I wanted to do them justice and be respectful of their contribution. I chose my words carefully. I was mindful that the comments made within the focus groups had to stand for themselves. I had some knowledge of their lived experience beyond what was shared with the focus groups. I was careful not to use any insider knowledge in my analysis. What was shared in the focus groups, I attempted to analyse at face value. This added to the complexity of the task.

### **5.7 Emergent Phase 3 Workshop Development Considerations**

There were many issues that emerged from the focus groups that were relevant to phase 3 workshop development (Table 5.6):

- Narrative development within a peer-led group setting.

What seemed particularly important was that narrative development should be part of a group setting (in preference to 1-1 working). There was evidence that the co-researchers used the responses of others to their narratives to anchor and further develop their narrative. The group response was a catalyst to further action. Confirmation, clarification and disagreements were all important elements of this process.

- It is appropriate to start narrative development work when the individual is ready. Access to workshops with the relevant level of support by peers is important.

The co-researchers narratives included knowledge, understanding and insight gained through doing recovery work. An important consideration was the possible role of therapeutic input (by professionals) within the process. Whether it was necessary to do formal therapeutic work first, to then develop the narrative or would the narrative development in itself support therapeutic work? Developing a narrative appeared to support the process of recovery (Leamy et al., 2011, Bird et al., 2014, Slade et al., 2014). Given the scarcity of access to formal therapeutic input within the statutory services, narrative development work would likely be outside formal NHS provision.

These are the emergent issues that were taken informed phase 3 focus group discussions (Table 5.8):

**Table 5.8: Phase 3 Workshop Considerations**

Issue	Workshop Considerations	Comment
Group Setting	- The value of developing a narrative within a group setting as opposed to one to one	- Others' perspectives may aid individual understanding, highlight commonality of experiences and normalize lived experience
Timing	- Begin the process of developing their narrative when people are ready.  - Allow adequate time to develop narrative.  - Time to share and be heard within the group	- Is it possible to address difficult life experiences through the development of the narrative itself or do you need to have done the therapeutic work before developing the narrative so that the narrative is essentially 'giving voice' to the lived experiences?
Media	- Working with peers to choose a suitable media – art/photography – (perhaps less explanation and more interpretative?)	- Access to other media  - Resource and cost implications
Facilitator	- Peer facilitation	- Training implications - Support for facilitator
On-going peer support	- Supporting people to get started	- Implications for where workshops are located (3 <sup>rd</sup> sector – take advantage of

in workshops	<ul style="list-style-type: none"> <li>- Level of peer support within and outside the workshops (for peer facilitators and participants)</li> </ul>	existing support structures and on-site staff)
Narrative development	<ul style="list-style-type: none"> <li>- Inclusion of work around the process of narrative development</li> <li>- Some individuals may not understand the concept of recovery</li> <li>- Supporting peers to develop a coherent/ structured narrative out of what they might have already produced</li> </ul>	<ul style="list-style-type: none"> <li>- Workshop content about <ul style="list-style-type: none"> <li>• Process and functions of narrative development</li> <li>• Programme to develop individual narratives</li> <li>• Theoretical/learning input (what is recovery?)</li> </ul> </li> <li>- Using artefacts and previously produced work</li> </ul>
Using narrative	<ul style="list-style-type: none"> <li>- Work on editing narrative for different purposes</li> <li>- Using narrative in different settings</li> </ul>	<ul style="list-style-type: none"> <li>- If this is what the individual might want to do?</li> </ul>
Relational ethics	<ul style="list-style-type: none"> <li>- Explore how peers could include the narratives/voices of intimate others within their narratives</li> </ul>	<ul style="list-style-type: none"> <li>- This has implications to the narrator and on-going relationships. It might involve a discussion around the possible ways to include others in our narratives</li> </ul>
Resources	<ul style="list-style-type: none"> <li>- Adequate resources and facilitation</li> <li>- Access to other media</li> </ul>	<ul style="list-style-type: none"> <li>- Cost implications</li> </ul>
Location	<ul style="list-style-type: none"> <li>- Where?</li> <li>- Safe space</li> </ul>	<ul style="list-style-type: none"> <li>- Outside the NHS</li> <li>- Less formal settings</li> <li>- Comfortable and private sharing space</li> </ul>
Workshop Participants	<ul style="list-style-type: none"> <li>- Narrative development may not be appropriate at a particular time??????</li> </ul>	

## 5.8 Chapter Summary

This chapter described the recruitment method for the focus groups (Figs. 5.1 and 5.2; Box 5.1) and how they were conducted (Box 5.2). It explained the procedure followed to develop the emergent themes for analysis (Tables 5.1-5.4). Within the analysis, important issues emerged which were used to inform the discussion in the phase 3 narrative development focus group. These issues were summarised in Table 5.7, which were carried forward into phase 3.

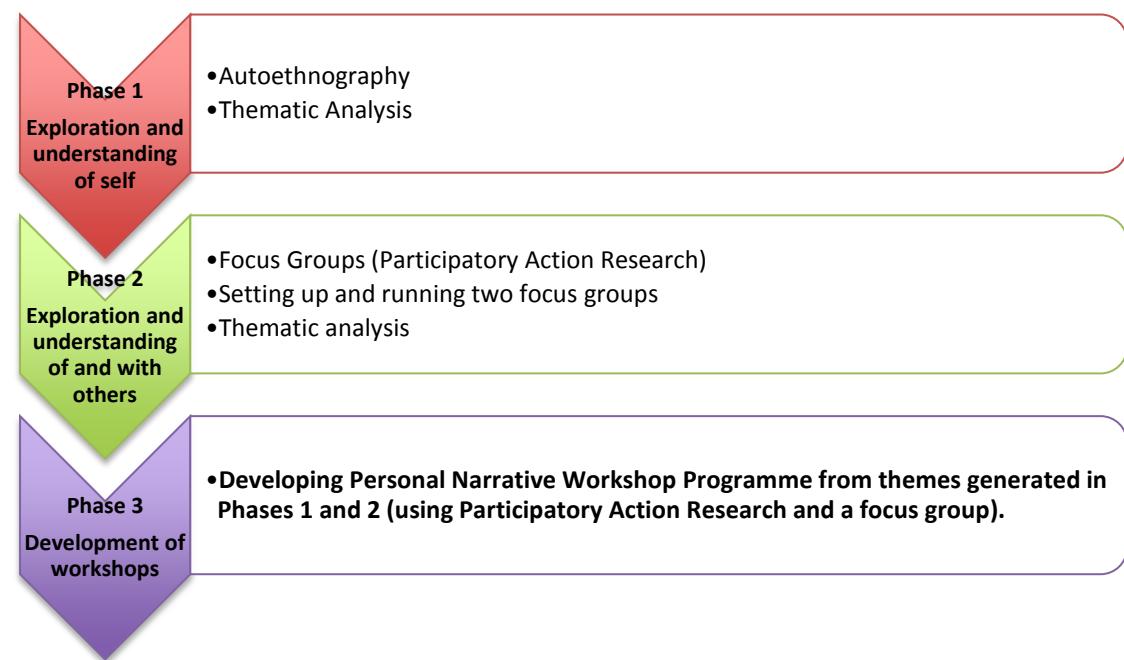


## CHAPTER 6 PHASE 3 DEVELOPING THE PERSONAL NARRATIVE WORKSHOP PROGRAMME

### 6.1 Introduction

Developing the personal narrative workshop programme is the culmination of the work undertaken in phases 1 and 2 of this study.

**Fig 6.1 The Three Phases of this Study**



Chapter 6 describes the method used (including recruitment and data collection) for carrying out phase 3 of this study (3 cycles of a PAR focus group). The workflow between phases and within the cycles of phase 3 is clearly defined. As in previous phases, thematic analysis was used to analyse the emergent data (Braun and Clarke, 2006). Each focus group cycle built on the work of the previous one and involved the production of material and documents. Each cycle is described and analysed separately.

Emergent themes (from phases 1 and 2) such as: a realisation of the difficulty of developing a narrative (reliving trauma); the value of developing narrative within a

group setting (supports factors such as collaboration and validation); and the role of 'the voice of others' in our narratives (implications for relational ethics) informed the work of phase 3 – the development of the framework model, scheme of work and session plans for the workshop programme.

## **6.2 Method**

As in phase 2, phase 3 used Participatory Action Research (PAR) as methodology (Ie May and Lathlean, 2001).

### **6.2.1 Co-Researchers Recruitment**

To complete phase 3, co-researchers were recruited to one focus group that met three times (over three months) following PAR cycles (Ie May and Lathlean, 2001). Whilst the co-researchers were recruited from those who took part in phase 2 (they knew the researcher and understood the aims and objectives of the study), it was important to acknowledge that they could be defined as 'vulnerable adults' (Tee and Lathlean, 2004, Lathlean et al., 2006, Tee et al., 2007). This was particularly important as phase 3 required more co-researcher time input and active participation in developing the workshop programme. This co-researcher commitment raised the ethical question of how much should we as researchers expect from our co-researchers/participants? The co-researchers were not offered payment for their time. As the study was self-funded, only travel expenses were offered. Whilst the researcher was very transparent about this (the co-researchers were told and accepted this at the time of recruitment), there was still a sense of inequity. This issue was discussed with the co-researchers who expressed that payment was not necessary as they believed the research to be very valuable and wanted to give their time and experience to it. As partial recompense and to acknowledge their value, refreshments were available at each focus group.

### **6.2.2 Inclusion/Exclusion Criteria**

The Inclusion/Exclusion Criteria that was used in phase 2 (Table 5.1) was applied in phase 3. None of the co-researchers who wished to participate in phase 3 were excluded.

### **6.2.3 Recruitment Process**

The co-researchers were recruited directly from those who took part in phase 2. All were contacted via an initial email (Appendix 6.1) (apart from one who preferred to be contacted via text). This email explained that the researcher was ready to begin phase 3 and to ascertain their continued interest (given that a year had passed between phase 2 and 3). Of the 11 phase 2 co-researchers, seven expressed an interest. The other four co-researchers were not contacted again.

The seven potential co-researchers were then sent the co-researcher information pack:

- Phase 3: Co-Researcher Information Sheet (v.2) (Appendix 6.2)
- Co-researcher invitation letter v1. 9.06.16 (Appendix 6.3)
- Phase 3 Consent Form v.2 30.09.16 (Appendix 6.4)
- Phase 3 Co-researcher flowchart v.2 14.06.16 (Appendix 6.5)

Three potential co-researchers asked to meet up to discuss phase 3 and what it would entail for them. This was done. All seven agreed to take part (although one withdrew before the start of cycle 1, for personal reasons). The co-researchers were Peter, James, Jodie, Alice, Harri and Ellie – their pseudonyms from phase 2. The co-researchers wanted to use their real names but ethics required that pseudonyms be used.

### **6.2.4 Focus Group Attendance**

The same focus group attendance considerations were applied in phase 3, as in phase 2. These were outlined in Box 5.1 (Chapter 5). It was not assumed that informed consent would cover all three focus group cycles, so it was asked for at the start of each cycle.

**Table 6.1 Focus Group Attendance and Participation**

Co-researcher	Cycle 1	Cycle 2	Cycle 3
Sam (Study Researcher, phase 3 co-researcher and focus group co-facilitator)	✓	✓	✓
Peter	✓	✓	✓
James	✓	✓	
Jodie	✓	Contributed via email comments	✓
Alice	✓		Contributed via email comments
Harri	✓	✓	✓
Ellie	✓	Contributed via email comments	Contributed via email comments
Maggie Donavon-Hall (Study supervisor and focus group co-facilitator)	✓	✓	✓
Diane Carpenter (Study supervisor)	✓	✓	

Two co-facilitators were required for each focus group cycle (in accordance with ethical requirements) - the researcher and Dr Donovan-Hall.

### **6.3 Phase 3 Procedure**

Using the workshop considerations that emerged from phase 1 and 2 themes (Table 5.8, repeated below), the purpose of phase 3 was to develop a workshop programme with the aim of supporting mental health service users to develop a personal narrative (core study aim number 4). This was achieved using a PAR framework (Ie May and Lathlean, 2001) with a focus group with co-researchers from phase 2 (core study objective number 5), who met in 3 cycles.

**Table 5.8: Phase 3 Workshop Considerations**

Issue	Workshop Considerations	Comment
Group Setting	- The value of developing a narrative within a group setting as opposed to one to one	- Others' perspectives may aid individual understanding, highlight commonality of experiences and normalizing of lived experience
Timing	- Begin the process of developing their narrative when people are ready.  - Allow adequate time to develop narrative.  - Time to share and be heard within the group	- Is it possible to address difficult life experiences through the development of the narrative itself or do you need to have done the therapeutic work before developing the narrative so that the narrative is essentially 'giving voice' to the lived experiences?
Media	- Working with peers to choose a suitable media – art/photography – (perhaps less explanation and more interpretative?)	- Access to other media  - Resource and cost implications
Facilitator	- Peer facilitation	- Training implications - Support for facilitator
On-going peer support in workshops	- Supporting people to get started  - Level of peer support within and outside the workshops (for peer facilitators and participants)	- Implications for where workshops are located (3 <sup>rd</sup> sector – take advantage of existing support structures and on-site staff)
Narrative development	- Inclusion of work around the process of narrative development  - Some individuals may not understand the concept of recovery  - Supporting peers to develop a coherent/ structured narrative out of what they might have already produced	- Workshop content about <ul style="list-style-type: none"> <li>• Process and functions of narrative development</li> <li>• Programme to develop individual narratives</li> <li>• Theoretical/learning input (what is recovery?)</li> </ul> - Using artefacts and previously produced work
Using narrative	- Work on editing narrative for different purposes  - Using narrative in different settings	- If this is what the individual might want to do?
Relational ethics	- Explore how peers could include the narratives/voices of intimate others within their narratives	- This has implications to the narrator and on-going relationships. It might involve a discussion around the possible ways to include others in our narratives
Resources	- Adequate resources and facilitation  - Access to other media	- Cost implications
Location	- Where?	- Outside the NHS - Less formal settings

	<ul style="list-style-type: none"> <li>- Safe space</li> </ul>	<ul style="list-style-type: none"> <li>- Comfortable and private sharing space</li> </ul>
Workshop Participants	<ul style="list-style-type: none"> <li>- Narrative development may not be appropriate at a particular time</li> </ul>	<ul style="list-style-type: none"> <li>- Participants may start the process and then realise that they are not ready. They should be able to try again at a later date</li> </ul>

It was intended that the outcome of the phase 3 focus group was a workshop programme framework model, complete scheme of work and a set of underpinning session plans. This programme will be piloted in phase 4 (post-doctoral research).

## 6.4 Ethical Considerations

### 6.4.1 Ethics and vulnerable co-researchers

The ethical consideration of working with co-researchers who are regarded as vulnerable adults (Tee and Lathlean, 2004, Lathlean et al., 2006, Tee et al., 2007) was detailed in Chapter 3, Section 3.7. Box 3.8 presented a summary of consent and participation considerations.

### 6.4.2 Ensuring the emotional well-being of co-researchers

In order to balance potential benefits of participation with potential risks (including co-researchers experiencing further trauma), it was important to plan carefully, be reflective and adapt accordingly. One of the key considerations was a concern for how much was expected from the co-researchers. Phase 3 required a 3-month commitment with 3 meetings at the University of Southampton. In order for co-researchers to feel comfortable, to feel valued and to acknowledge that life gets in the way, it was important that participation was not an 'all meetings or nothing'. If a co-researcher was unable to make the meeting, they could contribute via reading the transcription of the session missed and/or the drafted scheme of work and session plans, adding their comments etc. Co-researchers who were unable to attend a meeting, contributed in this way (Table 6.1). The movement away from an 'all or nothing participation' (more characteristic of a traditional research approach) also modelled the recovery model itself (Leamy et al., 2011) and how it is hoped that the workshop programme will be facilitated. Phase 3 co-researchers are representative of potential workshop co-facilitators so it was important that they

experienced this modelling too. It also promotes better and more meaningful involvement (Tew et al., 2004). This was felt to be a much more egalitarian approach and more ethically appropriate.

Box 6.1 outlines how the emotional well-being of the co-researchers was ensured. This included: being sent joining instructions; being properly greeted; offered refreshments; being briefed and debriefed; consent taken; group agreement developed; and the co-researchers being supported throughout (with two co-facilitators present).

#### **Box 6.1: Carrying out phase 3 focus group**

For each focus group meeting (about 2 hours with break for refreshments):

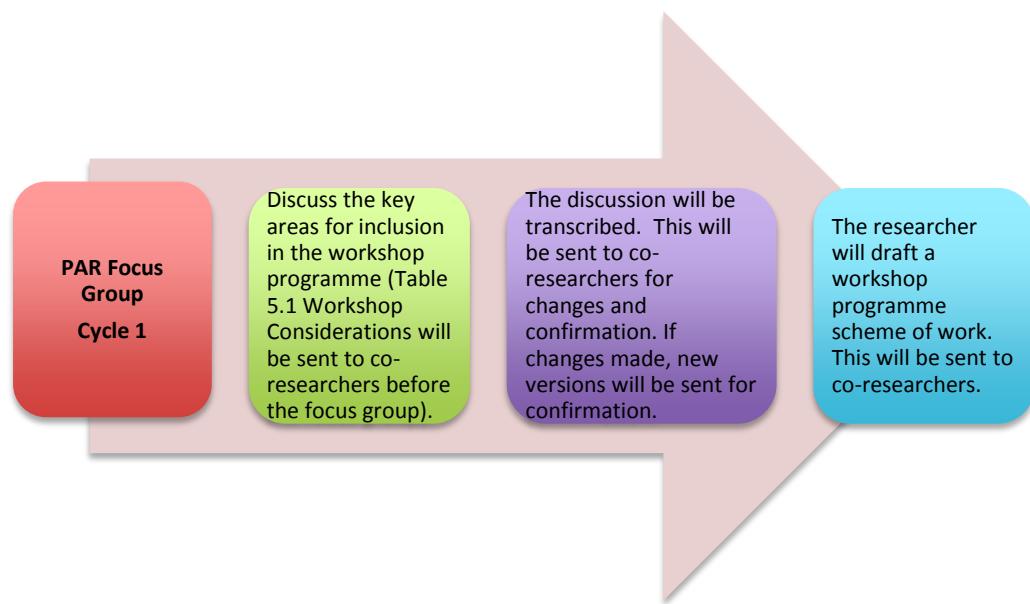
- Time will be available before the focus group is due to start (30 minutes). This will allow co-researchers to arrive, have a chat (including anxieties about the focus group), have a coffee and settle in.
- Time will be allowed at the start of each group to do a brief check-in. This is an opportunity to tell the rest of the group how they are. This also allows the facilitator to gauge the 'emotional temperature' of the group.
- Time will be allocated to do a warm-up activity
- Time will be allocated to develop/reminder of group agreement (rules etc.).
- Time will be allocated to reiterate the outline of the study, the reason for the focus group, to discuss continuing consent and ownership of data generated.
- Focus Group in session (iterative process).
- At the end, allow time to do a group de-brief and check-out (to make sure that they are ok). At this point co-researchers will be reminded of the importance of taking care of themselves, to talk to someone if needed and/or to use their nominated supporter.
- The facilitator will be available after focus group (30 minutes) to talk to anyone who requires it.

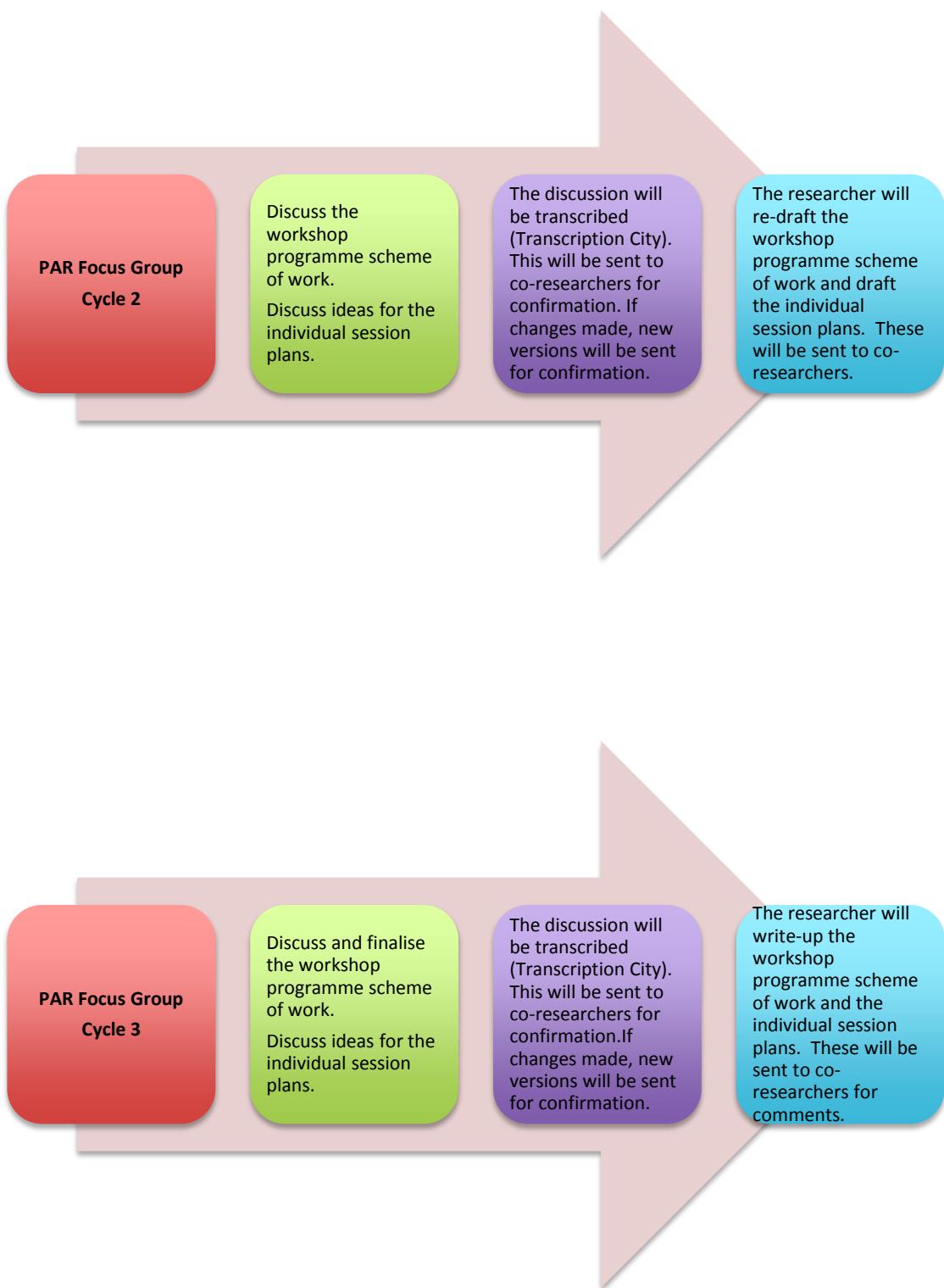
#### **6.5 PAR Focus Group Cycles – Plan of Action**

It was intended that the focus group would meet three times (Figure 6.2) over a period of 3 months. It was important to not over-extend the time between each

meeting (to maintain the momentum from each cycle), but equally not ask too much of co-researchers within a smaller time frame (Tee and Lathlean, 2004). Also the researcher needed time between meetings to write up the results and circulate them to the co-researchers for comments. At the end of each focus group, the group agreed the next meeting date.

**Figure 6.2. Phase 3 Plan of Action**





Not all co-researchers in the focus group were able to attend each meeting. It was important to ensure their inclusion in the discussion. Absentees were asked if they wanted to continue in the focus group. If yes, the transcription (of the missed group meeting) was emailed for their comments. Jodie, Alice and Ellie contributed to discussion via this process (Table 6.1).

## **6.6 Planned Data Collection**

A similar process to that conducted in phase 2 was followed for phase 3. Box 5.2 outlined how data was collected from each group.

Continuing consent was confirmed at the start of each meeting. In developing the PAR Focus Group Cycles – Plan of Action, the researcher had some expectation of the potential discussion flow of each meeting. The starting point for the focus group (cycle 1) was the Workshop Considerations (Table 5.1) which emerged from phases 1 and 2. The researcher expected that cycle 1 would be a discussion on the Scheme of Work; cycle 2 – the underpinning session plans; and cycle 3 – the overall framework model and tidying up loose ends. In between each focus group meeting, the researcher would draft the relevant documents and send them to the co-researchers for comments. The researcher's plan gave a starting point. The co-researchers, the data generated and subsequent analysis of previous meetings informed the focus of discussion for each focus group. It was an iterative process.

## **6.7 Data Collection and Analysis**

### **6.7.1 Focus Group Cycle 1**

For co-production (Boyle et al., 2010, SCIE, 2013) to be meaningful, it was important that the co-researchers were as informed as possible and were able to choose to participate at a level that they wanted. Prior to the start of cycle 1 meeting, the co-researchers were sent a number of documents (Table 6.2).

**Table 6.2 Co-Researcher Documents and Information**

<b>Document</b>	<b>Content</b>
Phase 3 Cycle 1 Co-researcher information (Appendix 6.5)	<ul style="list-style-type: none"><li>• Background information</li><li>• Aims and objectives of phase 3</li><li>• Plan for meeting 1</li><li>• Table 6.3 (See below). Revised workshop considerations to be discussed related to the development of the scheme of work</li><li>• A copy of the emergent themes from phases 1 (Table 6.4) and 2 (Table 6.5)</li><li>• What information will be sent to them after meeting 1, in preparation for meeting</li></ul>

	2
Phase 3: Possible Session Plan Proforma for Narrative Development Workshop v.1 (Appendix 6.6)	<ul style="list-style-type: none"> <li>• An example of a session plan proforma</li> </ul>
Phase 3: Session Plan: Cycle 1 Focus Group – Developing a SOW (Appendix 6.7)	<ul style="list-style-type: none"> <li>• Used in order to model: <ul style="list-style-type: none"> <li>▪ Developing and facilitating a session plan</li> <li>▪ Giving the co-researchers information at the start of the session (to reduce possible perceived power imbalance)</li> </ul> </li> </ul>
Factors for developing the workshop programme (Appendix 6.8)	<ul style="list-style-type: none"> <li>• All the topics were taken from Table 6.3 and separated and boxed. Separated from all the background information for clarity.</li> </ul>

The full table of workshop considerations that emerged from phases 1 and 2 (Table 5.7) were made up of development and implementation factors:

- Factors relevant to developing the framework, scheme of work and underpinning session plans (phase 3)
- Practical factors in implementing the workshop programme (this is relevant to the pilot phase in the post-doctorate phase).

The implementation considerations were excluded from the phase 3 focus groups, to focus the discussion on the development issues (Table 6.3).

**Table 6.3: Narrative Development Workshop: Points for Discussion**

Topic	Points for Discussion
Timing	<ul style="list-style-type: none"> <li>- Allow adequate time to develop narrative.</li> <li>- Time to share and be heard within the group</li> </ul>
Workshop Participants	<ul style="list-style-type: none"> <li>- Narrative development may not be appropriate at a particular time – why do it?</li> </ul>
Narrative development	<ul style="list-style-type: none"> <li>- Inclusion of work around the process of narrative development</li> <li>- Some individuals may not understand the concept of recovery</li> <li>- Supporting peers to develop a coherent/ structured narrative out of what they might have already produced</li> </ul>
Using narrative	<ul style="list-style-type: none"> <li>- Work on editing narrative for different purposes</li> <li>- Using narrative in different settings</li> </ul>
Relational ethics	<ul style="list-style-type: none"> <li>- Explore how peers could include the narratives/voices of intimate others within their narratives</li> </ul>
Media	<ul style="list-style-type: none"> <li>- Working with peers to choose a suitable media – art/photography – (perhaps less explanation and more interpretative?)</li> </ul>

On-going peer support in workshops	- Supporting people to get started
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**Table 6.4: Phase 1 Autoethnography Themes and Sub-themes**

	<b>Themes</b>	<b>Sub-themes</b>
1	Context	Background, places, time and my narrative
2	My Journey	Recovery journey
3	Impact of my illness	Impact of mental illness; internal and external world
4	Identity	Sense of self, stigma and roles we play
5	Relationships	John Doe, Don, relationships, family and external drivers
6	Emotions and behaviours	Emotional response and suicide
7	Power and control	Power and control; expectations
8	Communication and voicing my narrative	Communication, voice and sharing my narrative
9	Lessons learnt	Positive changes in me, on-going tensions and reflections
10	Reflections on my process of writing autoethnography	Revisiting trauma, creating distance and my writing process
11	Creating vignettes	Writing the vignettes, collaborations and making connections
12	Methodology	Autoethnography as method
13	Reflections on the process of Others	Reflections on the possible process of other's
14	What I have learnt as a result of writing my vignettes	What have I learnt?

**Table 6.5: Phase 2 Focus Groups Themes and Sub-themes**

	<b>Focus Group Themes</b>	<b>Sub-themes</b>
1	Recovery – Political, Social and Cultural Context	Social, political and cultural context and value of recovery as a concept.
2	Narrative Content	Personal narrative v recovery narrative; language of recovery and narrative content.
3	Narrative Form	Media and value of storyboard.
4	Timing	Time as context; recovery cycle and continuum of wellness.
5	Developing Narrative	Process of developing a narrative; value of developing a narrative; value to self; constraints on developing narrative; reframing and editing narrative.
6	Process of Sharing Narrative	Sharing narrative with others; peer narratives and telling our narratives is a political act.
7	Impact of Sharing	Value of sharing narrative; being believed and contribution

	Narrative	to recovery.
8	Working with Others	Commonality of experience; group dialogue and co-production.
9	Sense of Self	Sense of self.
10	Making Sense of...	Growing understanding.
11	Other Voices in Narratives	Family and peer group.
12	Phase 3 Workshops	Where to locate workshops?

Tables 6.2 - 6.5 gave the co-researchers detailed information on which to base the discussion.

### **6.7.2 Focus Group Data Analysis**

Braun and Clarke (2006) six-phase thematic analysis approach (Table 6.6) was used to analyse the data generated from all three focus group cycles in phase 3.

**Table 6.6: Six-Phase Thematic Analysis Approach for Focus Group Thematic Analysis**

Phase	Procedure	Each Focus Group (Cycle 1, 2 and 3)
1	Data familiarisation	<ul style="list-style-type: none"> <li>• Listened to data recording of focus group discussion (checked that it was clear for transcription).</li> <li>• Listened to the data recording whilst reading the completed transcriptions. Any third party names were redacted on the transcription. Any errors between what was said and the transcription were corrected.</li> <li>• The transcription was sent via email or post to all co-researchers for checking and to see if they were happy with the transcription.</li> <li>• The co-researchers used their phase 2 pseudonyms.</li> </ul>
2	Generating initial codes	<ul style="list-style-type: none"> <li>• Reread the transcription and highlighted text into units of code. These were colour coded.</li> <li>• Printed the transcription with line numbers.</li> <li>• Used an A3 sketchpad, glued one page of transcribed text per page.</li> </ul>
3	Developing themes	<ul style="list-style-type: none"> <li>• Reread each page of transcript as a whole.</li> <li>• Added comments about the codes on each page.</li> <li>• Added reflections and possible discussion points along side the text.</li> <li>• A 'colour code table' was produced' (e.g. Cycle 2 Colour Coded themes, Appendix 6.9).</li> <li>• Similar/same codes were placed in columns. Tentative theme headings (that matched the codes) were added to each column. When a code did not match any of the existing themes, a new column of codes was started and a tentative theme name assigned.</li> <li>• Some codes appeared to meet the criteria for different sub-themes. These codes were added to each relevant column. These codes were italicised and bolded.</li> </ul>
4	Reviewing	<ul style="list-style-type: none"> <li>• The original theme names were acceptable for what they intended to be used for: to develop a framework; scheme of work; and underpinning session plans.</li> </ul>

	themes	<ul style="list-style-type: none"> <li>• There was significant crossover of some codes (e.g. workshop facilitation and participant process). This reflected the complexity of the subject matter and will be analysed and discussed appropriately.</li> <li>▪ A further review was undertaken and some codes were moved into more suitable themes.</li> </ul>
5	Defining and naming themes	<ul style="list-style-type: none"> <li>• In the initial coding stage, comments were written around the text. These comments included ideas about theme generation and ethnographic comments about the codes themselves (e.g. links to phases 1 and 2, narrative and political/social/economic critique).</li> <li>• These comments were added at the end of each table (Appendix 6.10). The comments were also used in the analysis. <ul style="list-style-type: none"> <li>▪ Cycle 1: 9 themes were developed</li> <li>▪ Cycle 2: 8 themes were developed</li> <li>▪ Cycle 3: 8 themes were developed</li> </ul> </li> </ul>
6	Producing the analysis	<ul style="list-style-type: none"> <li>▪ For each focus group cycle, the themes were analysed and used to produce and discuss in the current UK social, cultural and political and theoretical recovery model context (Leamy et al., 2011, Bird et al., 2014): <ul style="list-style-type: none"> <li>▪ Cycle 1: Workshop programme scheme of work</li> <li>▪ Cycle 2 and 3: Underpinning session plans</li> <li>▪ Cycles 1-3: The workshop programme framework</li> </ul> </li> </ul>

## 6.8 Findings

Table 6.7 is a summary of the themes that were discussed in cycles 1-3 of the focus group. These were used to develop the workshop framework, scheme of work and underpinning session plans.

**Table 6.7 Themes and sub-themes generated from each focus group cycle**

<b>Cycle 1 Themes and sub-themes</b>	<b>Cycle 2 Themes and sub-themes</b>	<b>Cycle 3 Themes and sub-themes</b>
1. Why Develop a Personal Narrative? Sub-themes: 1a. Purpose of Workshop Programme  1b. Participant Process – the Emotional Impact of the Process	1. Why Develop a Personal Narrative? Sub-themes: 1a. Purpose of Workshop Programme 1b. Participant Process – the Emotional Impact of the Process	1. Why Develop a Personal Narrative? Sub-themes: 1a. Purpose of Workshop Programme 1b. Participant Process – the Emotional Impact of the Process
2. Framework and Model  Sub-theme: 2a. Role of Mental Health Services and Perceived Professional Attitude	2. Framework and Model	2. Framework and Model
3. Structure of Workshop	3. Structure of Workshop	3. Structure of Workshop
4. Workshop Education and Content  Sub-theme: 4a. Therapeutic Input	4. Workshop Education and Content  Sub-theme: 4a. Therapeutic Input	4. Workshop Education and Content
5. Participants	5. Participants	5. Participants
6. Timing		
7. Choice of Media		7. Choice of Media
	8. Context	
9. Workshop Facilitation  Sub-theme: 9.a. Venue	9. Workshop Facilitation	9. Workshop Facilitation
10. PAR Process and Facilitation of Focus Group	10. PAR Process and Facilitation of Focus Group  Sub-theme: 10a. Competing Roles	10. PAR Process and Facilitation of Focus Group

Most themes were discussed in all three cycles. Context (cycle 2), services and staff and them and us (cycle 1) emerged from particular cycles. This is likely to be as a result of each cycle initially starting off with a different focus and priorities. Cycle 1 was a more ground-laying generic discussion and also was the main group-forming meeting. This 'getting to know each other' in the new focus group and 'getting to grips with the task/brief' were two very important functions which determined the success of the focus group and what it was able to produce in further cycles.

With the continued need to balance free-flowing discussion with practical output and so that continued discussion threads from one cycle to the next could be facilitated, a ‘parking board’ was used (Appendix 6.13). The topics on the parking board such as ‘underpinning model’; importance of facilitation and participants matched the themes running throughout the cycles.

It was equally clear that the key themes such as: why develop a personal narrative; framework and model; structure of workshop; workshop education and content; participants; workshop facilitation; and PAR process and facilitation of the focus groups were the focus of all discussions. These themes resulted in the development of the framework model, scheme of work and the session plans.

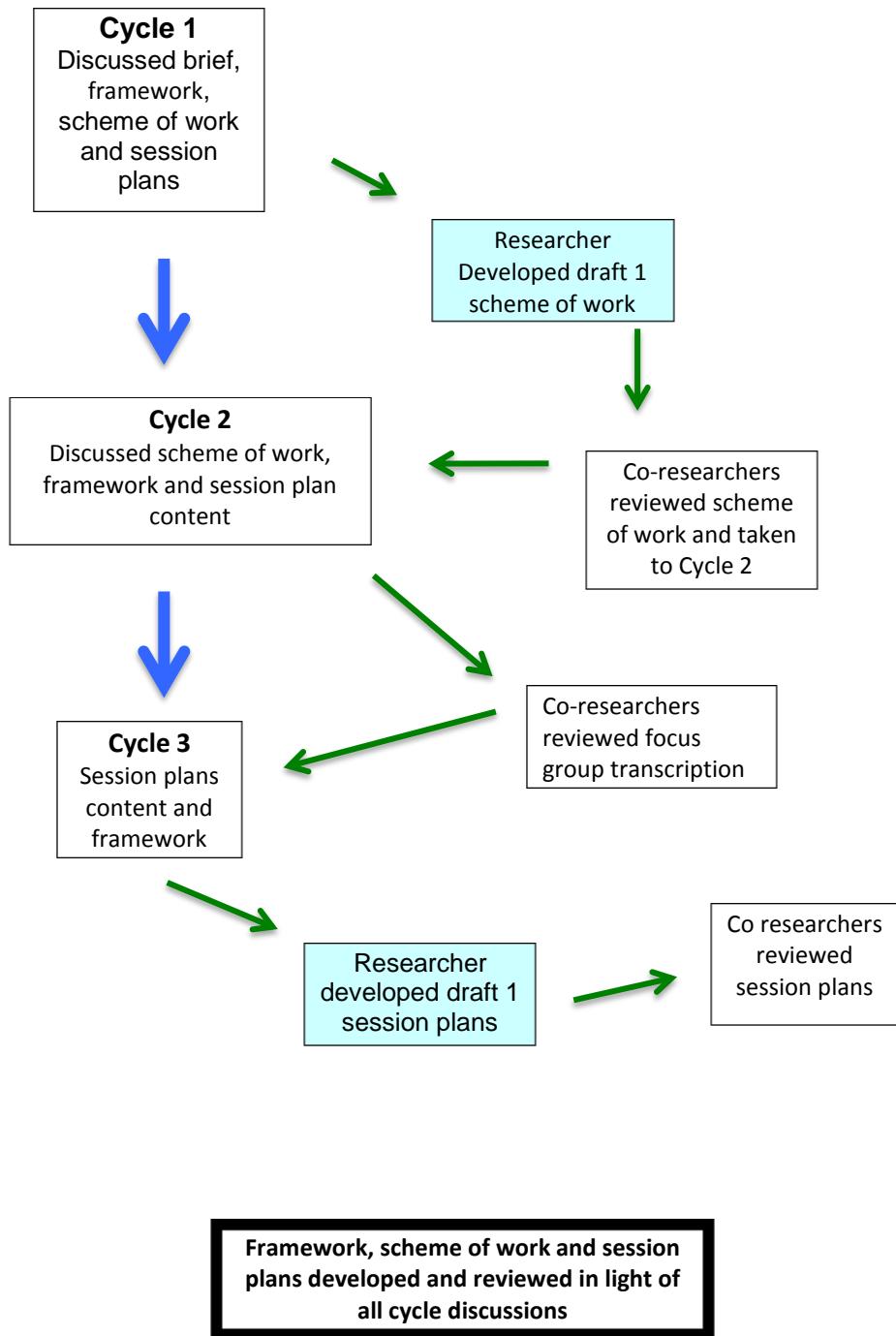
## **6.9 Developing the workshop framework model, scheme of work and the session plans**

### **6.9.1 Importance of PAR cycles**

Phase 3 was a building process, with decisions from one cycle determining the discussion and output of subsequent cycles (Fig 6.2).

As decisions were made and the documentation drafted, it was necessary to revisit previous decisions/drafts. For example the scheme of work was drafted as a result of cycle 1 discussion. From the scheme of work, content topics were extracted for discussion (Appendix 6.9) and were used to populate the session plans in cycles 2 and 3. Once the session plans were completed (Appendix 6.19), the scheme of work was checked and redrafted (Appendix 6.18) so that the scheme of work and the session plans matched. The framework model was developed as a result of all the focus group discussions (and was a reflection of the scheme of work and session plans).

**Fig 6.3 Developing the workshop framework, scheme of work and the session plans**



### **6.9.2 Parallel processing within the PAR cycles**

It was apparent throughout the 3 cycles that there were multi-layered processes occurring. The focus group task of developing the workshop programme involved discussing higher order considerations such as framework model, aims of workshop, workshop structure and participants. There was also the essential practical task of building workshop content.

This practical layer was further layered with PAR and focus group process issues: how decisions were made; the flow of the discussion; disagreements and consensus; co-researcher anxieties, interests and passions; their different levels of knowledge, experience; and contribution. A further layer of co-facilitator expectation was also added to this. For example the importance of co-production, of the free flow of discussion, of having space for consensus, disagreement and wonder (all important factors in choosing PAR as methodology) were key. Yet at the same time, there was a pragmatic awareness of achieving the practical aims (developing the workshop programme) of phase 3 in the time allowed.

### **6.10 Cycle 1**

The themes were multi-faceted and interlinked with each other. This was indicative of the complexity of developing the workshop programme for adults who were considered 'vulnerable'. Cycle 1 laid much of the groundwork for subsequent cycles

**Table 6.8 Information and Paperwork given to Co-researchers**

Name	Detail
Focus group (Cycle 1) Co-researcher information (Appendix 6.6)	Expectations of phase 3: - To produce a framework with a scheme of work with underpinning session plans - How information will flow between sessions (Fig 6.2) - Table 1: Points for discussion for phase 3 (which emerged from phase 1 and 2) -Table 6.2: Phase 1 and 2 Themes
Possible session plan proforma (Appendix 6.7)	An example of a session plan proforma – enabled co-researchers to see the type of factors to be included in a session plan (Aims, objectives, timing, content, method and resources)
Cycle 1 Focus Group – Developing a scheme of work session plan (Appendix 6.8)	A session plan for the cycle 1 focus group (using the proforma layout)

### **6.10.1 Cycle 1 Themes**

The themes in cycle 1 were: why develop a personal narrative?; framework and model; structure of workshop; workshop education and content, participants; timing; choice of media; venue facilitation; and PAR process and facilitation of the focus group (Table 6.7)

The underpinning aim of this study was the exploration of the process of developing a personal narrative and its possible contribution for mental health recovery. Both phase 1 and phase 2 have explored this from different perspectives:

- Phase 1 - researcher's autoethnography
- Phase 2 – service users (co-researchers) who had developed their personal narrative

The knowledge and understanding that emerged underpinned the development of the workshop programme that in phase 3. The discussion, in cycle 1 around the purpose of the workshop programme, guided co-researcher thoughts, reflections and decisions on all facets of the programme (e.g. framework model, structure, content, facilitation and participants).

#### **Theme 1: Why develop a Personal Narrative?**

This theme was made up of two sub-themes:

- Purpose of the Workshop Programme
- Participant Process – the emotional impact of the process

### **Sub-theme 1a: Purpose of Workshop Programme**

The purpose is interlinked with our experience and process of narrative development and the expectations that we, as co-researchers, had for potential participants:

- What is the purpose of the workshop programme?
- How can individuals benefit (and therefore support their mental health recovery) from participating?

For the co-researchers, there was often a reason why they had begun to develop their personal narrative:

*'purpose... It took me... mine was a narrative because I was actually doing the peer trainer work to deliver courses' (Peter 244-5)*

Few had any systematic support and practical guidance to do so. Narrative development has become a feature of NHS recovery colleges. An important reason for undertaking this study was my concern that I was being asked to deliver these workshops without substantial underpinning theoretical content or a real understanding of the impact that this work could have on the individual:

*'It was in that reflection thinking, What are we asking people to do here? What's going on? Is it right that we just send people away?' (Sam 255-57)*

The narrative development courses offered by the recovery colleges also tended to be for the benefit of the NHS Trusts concerned: to share 'recovery stories' as part of on-going staff training; to then deliver narrative development courses to other service users; or to model 'recovery' by offering a successful testimony to others (Frank, 1995). This idealised version of 'recovery' could also be detrimental to other service users who did not/could not match the model. For those service users who were held up as the 'model', it was difficult to sustain and could result in feeling a failure. It caused others, like James to walk away. Any benefits accrued for the individual were secondary.

The intention of the workshop programme is to offer a supported structure, theoretical content, practical information and a safe space to develop and share their personal narratives:

*'I think that goes back to the purpose. If it's a personal thing for you and your circle, then expletives in it will be a part of you. But if it's for a broader group, and you're wanting to share something, sometimes... why are you wanting to share with other people? Do you want to consider how you put it together?' (Peter 433-6)*

*'It's about that it's not for external organisation; it's for us... You know when I asked you the question last year about the difference between a personal narrative and a recovery narrative? Well we were trained to tell recovery narratives because of a purpose that wasn't ours. And that's got it place, but it can also keep a lot of people out of the process because they're not going down that route' (Sam 447-52)*

*'not self-censoring and not ending up with a highly polished recovery story, but having one that's authentic' (Jodie 600-01)*

James refused to develop his narrative through the recovery college route because he felt that it would no longer be his. This workshop programme aim is to support the development of the personal narrative for the individual.

*'There is no purpose without it' (Peter 455)*

Its purpose is to offer participants: an opportunity to develop/regain their own voice and agency; space to allow participants to talk in their own time; and individual choice and opportunity. We cannot determine what an individual should get out of it, when or what they take away from it:

*'It's about what the personal benefit is. We're not asking people to think about doing this for anyone else but themselves' (James 466-8)*

*'But it's also the most important thing when I wrote it down for myself, to connect with myself, which is something I hadn't done in a long time' (Ellie 492-3)*

*'the purpose is actually looking at that and that acceptance bit that when you start destigmatizing yourself, you start to be able to be the person that's in there, as opposed to the bits that go on around you when you feel completely isolated and out of control' (James 539-42)*

Reconnecting with self, acceptance, destigmatization and changing labels, reduced isolation and developing confidence and agency are all key aims of mental health recovery (Slade, 2009, Leamy et al., 2011) and are all deeply personal.

**Decision made:**

Workshop programme is about developing own voice and own narrative

**Sub-theme 1b: Participant Process – the emotional impact of the process**

The aim of the workshop is to develop a narrative. In the context of this study, the term process encapsulates two separate, yet interlinked functions – ‘doing’ and ‘feeling’. The ‘doing’ is essentially the practical elements and more visible parts of the workshop programme – the developing, sharing, listening, discussing and reflecting. These elements are essentially the product and therefore the purpose – why is the individual participating in the programme? The scheme of work and session plans are underpinned by these elements. Given the themes that emerged from phases 1 and 2, this ‘doing’ process will almost certainly have an emotional impact – the ‘feeling’ processes. It is this emotional impact that will likely be the factor that contributes to recovery. It is these emotions, reactions and feelings that need to be supported within the workshop programme by good co-facilitation and potentially signposting for additional support and/or opportunities.

Key considerations of developing a personal narrative – emotional response:

*‘It evolves though because actually in the early stages, some people might only want to share and discuss, but when you gain somebody’s confidence and trust – we do the personal on-going process where they work with other people and they talk to other people and they get involved in other groups – the sharing is phenomenal’ (Jodie 171-5)*

*‘in starting this process off, how do we allow the growth ... how does that help going forward? What do you do going forwards? Your helping someone to develop their narrative is almost like a lifelong process’ (James191-3)*

These quotes are at the heart of the anticipated emotional impact of developing a personal narrative. It acknowledges the evolutionary and on-going process. For many, narrative work is a continual process of doing, sharing, reflecting and refining. Developing a personal narrative is complex:

*'the story develops as you start talking about it and then you start putting it into either chronological order or, knowing my own story, there's so many paths come in that you have to then stop and tell the sub-story to one part because it's like train tracks. The main story might be going along there, but it will come up here. And the sightings will join in and they overlap each other to make the same story go the same direction (Peter 209-14)*

*'sometimes the first narrative we write for some of us is probably an angrier narrative. But that might not be... this might sound wrong but it might not be the right narrative. That's just the first draft and you're getting it out there, and it's getting everything out because it's all emotions. As you said, the story changes. But it's not the story changing – it's just maybe your healing process is changing the concept and its realising the different stages that you're going to go through' (Peter 548-53)*

*'narrative develops and we become more familiar with ourselves. I think the healing is about the acceptance of the reality' (Jodie 567-8)*

These are examples of the emotional impact of developing narrative and its link to mental health recovery. The quotes suggest that the starting point and motivations will differ and that participants are not blank screens:

*'How I present is not necessarily how I really am, and how I am in the sessions is not necessarily reflective of what I'm gaining from it. What mattered was that what I gained was sufficient to really get me started' (Jodie 369-71)*

It highlights the importance of doing this work within a supportive group setting – collaborating (reducing isolation) and developing trust and confidence. Which in itself helps understanding and insight:

*'when people talk about what's happened to them and they share it with other people, and then that leads to greater insight about what's happened to them' (Jodie 180-2)*

James suggested that the current recovery college routes to developing a personal narrative are biased into supporting the purpose of the system rather than supporting the needs of the individual:

*'And sometimes loads of things that the mental health system tries to suppress – it doesn't want you to talk about those things. So the more people share, the more likely they are to develop insights into what happened to them' (Jodie 175-80)*

*'my experience is that people become more psychologically-minded, don't they?*

*'They grow into their own understanding, which as you say is not always something that mental health services are particularly fond of, and will actively try to suppress with some people. But our experiences are actually a positive thing for people to do' (James 181-5)*

*'very often they've got a script. So there's a kind of socially acceptable kind of narrative that people in the service want to hear; they don't necessarily want to hear your story. They want to hear something that fits their template of what your story is' (James 196-99)*

Along with the sense of redressing actual and/or perceived power imbalances and a lack of agency, sharing appears to have important benefits that can contribute to mental health recovery. Whilst the workshop programme's emphasis is on supporting the development of the personal narrative for the individual; it is important to acknowledge that the process of sharing and having the confidence to do so also has an emotional impact and potential consequences (good and bad):

*'I suppose I was coming at it from talking to your guys that it's not a benign process' (Sam 258-9)*

Often there is a great deal of anxiety, perception of isolation (that individuals are the only ones to have had this experience), a fear of talking about intimate secrets and relationships of others (relational ethics):

*'It depends if it hurts for people to be told, but your first duty is to yourself. You say what you want to say. I suppose also I would never tell somebody what to say or what not to say; that's up to them' (Jodie 499-501)*

The co-researchers decided that the workshop programme should offer support in a safe environment (hence the two co-facilitators) to think about these issues and to make a decision of what is the right thing for the individual to do at this point in time:

*'and I think they would be amazed once they started telling it. I'm sure you found from your workshops, I think you did, that it's hugely beneficial in the previous sessions we had. And I don't think there was anyone who said that they found anything negative. It can be painful obviously but the long-term benefits are enormous' (Alice 269-73)*

*'not so alone when someone shares their story. You can see identification and you think you're the only one in the world that feels like this, but you hear*

*someone else and I think that's a huge benefit' (Alice 641-43)*

Whether to share or not or when is the right time to share is up to the individual (and will be based on their fears, anxieties, fantasies and their expectations):

*'And to be able to talk about it and have somebody listen' (Harri 277)  
'really important point that there's no pressure or expectation on everyone to share' (Jodie 309-10)*

*'I benefited from the training as I went along and I had the training. I had no intention of connecting with anybody; that's just where I was. It was absolutely irrelevant, my state of readiness, and I feel it's imperative that the individual chooses whether or not they're ready, and that criteria are not put in place' (Jodie 364-8)*

*'I tell part of my story. What I say depends purely on whom I'm speaking to and why I'm speaking to them. And I share only what I'm comfortable with sharing in that group' (Jodie 480-2)*

The co-researchers agreed that developing the personal narrative within a group setting was valuable. It offers the opportunity to share, listen and to learn from others:

*'But I think the richness... the real value in recovery stories is in their variety, and that means different cultures, different ages, and different styles of dress. It's that variety' (Jodie 411-3)*

*'benefit of being part of the process isn't just necessarily in the production of the narrative. It can be a lot to do with listening to other people, in my experience of developing insights, not just by talking themselves but by listening to other people' (Jodie 595-98)*

*'learning from others, I think the learning there is far greater than the learning that we go through doing it ourselves' (Jodie 629-31)*

Although Jodie specifically mentioned 'recovery stories' it was clear that the workshop programme would not emphasis 'recovery':

*'so I think breaking that down and explaining it and talking about the fact that there's no listener... there's no agenda to this. Its part of what you get out of it' (Maggie 475-7)*

It is about the individual's narrative:

*'It's not just recovery that we're talking about here because I think that would put a lot of people off because they would think they weren't well enough, you know? It's their story really' (Alice 420-22)*

*'the story has to be from the person' (Alice 433)*

*'And it's important to tell it how it is and not to make it fancy and light. In my writing, I have a fair bit of swearing but I tell it as it was and how I felt at the time. (Harri 439-440)*

*'It's my voice' (Jodie 441)*

*'There are no fancy details. It's all me' (Harri 442)*

Interestingly sharing an authentic voice will likely increase listener interest too:

*'An authentic one is one that other people are more likely to benefit from hearing' (Jodie 602)*

Rediscovering your own voice and gaining confidence in the fact that others will listen have important implications for recovery and that is why they underpin the workshop programme:

*'Your labels of yourself change' (Maggie 543)*

*'its about self-advocacy' (Jodie 993)*

James encapsulates the underpinning philosophy of the workshop programme - developing a personal narrative is a vehicle to communicate with others and ourselves. It acknowledges there may be positive and negative emotional impact too. That developing a personal narrative is a human need not just a mental health one:

*'about communicating, isn't it? You're doing it in a particular setting but actually everyone needs to know how to communicate and talk about themselves confidently, and to be able to share stuff that's difficult and stuff that they can celebrate' (James 988-92)*

### **Theme 2: Framework and Model**

The rational for phase 3 was to develop a workshop programme that would support people experiencing mental health difficulties to develop their personal narrative.

A peer-led model, with the workshop programme co-produced and co-delivered underpinned this. Ideally, the co-researchers wanted it to be fully peer-led, but this could raise practical difficulties with local delivery (would there be enough co-facilitators?). It was agreed that the co-delivery route (peers and clinicians), was the practical and sensible option. The clinicians should ideally have lived experience

and/or interest in narrative development. Co-produced also modelled the type of relationship and power dynamics that we would like to see across all service provision:

*'them and us'; there's a real divide between things that are led by service users and things that are led by staff which is a real shame.... We're working together as a team and it's about breaking down some of those barriers' (Maggie1030-3)*

*'My experience of statutory services is that they say that they don't like 'them and us' or there is no 'them and us', but all of their behaviour leads me to believe that actually they're quite happy with the 'them and us' situation. If you look at their behaviour that explains the way they behave. Predominantly, they're comfortable with 'them and us' and their behaviours demonstrate that' (Jodie 1120-24)*

### **Sub-theme 2a: Role of Mental Health Services and Perceived Professional Attitude**

The workshop programme model discussion was across all three cycles. In cycle 1, the discussion focused on the role of services and the perceived professional attitude - 'Them and Us' (Them - staff, professionals and clinicians; Us - service users). The discussion was characterised by heightened co-researcher emotion based on personal experience of service provision and clinical and/or therapeutic relationships - the extent that they felt had listened to and valued:

*'very often they've got a script. So there's a kind of socially acceptable kind of narrative that people in the service want to hear; they don't necessarily want to hear your story. They want to hear something that fits their template of what your story is' (Jodie 196-9)*

*'psychiatrists they don't need to know what happened to you or what your story is – they just want to diagnose you and put a label on you' (Alice 275-6)*

*'the key thing is we said about doctors and all this wanting to hear what they want to hear because they've got to diagnose. But they're time-constrained and they can only see you for so long in their appointments and they've got so many and it's a production line effectively' (Peter 288-92)*

There seemed a perceived/real disconnection between service users and service providers. For the professionals working within the medical model there is a need to diagnose, treat and discharge. Lack of time and resources are structural and organisational factors that severely impact on service users who need time and understanding. Add to this the implications of the Mental Health Act and individual detainment:

*'If you are in an acute setting... If conversation is suppressed by the staff, typically if you're detained you're highly motivated to tell the staff exactly what they want to hear and they don't want to hear anything negative. You very quickly... and that all adds up to a sense of isolation because you never ever hear any other story' (Alice 644-8)*

James described this as 'abuse' as a common experience for service users that provided connection but also perpetuated the 'them and us':

*'it's one of the first things that people, when they get together and connect, is the fact that they've been abused by the services' (James 603-4)*

The underlying philosophy and model of co-production in the workshop programme aims to be different from the existing system (with some exceptions e.g. recovery colleges), in terms of power and ownership:

*'the fact that mental health services aren't about what they say is on the tin. They're about controlling people and that's their function; that's what the unspoken mandate is it to control people for not fitting in for whatever reason... But that's not made explicit. So all the talk is about helping people. And most of the staff do want to help people, but they don't work in a help system but they work in a controlled system and I think it might be useful to somehow make that explicit somehow in your programme' (James 1018-26)*

The 'them and us' discussion with its apparent passion mirrored the need for individuals to produce angry personal narratives in the first instance – a sense that there needed to be an emotional release before a balanced discussion could take place:

*'have to decide if you want a partnership model, a separatist model...' (Jodie 1037)*

The co-researchers debated the merits and difficulties of both models. It was felt that a partnership model had significant benefits in terms of shared learning and understanding:

*'I have been doing workshops for Southampton University through Southern Health for three or four years.... Normally we have a professional mental health nurse. The benefit of that is that we can give both sides; the benefits of what I'm talking about' (Jodie 1041-4)*

If located outside the NHS this potential shared learning would be lost:

*'Think about that in terms of where we want to locate it. I've gone in with this being a peer-led outside the NHS...but my examiners said, "Actually though,*

*professionals could learn a lot from this. It could inform their practice. It could make a difference.” (Sam 1062-67)*

There was also the possibility of the workshop programme being valued less if it was purely peer-led. However, the fact that this work has been done as part of a PhD would give it weight and validity. In a sense we would be modelling the professional behaviour that we didn't like – not being open to different ways of doing things:

*'You've got that raw mix of people and it's opening eyes to both carers and people of people's experience of the services that they're going through. But if we keep being insular and staying within our own little group, we're just preaching to the choir...maybe we need to be the bigger group because as long as we keep shouting to them and trying to include them in, if we shut them out then we're just proving their point. We're perpetuating it' (Peter 1108-1114)*

Equally though, it was believed that to locate the programme solely within an NHS setting (with professionals being responsible) could lead to the programme becoming another treatment tool that is only available to the chosen few. Yet, the workshop model could be used to inform professional practice and be used to train future professionals:

*'But using your model, it could be a back door into the NHS. This is where they're coming to learn to do the job, so this is the back door into breaking down that thing. So we're training the people who go to the NHS that invite us in with them down the line. I suppose one of the things is we don't speak language from a whole. We teach ourselves the language. At the same time if we get in early, we can teach them the right language of the service user' (Peter 1154-9)*

*'I'm not trying to apologise for the NHS or anything but I do feel that there is a change happening ...lot of new rhetoric that's happening. But in practice, my feeling is that substantially things aren't substantially different. I'm not saying the NHS doesn't help' (Jodie 664-70)*

These quotes highlight the differences of opinion. There were perceived benefits and difficulties and at this point no clear consensus on where to locate the workshop programme.

There was discussion and disagreement about terminology of what a 'professional' meant and whether a session could be run if a professional was not in attendance:

*'And there's benefits, but I don't think that it should say not go ahead because there isn't a professional involved at that time. And the professional should be*

*used very loosely' (Jodie 1074-6)*

Initially it was assumed that a 'professional' was trained and regulated by an official body e.g. an occupational therapist. As such they would represent the expertise and detached experience. In the same vein the service user would bring their lived experience. Both would deliver separate parts of the curriculum. They are co-facilitators yet regarded as separate entities. It ignores crossover such as service users who are also professionals and professionals who also have lived experience. This is the model of co-production that many recovery colleges follow.

In cycle 1, we were at the start of our considerations about who is the 'other co-facilitator'. It shouldn't be tied to qualified staff, it could be a carer for example. It shouldn't be tied to a particular location in or out of NHS settings. The essential requirement is that both co-facilitators (as partners) believe in the importance of narrative work and the philosophy underpinning the workshop programme:

*'it could also be within the NHS, but it could still be peer-led' (Sam 1088-9)*

*'My thought about it is that because it's being developed with people who use services in an academic environment, that does give it weight. So I think my feeling is the risk comes later, maybe when you have a finished product. When you're developing it and allowing professionals in at that point. The history is as soon as you allow professionals in who are well-intended, eventually they end up controlling it' (Jodie 1096-1101)*

### **Pragmatism of model**

Discussing the model itself raised tension between practical requirements of running the workshop programme as a one-off (in the pilot, with the researcher as a co-facilitator) and rolling out the programme. This would have possible practical implications (e.g. co-facilitator availability and local resources). There was tension between philosophical desire and pragmatism (apart from James, the co-researchers were all passionate about the value of narrative development and mental health recovery). There was a sense that the co-researchers ideally would like the workshop programme to be fully formed and adhere to a pure model. However, in reality the programme may need to evolve and should be flexible in order to work

with differences in co-facilitators, local conditions and participant needs. Facilitating the focus group was a balancing act between the two:

*I needed to have a framework that was projectable so that people could follow the path and I could deliver it in a format that could be repeated regularly. (Sam 246-8)*

### **Theme 3: Structure of Workshop**

In cycle 1, the discussion of the structure of the workshop programme touched on a number of important factors: the possible overarching model; session structure and number; where and when to run the sessions; number of participants; and entry criteria. The workshop structure will frame the workshop content and determine how it is delivered and facilitated:

*'Will you turn up and be told, "Today, we're going to talk about this bit of narrative" and then just free-flow it? Or is there every week going to be within mini structure to each session, where if someone starts opening up, you might find this pulls them down the week before?' (Peter 793-6)*

*'you need basic structure or it's a danger of not achieving' (James 804)*

*'You need that bit of structure, but it also needs to be able to flow, doesn't it?'  
..... 'might need some of the tools to get them going, so perhaps look at some very simple things to sort of just even start a discussion about something' Harri 805-6)*

*'You don't even have to be on topic. You could start a conversation about a common theme in life that you have a discussion about, so that people would start to get to know each other and just start to feel able to speak' (Ellie 810-13)*

As a result of this discussion, it was decided that each session would follow a similar structure whilst at the same time allowing the co-facilitators to respond to the needs of a particular group. Structure of session plans to include specific re-occurring activities, such as recaps, icebreakers, check-in and check-out, theory/information tasks and 'doing' tasks. This will help those participants that need structure, especially given the nature of the potentially difficult material that they will be working with:

*'designing courses... with dyslexia I need structure... also conscious of the rigidity of structure... if it was a six-week programme and week one was an introduction thing, then week six was maybe your wrapping it up thing, then*

*'you had four weeks in the middle. In my head, you could have four subjects with one per week' (Peter 910-7)*

*'When you start the group, the group then knows what's available, and then the group can decide which week they want to do something. Or as you get to know the group, you might find we've got halfway through today but what about if we dip into next week? The next session you can be doing this. Are you in a position to dealt with that now? Do we want to do that now? Do people feel happy? You can bring it forward' (Peter 918-23)*

Peter's quote highlighted the importance of knowledgeable, confident and flexible co-facilitators.

The possible number of sessions and length of each session were discussed:

*'I know it's arbitrary that there's six sessions, but I wonder if there is a question of how many sessions would be right' (Di, 238-41)*

*'if there's twelve people in a group and you've got two hours for the group session, you break it down to how many minutes per person participate. And somebody like me takes over a lot of the time and then another person can't get one minute, let alone...' (Peter 292-96)*

Harri, raised the point that session one should be an introductory, 'getting to know each other' session:

*'Yeah, session one. It's gaining people's trust in that first session. So maybe not writing anything in that first session, but talking around each other in the group and getting people to know each other, and kind of be aware of what each person's situation is. So... and again, it's like creating awareness' (Harri 279-282)*

2.5 hours (with a break) was considered a good length of time for each session. At this point, the plan was for 6 sessions (but this changed in cycle 2, when 8 sessions was agreed upon).

The co-researchers discussed a number of important points. These included working with participant's possible process and motivation for developing their personal narrative:

*'is it a personal reason? Are you going to write a book out of the back of this? Is it for training purposes? Why is the person interested in this course? What is the motivation for the person? And then you can then tailor it to their needs in that respect' (Peter 249-252)*

A supportive environment and gaining trust; time to be able to sit and reflect; time to listen to the personal narratives of others; ability to choose to participate, to share or to listen; the importance of the group contract:

*'Do you want people to be participating every week? Do you want the freedom to sit quietly and just reflect and listen to other people talking? It's the balancing act of giving them the opportunity, but at the same time if you've got too many people... but then you could have six people in the first week sitting they're not saying anything' (Peter 295-300)*

*'more than one session is that people can go away and reflect. They can come back and actually say, "Last week I didn't want to answer that but actually on reflection..." (Sam 760-62)*

It was felt that in order to gain confidence to share, participants should experience listening to others' narratives (co-facilitators and guests). It may also help them with ideas for their own personal narratives:

*'it's about demonstrating different ways of sharing and their different mediums of sharing, so that people start to maybe formulate some idea about how they want to do that for themselves. It might take quite a while to know exactly how you want to do it' (Ellie 820-23)*

A number of concerns were raised around sharing their personal narrative: the listener or the audience; who gains from sharing narrative; protecting themselves when sharing:

*'So it's important to think about who's the listener. I've picked up before a lot of when you've been telling your stories; the listeners sound like they have an agenda. They want to listen to your story and pick out bits to help with the diagnostic strategies. So in this kind of setting, who is the listener? Your group?' (Maggie 459-463)*

*'being appropriate [for audience]... It's about protecting you and still getting the benefit of the group. You don't want to isolate the people you're trying to connect with and the connection, if you're speaking to others, is the most important thing.' (James 488-491)*

*'Take this bit out. Take that bit out... because I felt that wasn't my story. I'm not the one deciding... I want to be the one deciding what I'm sharing' (Alice 495-8)*

It is important to be able to talk about difficult experiences too. There was a sense of the need to support the integrity of the personal narrative development and to offer the opportunity to share or not and listen in a supported non-judgemental environment:

*'caveat at the start of it. I decided at the start of my session that I could*

*actually say, "Today I'm an open book. You can ask any questions. You can ask but I might say that's not where I want to go. And that was respected" (Sam 751-3)*

The discussion about the structure of the workshop programme was wide-ranging and provoked differences of opinion. This structure continued to be developed in cycles 2 and 3.

**Framework Decisions made:**

- Person centred – not one size fits all
- 8 sessions
- 2.5 hours (including break) for each session

**Theme 4: Workshop education and content**

Like the discussion on workshop and session structure, the content discussion ranged from more theoretical and philosophical concerns, to the practicalities of what specific activities (such as targeted ice-breakers) should be included, which in turn would potentially have implications on workshop facilitation. This highlighted the pragmatic tension between the co-researchers and the study researcher/co-researcher. There was a desire (by the other co-researchers) to consider at length, specific activities before any structural or proforma session design was considered or finalised – a sense of colouring in the picture before drawing the picture:

*'mood boards... whole load of magazines and everybody sat round together just chit-chatting, and you had to cut out different pictures out the magazine and relate it to you and your life, to tell a bit of your story through sticking these pictures on..... kind of building a picture, but it's breaking down in the first session as well' (Harri 903-9)*

This level of detail detracted from the overarching consideration of workshop development. It required more formal focus group facilitation in order to bring the discussion back on track. This highlighted the tension between PAR process and the practicalities of developing a workshop programme. This was an on-going concern throughout phase 3. Also this level of detail could undermine the ability of workshop co-facilitators to use their own creativity and experience. It was important that the scheme of work and the session plans were not overly prescriptive.

There was broad consensus on what content needed to be included (educational and process) in the workshop programme (Box 6.2):

**Box 6.2 Content to be included in the Workshop Programme**

- An awareness of what a narrative is and the difference between a personal and a recovery narrative
- Benefits and difficulties of narrative development
- On-going process of narrative development
- Different ways and tools to develop narrative
- Use of different media
- How to start?
- Importance of language
- The concepts of hope, recovery and trust
- Boundaries, keeping safe, self care and group agreement
- Sharing, how much to share and relational ethics
- Audience and listeners' agendas
- Listen to and reflect on the personal narratives of others

These topics and considerations were incorporated into the scheme of work (Appendix 6.18).

A key concern was the balance between educational/theoretical content and the time to actually develop the personal narrative:

*'And also it's about education. I mean a lot of them wouldn't even be aware of the benefits of telling your story' (Alice 268-9)*

*'so how do we sell that benefit? How do we encourage people?' (Ellie 467-8)*

There was a sense of not 'over-educating' participants because the real point of the workshop was ultimately their own narrative development:

*'We have to be really careful we don't overly educating. It's about supporting'*  
*(Ellie 558-9)*

Yet at the same time, important information needed to be considered and discussed in order for the narrative development to be as safe and supported as possible. For example the topic of 'boundaries' – how much to share and with whom:

*'But that could be part of the education process. One of the things around boundaries... as part of the educational process you could look at boundaries and if you do share with the audience. We're talking about audience and quite often you think people don't know, but our audience are also our loved ones'*  
*(Sam 502-509)*

*'where the education benefited me at the time because I was just told, "Take that out. You can't say that. It's just going to sound like a moaning session", instead of maybe someone sitting down and explaining to me why I should take it out and not just say it's a moaning session, but about protecting myself as well and about the audience I was speaking to' (Peter 518-22)*

As well as topics such as boundaries, group agreement and audience, it was agreed that an important part of the educational element of the workshop programme was the emphasis put on developing narratives for themselves (in their own voice); potentially using their narrative to connect with others; and to consider and reflect on the impact and on-going process:

*'not talking to somebody, you're still actually talking to yourself. So if you are processing about relationships, perhaps that's part of the education.... we process this stuff ourselves before we process it with... so it's about how do you support yourself in this process as well' (Sam 523-6)*

An important consideration was whether participants would need 'a starting point'? For each participant, there were factors such as: potential enormity of material of lived experience; their reality of living with 'chaos' (Frank, 1995); individual experience, knowledge and insight in their own recovery journey (Leamy et al., 2011); confidence and anxieties. The issue was around how the workshop programme could support people to start the process:

*'It was how do we know whether people are actually ready to start this process? So when introducing it, are there guidelines for when somebody might want to participate?' (Di 352-4)*

*'So we need to be able to demonstrate somehow how the power of it... the personal benefits' (Ellie 470-1)*

Where to start on personal narrative development would be addressed and supported by sharing examples of frameworks such as 'a storyboard' (Lahad, 1992) or using a 'timeline' to put a time order on lived experience (as the researcher did in phase 1). Both offer the opportunity to order lived experience for coherence (Saavedra, 2010); create a sense of distance, which aids reflection; and the ability to continually work on the narrative development.

What content should go in which session was considered in more detail in cycles 2 and 3 (when the individual sessions were populated). It was through this discussion that it was decided to have eight sessions rather than six with session one being an introductory one and session eight being a celebration:

*'So maybe it's about how you introduce the idea. We all know what it's like when you go to the first week in a group. And is that then about how that process is? And is that about having people that are telling their own stories to get them comfortable and to inspire them? And the way that they're able to tell the story and whether it's the written word or they record it, or however they want to do that' (Ellie 262-7)*

The introductory session should include: what the workshop is and what it is not; and an exploration of hopes, expectations and anxieties:

*'to make it clear from the start, the group is not therapy and it's not treatment'*  
*(James 740)*

Sessions two-seven would be the 'working and developing personal narrative' ones.

**Framework Decisions made:**

- Session one will be an introductory informative
- Session eight will be celebratory and showcasing

**Sub-theme 4a: Therapeutic Input**

If developing a personal narrative supports mental health recovery, then a key point of the workshop programme is for the process to be therapeutic:

*'It's therapy in itself...I found it amazingly therapeutic to be heard by people and taken seriously....So that was therapy for me, even though it brought back very strong emotions and I felt tearful, (Alice 228- 234)*

The importance of being heard, sharing with others and being supportive of each other were all considered to be therapeutic benefits of the workshop programme. It was felt to be very important that whilst personal narrative development can be therapeutic, the workshop programme was not therapy (in a clinical sense). This can also be achieved in more formal therapy. In therapy there are assumed underlying conditions such as: it takes place as a result of referral; reference to an underlying diagnostic condition; and is led by a professional. The co-researchers considered the

issue of whether a participant should have had clinical therapy before taken part (i.e. did they need to have a reasonable understanding of themselves first?). It was very clear that we as co-researchers and potential co-facilitators did not want to make this kind of decision because it would potentially have an impact on who could participate. This would be at odds with the important aim of the workshop framework of being open access. It was important to treat all participants as individuals:

*'is this something that should be within a therapeutic session? Is it something that should be kept out of it? Or should it be... are we going to be more flexible? Is it something that you need to have done some therapy before to do, or is it therapeutic in itself? Or how do we support, bearing in mind that for the majority of people if we say they need to have therapy beforehand, we're cutting off a huge raft of people... I suppose for me I'm thinking if I wanted to get the most number of people potentially, it's how does this programme support people to do all these kinds of things that we're concerned about?'*  
(Sam 219-227)

It could mean that co-facilitators would need to offer participants varying support in line with individual needs. It might mean that participants may decide that they are not ready to develop their narratives and may choose to do so at a later date. There may also be the need for signposting (for further individual clinical support). This point was continually emphasised and debated in all 3 cycles.

<b>Decisions made:</b> - Therapeutic but not therapy
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### **Theme 5: Participants**

The issue of whether the workshop programme is therapy or therapeutic has implications on who can participate (service user, professional, carer and/or someone who is interested in narrative and mental health) and who then can co-facilitate (a peer and/or a professional?). The underlying ethos of the workshop programme is that individuals are free to choose to participate or not. There was consensus that there should be no formal application, referral or screening process:

*'whether there needs to be any sort of preamble or pre-information to sort of screen people'* (Di 152-3)

This did highlight the need for information about the workshop programme so potential participants are able to make informed decisions on whether to participate or not. There is the possibility that individuals might not be ready in terms of timing and where they are on their own recovery journey:

*'how you know the person is right to be on the course. For some people, it might be too raw to continue on that course because it keeps bringing back episodes that they've not managed to deal with ... So doing a narrative might not at that time be the right thing' (Peter 586-9)*

*'One of the things as well that I'm very aware of is that this is important to me – recovery is important to me in terms of my life, but actually that's not true of everybody. If I was saying, "Actually it could work for anybody", how can that be achieved in general?' (Sam 984-7)*

Participation should not be about someone else's decision on the readiness of another – a sense of someone not being well enough. This often happens within mental health, with the professional deciding what is appropriate for the service user (Slade, 2012, Slade et al., 2014) . Given Alice's experience as a peer worker on an acute ward, it was agreed that level of perceived wellness should not determine workshop participation:

*'having worked as a peer support worker in an acute ward where people are very unwell, the one thing people are desperate to do is for you to hear their story' (Alice 161-3)*

*'discussion with someone in the recovery college in Southampton about getting some groups courses into the hospitals. The answer I was given was that people haven't enough concentration. That's not true. That's a big assumption' (Alice 995-7)*

When an individual is at the start of their recovery journey; is experiencing unremitting 'chaos' (Frank, 1995); is acute; or lacks the tools and/or awareness of their mental health, they may have difficulty recognising aspects of their lived experience which are positive and hopeful. Any narrative may be predominately angry and 'less balanced' (as my initial vignettes were):

*'Often when you get people at the acute phase of unwellness, they only want to share the despair. They don't want to talk about the good parts of their life as well. (Alice 176-78)*

First, the personal narrative is the individuals' and it is their decision what to include. Second, talking about their anger and continuing to talk about their anger may be a crucial task that they have to go through. It might result in dissipation of intense emotions so that they can then move on with their narrative development. In my case, it allowed for insight and epiphanies to occur. For others, their 'angry narrative' may be it. It is important that the workshop programme is supportive, and that there is space to explore this.

The workshop programme will not be relevant to all – it's all about individual choice:

*'it could be open to people if people want to learn how to develop their own story' (Peter 1078-9)*

Practically it was felt that a maximum of six participants would be acceptable for each workshop programme. Participants needed time, space and a sense of security to develop and share their narrative. Any more than six participants could be detrimental.

**Decisions made:**

- No participant screening
- Open to service users, carers, professionals and those with an interest in narrative development and mental health
- Maximum six participants

**Theme 6: Timing**

As with the other themes of phase 3, timing is linked and dependent on the other considerations for the workshop programme, such as who can participate and therapeutic input. It was agreed that there should be no criteria for 'entry' or 'readiness' for the programme. Phase 2 highlighted the fact that there was no 'ideal timing' for narrative development. The 'right time' was dependent on the individual and could involve many false starts. Also some participants will have already started on the process and will attend the workshop programme to continue the process. It is unlikely that everyone will be starting from the same place with a blank screen.

The dates and times for each workshop programme will likely be determined by local needs and co-facilitator availability. It is essentially arbitrary and doesn't allow for the 'readiness' of individual participants. Participants have to fit in with the programme. For many, this will involve taking a chance. It might be too soon or too difficult, but it is important that individual's make their own decisions:

*'give people the opportunity to know whether or not it's the right time' (Di 153-4)*

Timing is not dependent on how well/unwell an individual is or their degree of insight and understanding with their own recovery journey:

*'does it matter if people are at different stages?' (Peter 242)*

*'I benefited from the training as I went along.... I had no intention of connecting with anybody; that's just where I was. It was absolutely irrelevant, my state of readiness, and I feel it's imperative that the individual chooses whether or not they're ready, and that criteria are not put in place' (Peter 364-68)*

The level of support available to the participant might make the difference though. For Harri, having therapy first allowed her to develop her narrative:

*'It's being able to talk about your situation and then be able to write it. If you can't talk about it, it's going to be harder to express it. So it's a matter of, I think, getting that support first as well' (Harri 157-60)*

Timing is a nebulous concept and one that is often imposed on the individual by others (Slade, 2012, Slade et al., 2014). It was felt that it was important for the co-facilitators to be available to discuss any participation concerns in both a group setting (session one) and individually.

Given the arbitrariness of when the workshop programme would run, it was deemed important that participants were given enough time to develop, share and reflect. For some, it might take a number of sessions to feel comfortable to take part:

*'only constraint I've ever had in any session is time. That's where it's only ever been constrained for me to have the opportunity...I'm trying to hear, it will take seven sessions of a twelve session meeting group for me to actually open up to the points that I want to share' (Peter 203- 7)*

What constitutes enough time has been carefully discussed and incorporated into the programme, although it was acknowledged that this would not be enough for everyone. In reality there is a time constraint because the number of sessions has been set at eight. It is hoped though that participants could attend additional workshop programmes and or the possibility of running top-up sessions outside the formal programme. This will be considered in the post-doctoral pilot work.

**Decisions made:**

- It was agreed that there should be no criteria for 'entry' or 'readiness' for the workshop programme
- Individuals choose whether or not to participate
- Availability of co-facilitators to discuss ant concerns with individuals

**Theme 7: Choice of Media**

There are different ways of developing and sharing narratives. Chapter 2 literature review explored the ways an individual could develop a personal narrative using different media. The review focused on: how different media was used; in what contexts; and what the benefits and problems of using different media. This was an important part of the discussion with co-researchers in phase 2. It was very clear that the co-researchers had developed their narratives using a range of media (e.g. Harri wrote a book and performed in Forum Theatre (cardboardcitizens.org.uk, 2015); Tina – poems; and Mary – art and the Human Library). This highlighted the importance of taking into consideration individual differences, expertise and interests. Individual choice underpins the ethos of the workshop programme.

It was important that the workshop programme should support participants to develop their narrative using media that they wanted to – and not assuming that the narrative had to be developed in a written form:

*'what's come out of the research is that I would be very keen that this is not necessarily a written-based narrative. It's about supporting people to develop their narratives in whatever way they want – maybe through photography, art, dance' (Sam 382-5)*

*'research shows... if you ask them to write it that can stop a lot of it. Things like photography as well, you can create much more distance. You can go where you can go at that point' (Sam 390-2)*

Although for Harri, the written word was a medium that she was comfortable with:

*'And I've found keeping diaries and journals, which helped. And then when I actually come to write, I looked back on my past events and was able to write it into my book, so that helped a lot' (Harri 168-70)*

Supporting participants to use different media and to be creative is the key.

*'I think it's down to the individual what medium they choose; whether it's stick pictures on a story board, photographs, anything' (Jodie 415-6)*

This is particularly relevant regarding participants with mental health issues, when there are times when cognitive processing and using language is difficult:

*'research suggested that... and I know myself that when I'm unwell I find language difficult. But equally, people can find art, or ask them to write a poem... allowing people to use whatever is their route to talking about it, or even starting to reflect themselves' (Sam 409-12)*

*'lot of people in acute wards because they're not heard. They go into therapy session and they express their story in the bit of art they do. I've seen that happen over and over. And when you question them about it their story comes out' (Alice 397-400)*

*'often use art as a way of getting the story out with pens and paper, or with toys and stuff. And it's through those mediums, those ideas, which the child's story comes out in a similar way to perhaps ours. I've got family with dyslexia so I've met people who say that writing would be such a scary thing that the prospect of having to write it down would alienate them' (Peter 402-406)*

Use of non-written media for narrative development will also be advantageous with other groups of individuals (e.g. learning disabled, young people and non-native speakers).

### **Resources**

There are potential resource implications to supporting participants to choose any medium. For example the availability and cost of camera and/or art equipment needs to be considered. Would it be the responsibility of the workshop facilitators or the participants to provide all necessary equipment? Interestingly in mental health, day services have tended to take responsibility and expense of resource provision, which in itself can add to infantilisation and reduced agency. In the workshop programme, it was deemed important not to assume that participants

haven't got access to resources (such as a camera). This is especially true if the point of the choice of media is to tap into existing interests and expertise:

*'not assuming that people come at it as blank screens, that they might have already been doing some of this work. They might have photographs, art or... and it's not about us providing everything for them; they're not children' (Sam 888-90)*

*'being realistic as well, is that if it's photography they might have their own camera' (Sam 899-900)*

If the workshop participants are using a range of media, there are potential workshop facilitation implications:

*'It's always the practicalities of saying we can all make a story with imagery or music or dance, but then how would we facilitate five people wanting to do a dance thing with one or two on drums, and two other people wanting to do a more thoughtful process in the same room? Or are we going to do collage so providing magazines? What resources do we put in? What does the person put into this? What level of support from a practical element are you looking at?' (Peter 834-39)*

These are important considerations and are ones that should be negotiated within each workshop programme between facilitators and participants. There is an implied assumption that most of the narrative development will be within sessions but for many participants this is not likely to be the case. Much of the development will be between sessions:

*'Park the practicalities and resources... Because linked to that is the sense that it doesn't have to all happen in that room' (Sam 846-8)*

### **Using tools to get started**

One of the key issues and potential stumbling blocks of narrative development is 'getting started'. The workshop programme will introduce participants to tools such as storyboards (Lahad, 1992) and timelines. Both are methods that help break down the process into manageable chunks and offer the possibility to reflect and to continue working on their narrative piece-meal. This mirrors the sense of the on-going process of narrative development:

*'I'm just thinking back to the way it was introduced to you. It was a storyboard template which actually had headings in. So what brings you here today, what have you learned, where you go from here. Where do you start? And to start with this feeling that you have to tell everything, the storyboard gave me the*

*structure in a very... graphic's the wrong word, but it was images... the image of that storyboard and I still use that when people are struggling with things. (Sam 418-25)*

Listening to others, who have developed their narratives in a range of media, is also an important way of supporting participants to get started; showcasing possibilities and ideas; and reflecting and discussing the process of others. The workshop programme scheme of work and session plans reflects this.

### **Cultural appropriateness**

James suggested that we needed to consider cultural appropriateness in terms of what the workshop programme assumes and provides:

*'everyone in the room today is white, western European, and often people who come from other backgrounds feel that a lot of what is offered is culturally inappropriate' (James 382-4)*

This is relevant given where the workshop programme has been developed – in the South of England with predominately white European demographics. The workshop framework and scheme of work should be flexible enough to work with any given local conditions and group of facilitators and participants.

<b>Decision made:</b>
- Participants should be able to develop their personal narrative using a range of media

### **Theme 9: Workshop Facilitation**

Supportive and well-prepared workshop facilitation is a key factor in delivering this programme:

*'the facilitator's ability to connect with people. And in my experience that comes from being genuine and sharing something about yourself that is pertinent to what the group is discussing' (Jodie 310-312)*

*'The importance of the facilitation. And for me as well, with my teacher's hat on, is the training required to facilitate, and the support for the facilitators' (Sam 313-15)*

Working as co-facilitators is multi-faceted and can be time-consuming (beyond the time spent delivering the programme). Facilitation activities include preparation such as: deciding who the co-facilitators are; recruiting participants; choosing venue;

preparing room so layout is conducive to workshop aims; and gathering necessary resources. Time needs to be spent on adapting session plans (based on framework) that are suitable for local needs and conditions:

*'PowerPoint point of view... it's an aid memoir for me and I use images... interest for the participants... they get the print-out as a form of workbook... you cannot rely on technology to work. So for me, if I've got my print-out, I know exactly where I am and I'm going... I always print them off in colour'* (Jodie 952-61)

Co-delivery requires decisions on: 'who does what' (how best to use expertise); 'who takes the lead and when'; and how they will support participants (practically and emotionally):

*'from a practical group point of view ... somebody who opens up... not only in the group, but are they taking that away with them at the end of it? What mechanism is in place to support that person should they need it? Is it something that could be recapped... sorry, back to the facilitator type, but recapped the following week, or the opportunity for that person to then open and share on a one-to-one? At the start of the mission, "Sorry, can I have two minutes to have a chat with the person running it? This helped me last session but I'm not sure how I can share it with the group"'* (Peter 574-82)

*'how we facilitate it and as facilitators, where are we willing to go with this? Sometimes it can be... one person would say one thing and instead of positive experiences, it becomes a very negative experience. Okay it's about the ability of the facilitator to control that but how open are we making these sessions? Are we setting an agenda each week? Has it got to be to a set idea? Do we set a specific... middle week this is what we're going to do. Throughout all the anger and bad experiences, could that be a positive way of dealing with it so that its controlled?'* (Peter 694-701)

*'Maybe having the skills to maybe do something at the end of a difficult session that helps to diffuse that and leave everyone feeling okay. Maybe that's the part of how this is put together – that training and stuff'* (James 719-21)

For peer support, Jodie suggested that '*a peer buddy*' (774) may be appropriate alongside, self-care and appropriate signposting – so that the weight of emotional well-being isn't just the responsibility of the co-facilitators:

*'You don't want to be setting up that you're going to be providing me with therapy inadvertently – that's not what we want to set up, but it's about having someone like a facilitator taking on the responsibility to be available'* (Jodie 783-6)

At the same time as delivering the content and ensuring a safe and supportive space, co-facilitators have to manage timings – to think about time allocation for each activity and per person:

*'You need a basic structure. In my experience, you can work out rough timings but the group that takes the timings, they might spend a lot of time on one section and much less time on another...That can take too long. What you would do is you set it up and you give yourself... you've got a two hour section and you say, "This is what we're going to do in this first block and we'll set the first block as an hour. And this is what we'll do in the second block." But it doesn't mean that this first block doesn't run in the second block' (Jodie 944-51)*

Co-facilitation requires working with the group dynamics and individual needs and processes of the 'vulnerable adults' that are in the room:

*'But if you've got a good facilitator in the group, that facilitator should be able to pass round to each person and bounce off of each person' (Harri 297-8)*

*'not just for the people in the group but for the people running it. You don't want those people going away angry or upset because you' (Peter 703-5)*

After each session debriefing, evaluation and the planning for the next session and/or workshop programme will be required.

Given that it is expected (and hoped for) that participants will have emotional responses to the development of their personal narrative, co-facilitating this process is very complex:

*'It could potentially be an extremely powerful process for some people and that's a side of things that has got to be really managed and the support is in place for that to happen' (James 583-5)*

*'is that when you're in the group, even if I was co-facilitating, I am a part of the group. I'm facilitating the group. I'm not training. I'm not leading the group; I'm part of the group. But I'm always ushering the group into where we're trying to get to' (Jodie 1143-6)*

In addition to this, co-facilitators will be expected to model and share elements of their own narrative development and process. It is likely to be stressful (at times) and rewarding. As part of co-facilitation considerations, support for the co-facilitators is essential. This should involve thorough prior training, on-going peer-supervision and organizational supervision (depending on where the programme is located):

*'training is imperative and the experience, i.e. shadowing experience for facilitators' (Jodie 316-7)*

These factors will be developed as part of the post-doctoral work and prior to carrying out the pilot.

#### **Sub-theme 9a: Venue**

Where to locate the workshop programme (e.g. within NHS, 3<sup>rd</sup> Sector, peer support group or as a completely separate entity) will have important implications in terms of underpinning philosophy, organisational and managerial structure, and peer and volunteer policies (e.g. employment and safeguarding). There will also be practical implications – where and accessibility of workshop room and facilities. There was a concern about the workshop being seen in terms of therapy if located in an NHS setting (and potentially more stigmatising) and perhaps more educational and humanistic if set in a community venue:

*'is it going to happen in a hospital? Is it going to happen in a college? Is it going to happen in a church hall? The venue itself can also have connotations....Whereas if you say, "I'm going to Highbury College" or the scout hut round the corner, you can say you're on a course and it changes the narrative of your external discussion to people when you're drawn into why you're doing this. It's a course; it's not treatment if it was run at a hospital, the assumption... and then the people themselves might shy away from participating because they feel negatives, thinking whose agenda they are working to...' (Peter 851-63)*

Pragmatism is important here. For example, Alice had expressed the importance of narrative work, and lack of it, in acute settings. If we want acute service users to benefit from the workshop programme, then it would need to be located within this environment. It is about meeting the needs of the participants as opposed to being too rigid.

#### **Theme 10: PAR Process and Facilitation of the Focus Group**

Like phase 2, phase 3 was carried out using PAR methodology. Each cycle focus group discussion, considerations, shared knowledge and experience, and decisions that emerged were the result of the PAR process. Given the need to achieve practical outcomes and therefore fulfil the aims of this study (e.g. produce a

framework model, scheme of work and session plans for the workshop programme), it was evident that there were strengths and difficulties of working within this methodology. Alongside the overarching PAR methodology for phase 3 as a whole, there was also the importance of the researcher facilitating the focus group in each cycle to model both PAR whilst also acting as co-researcher. As such, for each cycle focus group, a session plan was produced which all co-researchers received and each focus group was carefully briefed (Appendix 6.8):

*'In the first phase I looked at my story, and the themes that came out of developing my narrative, in terms of both content – so I analysed what was in it – and then I also looked at process; things like what left unsaid, what's said, how we talk about the others in it. It's stuff that came up in our meeting last year. And in phase 2, which you were involved in, we were looking at the process. So we didn't really talk about what was in people's... what came up for you when you were developing your narratives and issues, and things like that (Sam 119-26)*

*'we'll be doing in the next session; in terms of how do we get a session together – the session plan' (Sam 64-5)*

*'The themes that came out of my work, and then the themes that came out of our work ...this is nothing other than what we've talked about' (Sam 85-7)*

*'So to start us off, are there any questions about what scheme of work? Is anyone unsure about the current thing? We know what we're coming at; what we're trying to achieve. What are people's views on that?' (Sam 114-6)*

At the same time, flexibility of approach and a sense that we were all working together was emphasised:

*'it's very flexible...It's our session...I'm part of this one...So we'll be working together, as opposed to me just facilitating' (Sam 61-3)*

*'it's just a pro-forma. We don't need to follow' (Sam 70-1)*

*'So if I said, "I'd like to actually run a workshop for people to develop their narrative", how do we go about that? What's the structure? What do we want included?' (Sam 130-33)*

It was a balancing act between 'going with the flow and following the discussion wherever it went', supporting individual co-researchers and their 'right to speak' (APS Group Scotland, 2012) and their personal development within this process and actually achieving the required product and output. It was not an easy journey:

*'I've put a whole table together and there were some top points which were not really relevant to talk about, in terms of the scheme of work, but there's stuff that we want to talk about later, in terms of where we locate this, where we put it, and how we support people... which probably isn't relevant to the scheme of work, but it's really important to be overall where it's going to be. So what I'd like to do, because I've been talking to you, is I want to set up a parking board. If there's stuff that we talk about that stuff that comes up that's not particularly relevant to what we're talking about, but it's really important, we'll park it'* (Sam 85-96)

*'And I think perhaps it's really important to start on the basis that not everyone will want to do a narrative; some might need much more discussion around it. How do we scope that? If you were to do your narratives again, what would you be looking for in a workshop? What should we be including? What should we not? So it's that – it's the nitty-gritty. How do we put this into something that we can actually deliver to people?'* (Sam 134-40)

*'But what I'm aiming for practically at the end of the PhD is something that we can use to actually use this to support other people in developing their narrative. So it's a practical application of what we've done up to this point. This is the summary of what's come out of the themes at the moment'* (Sam 127-30)

It was also important that I as 'researcher' and 'focus group facilitator', was not '*seen to be holding all the knowledge*' (59-60) and I did not 'want to pre-judge anything' (68). We worked as a team and made joint decisions:

*'So if you all agree that it's actually a whole range of media...'* (Sam 395-6)

*'I think that's a key important thing to say that this is the purpose of the group'* (Peter 453)

*'can we have a think about this? I suppose in a way the decision we make now isn't necessarily for forever and ever'* (Sam 1134-5)

One of the key aspects to emerge from phase 2 was the importance of the group process – it allowed for debate, agreement, consolidation of ideas, and a sense of togetherness (modelling the emotional impact of sharing narrative). It offered co-researchers their voice (modelling a key aim for developing their narrative):

*'It's very good that there's a practical side to it at the end'* (Alice 143)

*'I feel that's underlining what Alice just said'* (Jodie 516)

Phase 2 discussions were richer for this process, hence the emphasis put on developing the personal narrative within a group setting in phase 3. What was

evident in phase 3 cycle 1 was that there was also passionate disagreement – specifically relating to the ‘model’ (a peer v separatist model), who the co-facilitators will be and where would the workshop be located:

*‘I’ve had this discussion many times as you know, as I’m told, “We can’t do it because the staff don’t have time.” So bring the facilitators in. “Oh, but we have to have a professional and a service user, and we don’t know if the service user will really be okay when they’re in there.” Rubbish’ (Jodie 1015-8)*

Moving towards a pragmatic resolution of these issues required all three focus group cycles.

‘Wondering aloud’ as a technique allowed the discussion to open up to all the co-researchers:

*‘Peter, you were suggesting whether the sessions were free-flowing or a bit more structured. What do people think about that? (Sam 802-3)*

*‘So hearing you and Peter, you were saying Peter that you don’t feel ready to talk until week seven of twelve, or session seven of twelve, and you might not have had the opportunity to talk until later on. But here trying to think of a way of structuring it so that people do get the opportunity. And I know it’s arbitrary that there’s six sessions, but I wonder if there is a question of how many sessions would be right and what you could hope to gain. Is it like getting people started?’ (Di 236-41)*

Interestingly Di’s comments revealed the evolving role that she and Maggie (the researcher’s supervisors) played in this research. In phase 2 focus groups, their involvement was very much as ‘study supervisors’ – observing and monitoring my facilitation. Both were on hand, if they were needed to offer support to a co-researcher. Initially in phase 3, it was assumed that they would both carry on with this role. At the start of cycle 1 focus group, both sat away from the co-researcher table, prepared to observe, write notes and make tea. This felt artificial. With the free-flowing discussion, it became apparent that it was useful for them to initially ‘helicopter’ in – summarizing what was being discussed and/or asking questions that would move the discussion back on to a practical resolution. From this point, it felt natural for them to join the discussion and talk about their own lived experience – they became co-researchers. On reflection, this was incredibly important:

1. It modelled the breakdown of 'them and us' – with them as professionals with status and holders of the knowledge. They became 'us' and shared their ideas and lived experience as equals – we 'formed this path together'. This is the workshop programme model that we are striving for.
2. Maggie and Di both offered their 'vulnerable selves' in discussing their lived experience. This modelled the value of sharing and the potential risks involved – key aims of the workshop programme.
3. Both were accepted as having a valid opinion by the other co-researchers – 'they became we'. Only Maggie was involved in cycle 3 and 3, which further strengthened her role as a co-researcher.

### 6.11 Cycle 2

Cycle 2 took place a month after cycle 1. The following information was prepared for the co-researchers.

**Table 6.9 Information and Paperwork given to Co-researchers**

Name	Detail
Scheme of Work v.1 (Appendix 6.11)	The first draft of the scheme of work based on the discussion (and emergent themes from cycle 1)
Cycle 2 Focus Group – Developing a scheme of work session plan (Appendix 6.12)	A session plan for the cycle 2 focus group (using the proforma layout)
Parking Board – from cycle 1 discussion (Appendix 6.13)	A list of topics raised in cycle 1 but not fully discussed – they can be picked up in cycle 2.
Session plan overview (Appendix 6.14)	Blank proforma of session plan for all 6 sessions

The draft scheme of work (Appendix 6.11) had been sent to the co-researchers for comment, prior to cycle 2 focus group. At the start of the session, all the information was reviewed with the co-researchers and they were reminded that the key aim of cycle 2 was the development of the session plans – taking the content from the scheme of work.

#### 6.11.1 Themes

As cycle 2 built on cycle 1 discussion results, only additional comments, insights, reflections etc. will be included here. Apart from 'context', the themes are the same

in cycle 1 and 2, yet the order of analysis is different in both cycles. To aid understanding, the themes are numbered as in Table 6.7.

In cycle 2, it was clear that parallel processes were occurring. There was evidence of 'getting on with the task' – i.e. developing the session plans. At the same time, the co-researchers were very keen to continue discussing the underpinning philosophy, model and framework. It felt that the group wasn't quite ready to move on. There was a sense that the co-researchers wanted every possible outcome and topic incorporated and to include all possible participants from the start rather than thinking that phase 3 was the first stage of a development process.

Overlaying the 'task' processes was the focus group process itself. It was evident that the group was still 'forming'. This was probably exacerbated by the group being different from cycle 1 (Alice and Ellie were absent). The group was still attempting to develop consensus on what they wanted from the model. It appeared that there was a significant amount of tangential discussion before any decision could be made. Although frustrating (for the researcher and facilitator), as anything concrete was difficult to extract – this was necessary for the PAR process as a whole. In some ways the cycle 2 discussion was what had been anticipated for cycle 3, once the session plans had been populated (Figure 6.2). The group needed to go through the process of thinking, reflecting and putting ideas out there first. At the time it felt that little had been achieved in cycle 2. However, when the data was analysed, this was found to be incorrect. On reflection, this modelled the process that we are anticipating with some of the participants in the workshop programme itself – not everyone will be able or willing to commit to a decision at the start. We have acknowledged in the scheme of work that participants will need time and space to explore, consider, do and reflect. The co-researcher focus group was no different.

### **Theme 8: Context**

*'do we need to be fixed?' (James 4:6)*

An underlying assumption is that the process of developing a personal narrative contributes to mental health recovery. Is there an assumption preceding this, that in order to benefit from, there is a deficit or something wrong in the first place? In phase 2, James had questioned the rhetoric of mental health and recovery. He suggested that: externalising and individualising mental illness; pathologising mental distress; and the concept and need for recovery were the products of, and due to, the emphasis placed on the dominant medical model within western society. James rejected the notion that mental distress meant that there was something wrong with the individual that required 'experts' to fix and by default the workshop programme (as a therapeutic device) was trying to do the same thing:

*'people setting out their experiences , the assumption is that your experiences have led to somehow you being psychologically wounded and so you are saying you have something wrong with you' (James 484-524)*

James suggested that by engaging in the workshop programme, any benefits accrued:

*'would obscure the injustice in the world....does that make sense? Rather than just say I've dealt with the injustice and I've sucked it up and I'm okay going forward. To me that is the danger, not that it is what is wrong with you, rather it is what happened to you. But also why did that happen to you?' (James 501-6)*

However, it is not necessary to either accept or reject the prevailing and perceived rhetoric completely. Within the narrative development, there is the opportunity to reflect on what factors may have lead to any mental distress (such as family breakdown, poor housing and unemployment). There may also be a need to individualise mental distress and experience in terms of 'why me?' (Frank, 1995) and to therefore gain a better understanding. There may be both internal and external factors that have contributed to mental distress in any individual. The key point is that any individual has the opportunity and the agency to choose whether to engage in the narrative development process or not:

*'reflected and gone through the process I have learned this about myself, or I have learnt that this helps me in certain circumstances.... In different times and these are the contexts...things with my personal control that are issues to be addressed and do I want to engage or not?.....comes out of it that you may feel empowered to do something more about that or you may feel empowered not to engage in that. You make that choice though' (Di 508-24)*

## **Theme 1: Why Develop a Personal Narrative?**

### **Sub-theme 1a: Purpose and Participant Process**

One of the key aspects for individuals taking part in the workshop programme is getting to grips with being part of a new group. It is a multi-layered process that involves:

*'gaining people's trust.. getting people to open up.. to communicate' (Maggie 67-8)*

Equally the 'doing' process of developing their personal narrative through reframing, sharing and reflection also offers the opportunity to build resilience, which contributes to recovery (Leamy et al., 2011, Bird et al., 2014):

*'coping better to deal with stuff, if done more than one time' (Maggie 87-8)*

There is an on-going movement from living within a 'chaos' narrative (Frank, 1995) towards a more balanced and integrated narrative (the separation of the 'me/it' (Slade, 2009)) – evidenced in phase 1 and 2. Maggie suggested that participants would probably need to continue working on their personal narrative to achieve this. Developing a personal narrative is an on-going process as: new lived experience; reflection; epiphanies; and continued learning and understanding are integrated within the narrative – a sense of continual reframing and new discoveries. This is certainly true for the co-researchers.

### **Commitment to participate**

There was discussion around participants '*being committed to the process*' (Sam 96) given the uncertain vagaries of the recovery journey and the 'nebulous' nature of wellness (Leamy et al., 2011):

*'potentially quite scary stuff and committing to a number of weeks is... especially if you are not... you never know from one day to the next...' (Sam 151-2)*

There was a sense that as facilitators we had expectations of what participants should gain from the programme and that this would be measured by how participants took part and were committed to the programme. This could be at odds with the programme aims of encouraging agency, adulthood and choice. As co-researchers and potential programme co-facilitators, it was important to accept that

we had little control over the degree of commitment and the level of participation. Putting the control and power back into the hands of the participants supports increased agency, adulthood and choice. It is about equipping participants with the tools to develop their narratives – if and how they use them is their choice:

*'Maybe after the period of being through [the programme] something that comes out of it so you may feel empowered to do something more about that or you may feel empowered not to engage in that. You make the choice though... leave for students to decide whether it is therapeutic for themselves and the way they understand it' (Di 521-4)*

The aim is to make it as easy as possible, as long as logistics such as time and place are conducive. It should also be acknowledge that commitment and participation are not always overt and active – it is equally important for people to listen and reflect – and acquire the tools passively:

*'some people learn a lot just by experiencing the group and listening to what is going on around them' (Maggie 827-8)*

What participants take away from the workshop programme also links to the issue of what kind of narrative they choose to develop. How the workshop programme would promote the development of the personal narrative over the recovery narrative was further discussed. A recovery narrative tended to be commissioned by a third party (NHS Trust and/or Recovery College), developed for organisational purposes. The recovery narratives developed tended to reflect the prevailing cultural and organisational 'meta-narrative' (Chase, 2013) that working with mental health services is the way to ensure recovery is possible for all and is a good thing:

*'I think that we decided that it is not interchangeable ... If you were developing a recovery narrative you are being pointed in one direction... that is not necessarily what people want to do... Linked into your angry narratives Peter... do we want to give them a sense of the idea that the personal narrative is whatever is yours?' (Sam 394-8)*

*'your perception, your views never going to be tested by others.. your construction. I think that getting that across that nobody is going to come along and check it, it is how you feel and what is important to you. No-one is going to question the ownership' (Maggie 402-8)*

Developing a personal narrative is not a benign process. Maggie queried whether it was our role as co-facilitators to just listen and acknowledge the narratives of

others, or should we also challenge negativity, wonder about any learning outcomes from negative experiences and the potential impact on individuals of allowing them to continually sit in their negativity?

*'despite we are not therapists... we still have a duty of care as a human being to another human being' (Maggie 588-9)*

Maggie suggested that challenging negativity should be explicit in the framework. This is a dilemma that is not easily rectified and is at the heart of the issue of narrative truth (Craib, 2003). It also highlights the difference between 'therapy and therapeutic'. Supporting participants to develop their own voice and asking participants to think about what they include is fundamental in the workshop programme. In phase 1, my husband suggested that I hadn't written any positive vignettes. This gentle challenge allowed me to reconsider and add more positive vignettes. I could equally have said 'No - this is my narrative and my voice'. This is a delicate balancing act that might have a negative impact on confidence and agency, yet at the same time lead to a better understanding of their own experiences. Careful and observant co-facilitation will be necessary because everyone is an individual.

Choosing what aspects of personal narrative to focus on (including Peter's angry narratives), there may be both a positive and negative emotional impact. The narrative may help the participant come to terms with difficult emotions rather than avoiding them:

*'looking at the anger in a way that the person can themselves cope' (Peter 594-5)*

*'fear of using hope... it is important to talk about hope but we are not expecting... we don't have expectations of people as an individual, we have a collective expectation of what we are delivering is used by people' (Peter 600-4)*

Again there is the balance between individual agency and the expectations of what individuals should gain from participating. Peter suggested that if people didn't use the tools, knowledge and opportunity to develop their narrative, then what was the point of the programme? It is a valid question but one that it is difficult to answer.

*'does it sometimes help to say this happened, this wasn't very good, this was awful... and then say...what did you learn from this?' (Maggie 609-11)*

Often, mental illness is characterised by a sense of isolation, stigmatisation and loss of hope. By sharing and listening to the narratives of others, an awareness of commonality of lived experience may become apparent. The greatest impact of the workshop programme could be the opportunity for the participants to share their lived experience in a safe environment.

It is really important to treat people as adults. A personal narrative is likely to express positive and negative lived experiences. It is not the role of the workshop programme to shield people from difficult emotional responses but to offer a supportive group environment to explore and reframe. The act of reframing suggests that learning and growing understanding is happening.

### **Theme 2: Framework and Model**

The discussion centred on the need for the framework and ethos to be very clear, so that co-facilitators would know what they were delivering and participants would know what to expect. The discussion was also more pragmatic, with the consensus that the framework (including scheme of work and session plans) and structure should be flexible enough to allow for local requirements, conditions and therefore wide availability:

*'CAMHS service, the children's mental health service who could use it specifically for under 18s' (Peter 297-8)*

Given the desire for inbuilt flexibility, Peter was still concerned about the fidelity of co-facilitators and how they might deliver the programme. There was potential for the workshop programme to be bent out of recognition:

*'people don't stick to the model, that they have other training or other influences, that they start delivering therapy rather than...' (Peter 306-9)*

These are the kind of issues that needed to be set aside and picked up during the implementation stage. Whilst the workshop programme has been developed for adult mental health service users, there is the potential and expectation that it can be adapted to suit anyone with an interest in narrative development. Testing the model by running a pilot and evaluating it will form the focus of post-doctoral work.

The co-researchers considered factors relevant to the implementation stage, such as facilitator training and pilot practicalities:

*'....the training pack for the facilitators, would that include things like model leaflets, model posters, the things that people see that would draw them in'*  
(James 333-5)

*'even when you run the pilot we make assumptions, and what we assume is that we are hitting the right target with what we set out in the pilot. You come back to the pilot and go....we completely missed that didn't we'* (Peter 342-4)

Whilst it is important to look forward, decisions were still to be made regarding the present task. This study relates to the exploration and development of the programme – implementation and evaluation are outside its scope:

*'It is a stage process... like the narrative itself it is an on-going evolutionary type of thing'* (Sam 337-41)

*'So this could be a one-off or it might never bee the same again'* (Peter 350)

As the researcher and focus group facilitator, I had to continually remind the co-researchers of this - to remind them that we hadn't reached a consensus on whether the model was exclusively peer-led:

*'the lock in, is it peer-led, you are going to have two people leading it, whether both are peers it can be ... but at least one of the two will be a peer'* (Peter 949-50)

*'there is no reason why if it was co-delivery, co-produced and co-attended, that the other peer, the professional peer isn't a peer by experience anyway. They might have a hat but I think it could be peer led'* (Sam 952-5)

*'two co-facilitators, that they interchange on who leads'* (Sam 961-2)

It needs to be flexible and take into consideration the experience and confidence of any co-facilitators:

*'if you are developing a pack that somebody else might then pick up and run with, have some suggestions [about activities]. Because whilst you are very experienced other people might not be so'* (Di 990-2)

### **Theme 3: Structure of Workshop**

The initial decision from cycle 1 was that there would be six sessions. As the discussion progressed it was clear that this might not be enough:

*'would be 8... I've experienced courses through counselling... usually got 6 weeks, usually first one is introducing you to what is happening and the last one is a recap of what is going on. So in theory your first and last are spares and you have got 6 weeks of work' (Peter 70-4)*

Eight sessions would allow for a thorough introductory session – information giving (so that participants know what to expect), getting to know each other and trust building – so that participants will be able to make an informed choice as to whether to continue. It will be important to allow time for questions and time to digest any written material in session one:

*'but the danger of having written stuff is you read it and sometimes reading it is intimidating. If you have someone there to talk to you, the intro could be an open session' (Peter 328-331)*

Session eight could then be about showcasing, signposting and evaluation:

*'is it worth some type of celebration...showcase? It is not the whole narrative but people draw something out of the narrative...almost symbolic, and they just share it' (Maggie 870-5)*

With six working weeks to deliver content and time and space to develop and share their personal narratives within a supportive environment. It was agreed that the session plan would be based on eight sessions. Having eight sessions meant that the likelihood of missing a session would have less of an impact and as such participants would be more likely to continue:

*'if it is just 6 weeks, people think I've missed one, I'll not bother going back...it is just finding that optimal number that you feel comfortable missing one, if need be, but you are not alienated by missing it' (Peter 102-7)*

This is particularly important when committing to an eight-week programme could be over-whelming. Equally life does happen too!

It was decided that each session would be 2.5 hours long:

*'two and a half hours is really good because when people are in recovery phase... they don't want too long and then you have a break ... not too much overload for them' (Maggie 64-7)*

*'other courses are 2 hours long. Quite often I feel that we are chasing out tails to try and condense everything in and have a break' (Peter 214-6)*

The number and length of sessions led on to discussion about the frequency of sessions. There is a trade off between allowing time for reflection and continued work on their narrative between sessions and the programme seeming to never end, and thus potentially losing participants. It was agreed that weekly and at the same time seemed appropriate, although it was acknowledged that this could effect accessibility for some people e.g. holding the sessions during the working day, evenings or at the weekend. Again this relates to the availability of co-facilitators and resources. There is potential for the workshop programme to run at different times and at different locations so as to reach a range of target groups, but again the focus of phase 3 is to develop the programme for the pilot.

### **Topping-up**

Given the unique nature of an individual's recovery journey (Leamy et al., 2011) and the anticipated differences in levels of wellness, readiness and ability to participate, it was important that the workshop programme wasn't considered to be 'a one time only opportunity':

*'not a one stop you have done it and never done it again.... Okay after a given period of time you could then come back to it again to top up' (Peter 75-7)*

This ideal reflects the on-going aspect of narrative development as well as the principle of recovery itself – it is an on-going non-linear process. Logistics and availability of resources will invariably have an impact on continued access too.

### **Theme 4: Workshop Education and Content**

It was hoped that in cycle 2, the focus group would begin to populate the blank session plans with content (bringing the scheme of work to life). Underlying this practical process were the following key recurring questions that appeared to frame the discussion of the workshop content:

- To what extent should the focus of the narrative development emphasis positive experiences? (Highlighting the difference between a personal and a recovery narrative)
- What behaviours and emotional responses are we as co-facilitators expecting/hoping for? Is it our place to do so? Would this potentially have an impact on participants' developing agency?
- Content and delivery should model good practice (education, therapeutic and working within a supportive environment). Who determines this?

### **Session One**

The initial starting point was session one - the introduction:

*'what might really help is the information that people get beforehand could be critical so they know precisely what they are getting into, what the expectations are, and the sort of issues....clarified in the introductory information' (James 123-7)*

Rather like the information that potential participants taking part in research receive (to inform their choice to participate), James suggested that a workshop programme information sheet be developed and given out prior to session one. The language, tone and sense of inclusivity are important factors in developing this advanced information:

*'And the language is written in a style, it is really important because it really frames the whole thing... I'm on a course and they send me emails because I've not accessed this. I feel like a naughty schoolgirl...it's putting me off the course' (Maggie 132-7)*

*'I've been asked by the Trust to ask service users to attend an event...a clinical services review...sounds so unexciting' (James 188-40)*

*'when they are calling it things like that people might say I'm a service user, does that mean anything I say then might affect what service I'm getting?... might I not need it anymore...frightening off participants...' (Peter 141-8)*

As a result, some may choose not to attend session one – which supports individual agency. As researcher, this had not been on my agenda, but I readily saw the value of it and agreed to develop it to the pilot.

Another aspect that co-researchers thought needed to be raised early on in the workshop programme was any potential emotional response to narrative work:

#### **Discussion Thread 6.1**

<p>-‘narrative...can trigger...facilitators have to be aware ...that people can be triggered by what they are writing... when the writing goes into free flow and then all of a sudden everything is out...what do you do with all this sudden emotion?’ (Harri 466-73)</p> <p>-‘those things need to be addressed in the introduction’ (Di 474)</p>
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It was another reminder that participants should be fully informed (i.e. discussing possible emotion responses), from the outset. The workshop should be set up to provide appropriate support and safe practice (two co-facilitators and relevant signposting). Key content would be covered in session one:

*‘keeping safe, the role of boundaries and trust.. and the group agreement [participant guidelines]’ (Sam 481-3)*

*‘confidentiality’ (Peter 704)*

Developing the group agreement is also an example of modelling good practice including developing confidence and agency. In summary, session one should include:

*‘the overview, agreement, guidelines, and I suppose it is very much getting to know each other and building the trust’ (Sam 706-7)*

#### **Session Content**

As focus group facilitator it was necessary to encourage the co-researchers to focus on the content to the session plans:

*‘I suppose I was looking at the sessions being some input, some of the things that we want to cover.... but also doing, plenty of time to do in a supportive environment. And have other people that have developed their narratives to come in and share as well. So people are getting the experience of listening, sharing, reflecting’ (Sam 224-8)*

It was necessary to adopt a much more directed approach in order to achieve any tangible output from cycle 2 focus group. At the same time it felt uncomfortable to do so, because as co-researchers I had hoped for more equality. The following is an

example (repeated a number of times in cycle 2) of an attempt to encourage the co-researchers to think practically:

#### **Discussion thread 6.2**

- 'in the scheme of work I have highlighted in my copy the areas that we wanted included' (Sam 359-60)
- 'if I do a spider diagram' (Maggie 361)
- 'looking at the scheme of work... there are the specific things... teaching and learning points and then there is...listening, building and sharing that is across all sessions. On the scheme of work, we have got explore participants reasons for wanting to develop a narrative, so would that be part of session 1...?' (Sam 362-7)
- 'topics that we came up with...were in no order' (Sam 388)
- '... mental health recovery, what is hope?.. recovery and the personal narrative..' (Sam 392-3)

As a further example of directing co-researchers to consider content, I asked them about using the medium of the storyboard (Lahad, 1992), as a way of supporting participants to get started:

#### **Discussion Thread 6.3**

- 'storyboard format enables people to actually start to develop something.. Because the question is where do you start? Who is the main character? ...What is the task? What hinders them? What did they learn from it? What follows from there? So where do you go from there?' (Sam 618-637)
- 'it could be used across sessions' (Peter 640)

There was considerable debate about what topics went in what session. All the topics were considered important and interlinked – one flowed into another. There was a sense that the educational content should be delivered in all the early sessions so that participants could reflect on it and potentially make use of it in their narrative development:

*'of those topics, is there a sense that there are things that need to be earlier on than later? ....needs to go in the first session or the second... could end up having the first couple of sessions really top heavy which we don't really want to do, we want to be able to introduce the learning points throughout... it allows time for people to do?' (Sam 841-6)*

This would result in 'learning rather than doing', which was not the aim of the programme. It was agreed that too much heavy content could be off-putting and demotivating, especially if participants were not particularly well. It needed to be carefully balanced:

*'...I've noticed today there is a lot of structural stuff. When I am putting courses together what I usually do is map it all out on a big grid....and then I put the times of the sessions so activity, taught bit, activity...' (Di 1029-32)*

The practical activity of topic placement occurred in cycle 3. Linked to this dilemma of what goes where, there was debate on how to share and/or showcase the narratives of others. Theoretically, sharing and listen to the narratives of others has been shown to be an important contributory factor in supporting recovery ((Frank, 1998, Macias, 2009, Slade, 2009, Saavedra, 2010, Scottish Recovery Network, 2011). It needed to be a key component of the workshop programme. Given that it was felt that participants should be able to choose any medium for their narrative development, equally they should be offered the opportunity to try different approaches and listen to narratives that had been developed in different ways. As well as sharing their narratives, it was important to allow time for the guest speakers to share some of their process in developing their narrative - important that participants didn't just hear positive experiences:

*'...have a mixture of experiences from somebody that found it really difficult and got there' (Maggie 867-8)*

This would hopefully give a more balanced perspective of narrative process whilst at the same time modelling the reality of the recovery journey (Leamy et al., 2011).

### **Linking Sessions and Reoccurring Activities**

Session and content flow were considered to be important. Recapping, linking and reflecting on prior content were built into every session. It allows for participants to be reminded of what has been done before and how it fits in with new content. This is particularly important if concentration is difficult. Generating and reinforcing a seamless flow of balanced content whilst at the same time offering space and

support to develop their narratives also models the on-going nature and complexity of narrative work:

*'you could link that with your last session... by saying what you said on day one, get to the end of it and you find out people's reasons for doing it' (Peter 369-70)*

*'that would be part of the last session... actually recapping but also putting the whole experience into a wider context...so having reflected and gone through this process I have learnt this about myself, or I have learnt that this helps me in certain circumstances' (Di 507-1)*

### **Icebreakers and Emotional Checks**

Icebreakers are important activities that can provide valuable teaching points as well as provide fun and gentle warm-up activates (MindTools, 2017). They can also get people moving physically and communicating with others. As regular activities within the programme, icebreakers offer a comforting pattern and regularity (may help reduce participant anxiety), whilst actually working with difficult material such as building group cohesion and supporting trust-building and sharing:

*'if you choose the icebreaker carefully and it is a team building, a sharer, a trust...' (Sam 764-5)*

It was agreed that icebreakers should be targeted (linked to specific learning outcomes), of a time-limited duration (10-15 minutes) and varied to support different learning styles. Whilst the session plans might provide examples, there should be flexibility to ensure that co-facilitators used icebreakers that were appropriate to local needs.

Check-ins and checkouts – ‘to report, as by presenting oneself’ (Clemans, 2010), used as therapeutic devices, were considered to be a vital component of each session plan. Given the potential emotional impact of the work, these activities allow co-facilitators and participants to be aware of the emotional energy in the room and whether additional support is required.

### **Sub-theme 4a: Therapeutic Input**

The debate between whether the programme is therapy or therapeutic continued to underpin cycle 2. Different people find different things therapeutic:

*'my therapy is going for a run...walking my dog...writing was always therapy' (Maggie 428-39)*

From Maggie's quote it is apparent that often the terms 'therapy' and 'therapeutic' are used interchangeably. For this study, 'therapy' is used to mean a formal clinical interaction between a qualified professional and a service user/client. 'Therapeutic' suggests that a benefit may accrue as a result of doing something e.g. developing a personal narrative, doing courses at a recovery college or having lunch with a friend.

To be therapeutic, it does not need to take place within a clinical setting. Equally therapy, itself, may provide therapeutic benefits. Also the workshop programme co-facilitators may not necessarily be trained or qualified therapists.

It remained clear that the workshop programme was not therapy (in a clinical sense):

*'we are not treatment, we are not therapy... we are not linked with the health authority or DWP... so it is not going back to them. What we are working on is helping them' (Peter 166-9)*

*'so rather than setting it up and saying this will be therapeutic, really it is leaving it for the students to decide whether it is therapeutic for themselves and the way that they understand that' (Di 452-4)*

*'framing it in terms of what it isn't, saying this isn't run by therapists, it isn't seen as part of your therapy or clinical treatment' (Maggie 455-6)*

### **Confidentiality**

Developing a personal narrative will potentially have an emotional impact. It may bring to light: previously not thought-about material; deeply shameful experiences; dysfunctional and/or abusive relationships; and a catalogue of loss and despair. The process also contributes significantly to recovery in terms of: reframing; separation of the illness from the person (Slade, 2009); connectedness through sharing; and a developing sense of self through growing understanding and agency (as phase 1 and 2 have shown). Integral to narrative development work is the key need for confidentiality – to feel safe and supported within the process. The initial information sheet and the group agreement would lay down the ground rules for confidentiality and these are continually reinforced throughout the programme.

One of the key tenets of confidentiality is:

*'house rules...when we share within the room... what is said in the room stays in the room' (Peter 177-9)*

However this needs to be balanced with the 'potential risk of harm to self and/or others' and the sense of how much is a co-facilitator or other participants expected to hold. The issue of disclosure is ever-present and that needs to be addressed when developing the group rules. There is an additional concern as how to navigate through confidentiality issues when the workshop group is a potential source of developing new social networks (participants may become friends).

### **Theme 5: Participants**

An important aspect underlining the discussion on participants was our expectations of what individuals should get out of participation and their possible contribution to the group. In essence, what aspects would make individuals a good group member (e.g. motivated, contributing and good attendance?). There is also an issue of how the facilitator balances supporting 'positive' group membership whilst fulfilling the primary aim of developing a personal narrative? In reality there were no concrete answers and we should not expect any, given that the key recovery characteristic of the 'uniqueness of each individuals' journey' (Leamy et al., 2011, Bird et al., 2014). We cannot determine an individual's commitment to the process or their '*different states of readiness*' (Peter 109):

*'because then as facilitators you might not feel so under pressure that you have got to teach them about recovery... about boundaries..'* (Sam 120-2)

There were practical things that the framework and programme could incorporate including: increasing sessions from six to eight; promoting flexibility of delivery to reflect different target groups (working participants, in-patients, young people etc.); and consideration of time, place, specific activities and task differentiation).

### **Theme 9: Workshop Facilitation**

Workshop facilitation considerations impact on and are reflected across all themes.

For example, providing a supportive and inclusive environment may allow

participants '*to feel more comfortable*' (Peter 118), which may have a positive on an individual's emotional responses.

One important issue is the possible responsibilities and pressures that a co-facilitator will have – the main one being an implicit one of 'being all things to all men' and ensuring 'each participant gets the most out of the workshop programme with the minimal negative emotional impact'. This implicit assumption is based on an unbalanced power dynamic because it assumes that the facilitator is the adult and the participant the one in need of protection. This approach does not support the recovery model:

*'...it is important not to rescue' (Sam 478)*

*'I think that starting out with the assumption that this is something that is going to enable people to be positive is something that, perhaps, to be avoided. There is an assumption that there are attributes that we should aspire to and be positive and optimistic... how you should be... if not there is something wrong'*  
*(James 584-53)*

It is important to acknowledge that: participants will drop out; may need a second go at the programme; and may be upset – this is not the fault of the facilitator but part of the process. Also, there is always the potential for the unexpected, hence the importance of two facilitators. Much of these issues will be addressed within the facilitator training (which will be developed post-doctoral).

### **Modeling and Reinforcing Good Practice**

*'A key aspect of facilitation is modeling and reinforcing good practice. For example, whilst acknowledging that the narrative is personal and that there might be a process need to develop and continue to produce an 'angry and/or destructive narrative', it is important for the facilitators to also model a more balanced perspective – to reflect on what has been learnt and how they have moved forward...ultimately we don't want people to remain stuck'* (Sam 590)

Sharing narratives and also reflecting on the individual's process in developing their narrative can achieve this balance.

Another important example of modelling is the reinforcement of the group agreement, which the participants have developed. The group agreement reinforces the structure of the workshop, the supportive environment and the agency of the participants.

### **Theme 10: PAR Process and Facilitation of Focus Group**

As the researcher, I had expected cycle 2 to concentrate on populating the session plans (Appendix 6.7) with the topics (Appendix 6.9) that had emerged from phase 2 and agreed upon in phase 3, cycle 1 (Fig 6.2). I had assumed that we had fully discussed the underpinning philosophy, workshop model and key aims in cycle 1 – especially as the scheme of work had been developed from cycle 1 discussion. I assumed that we would tie up any loose ends in cycle 3 – using this time to make our final decisions. I expected cycle 2 to be practical. I outlined this expectation in my introduction to this focus group and it was reflected in the session plan for this group (Appendix 6.12):

*'So today it is about actually putting some of this scheme of work into where people want it to go in the sessions, how do we want it included? So that is what I mean by the nitty gritty. Again, in the pack there is a pro forma. It is a very basic session plan, and hopefully I modelled that in terms of the one I've got at the top end of your pack, which was what we were going to do today. So that is modelling the kind of thing that we would be delivering in the workshop. But we don't need to get into that detail, it is literally populating it. What I have got for you is a blank, just six sessions and the kind of thing you would want where' (Sam 45-53)*

What seemed like a logical progression from the philosophical to the practical did not occur without direct facilitation. It felt that there was reluctance to populate the session plans until all other matters were fully resolved (pragmatically, this was highly unlikely):

#### **Discussion thread 6.4**

- 'before we start filling this would it be useful to get some big paper and think of the things that you want to include, and then you can pick the order' (Maggie 356-7)
- 'in the scheme of work I have highlighted in my copy the areas that we want included' (Sam 359-60)
- 'I do one of the spider diagrams then' (Maggie 361)
- 'Looking at the scheme of work there is two parts to it. There is the specific things you want to do for teaching and learning points, and then there is other stuff like the listening

and building the sharing that is across the sessions. On the scheme of work we have got to explore participant's reasons for wanting to develop the narrative, so that would be part of session one because that is why are you here, why do you want to do this?' (Sam 362-7)

Once the co-researchers were directed to consider the session plans, the discussion did focus on the topics, where topics may fit in and the possible links between sessions:

#### **Discussion thread 6.5**

- 'You could link that with your last session as well by saying this is what you said on day one, get to the end of it and you find our people's reasons for doing it' (Peter 369-70)
- 'you want to go back to that. What did you say about towards the end of the course going back to it? (Maggie 379-80)
- 'possibly week 5, week 6. But at the end of the last section' (Peter 381)
- 'the last session was saying where do we go now? It is that question to recap' (Sam 382-9)
- 'so the initial question is what do you want to get out of attending the...' (James 384)
- 'So the topics that we came up with, again, these were in no order. It was a bit about what is meant by recovery? I'm on the scheme of work. In the aims...So we have got explore participant's reasons for wanting was why are you here. Then we have got mental health recovery, what is hope? I think is it useful as well to talk about the recovery and the personal narrative? Because I think we decided that it is not interchangeable and that actually if you were developing a recovery narrative you are being pointed in one direction, that is not necessarily what the individual wants to do. Linked into your angry narratives Peter. Do we want to give them a sense of the idea that the personal narrative is whatever is yours?' (Sam 388-98)

#### **Discussion thread 6.6**

- 'Of those topics that we have got on there, is there a sense that there are things that need to be earlier on than later on? I can look at this and think this needs to go in the first session or the second session, or whatever. But you could end up having the first couple of sessions really top heavy which we don't really want to do, we want to be able to introduce the learning points throughout. But also allow the time for people to do. What do people think about the idea of actually having people that have developed the narratives, so people can listen to other people sharing. And also I was thinking not just sharing written narratives but if people have done it in different ways as well, showing what is possible' (Sam 841-9)
- 'Could that be a specific week? Say we were doing six weeks and week three you had invited somebody in that has already done a narrative, and say this is a live example of a narrative, this is what the person does. So they can then do a Q&A with the people who have come in' (Peter 850-3).
- '*I was wondering if it was more than once. If we have more*' (Sam 854).

Specific aspects of the discussion were important, as they determined how the programme would be structured and delivered. It was time consuming (and our time as a group was limited). We did not get to the point of putting anything down on paper in cycle 2. This led me to reflect on the success of cycle 2 (because the product had not met my expectations – in some ways rather like the workshop participants not matching the expectations of the facilitators). In retrospect, it was a necessary part of the process for the co-researchers to go through (so that we were clear as to what fitted where and why). It also emphasised the careful thought and consideration that was involved in developing the workshop programme and how hard it is to anticipate what will be achieved in any particular group session. It mattered to the co-researchers.

Between cycle 2 and 3, I needed to reflect on how we were going to populate the session plans in cycle 3:

#### **Discussion thread 6.7**

- 'So how are you doing populating the ...?' (Di 916)
- 'I need to go away and ...' (Sam 917)
- 'Yeah go away and do it and bring it back as a suggestion. What would be good when we meet next time, just a suggestion, is for you to do it and then to be like Fuzzy Felts' (Maggie 918-20)
- 'I wondered that. I wondered about putting it on pieces of card that could be moved around' (Di 921-2)
- 'I'll go away and listen to what we have discussed, put it in a structure like I've done with that and pulling out the principles' (Sam 925-6)
- 'That is why I was suggesting four things in a session. You can set yourself up with topics that you want to deal with and then break them down into say three key topics you want to deal with over the whole course. So three of them divided between the six weeks is going to be two days per topic, and that gives you eight items potentially per topic' (Peter 927-31)
- 'Shall I work on the basis of the eight?' (Sam 932)
- 'Yeah' (All 933)
- 'So it will be six, very much, working sessions' (Sam 934)
- 'And then top and tail, I can do that. I'll get them out to you beforehand so you can have a look and start to have a think about this needs to go here or we have missed out this or that' (Sam 936-8)

#### **Sub-theme 10a: Competing Roles**

Facilitating cycle 2 was a balance between my various roles: as researcher; focus group facilitator; co-researcher and peer. At times it was uncomfortable, because the power dynamics were not always equal (especially as I had hoped that PAR would enable equality). There was the tension between discussion and achieving

output. It made me reflect on my expectations, motivation and anxieties against those of the other co-researchers – they also felt the pressure:

#### **Discussion thread 6.8**

- 'do you feel you have got stuff from us today?' (Peter 1014)
- 'yeah, I need to go and collate' (Sam 1015)
- 'the famous last words was is it what you aimed to get today or do you think we have added or you wont know until you have gone through it?' (Peter 1017-8)
- 'No. I need to go away and...' (Sam 1019)
- 'I'll give you that get out of jail free card then' (Peter 1020)
- 'I need to reflect on it. But one of the things I'm doing as part of the PHD as well is I'll be reflecting on the process of this as a process as well, as a methodology. But I need to go away and breathe and take it all in' (Sam 1021-3)

This exchange highlighted both the importance of reflection in the PAR process and the work that needs to be done between focus group meetings in each cycle. Cycle 3 represented the last planned meeting with the co-researchers.

#### **6.12 Cycle 3**

Cycle 3 took place 3 weeks after cycle 2. The following information was prepared for the co-researchers.

**Table 6.10 Information and Paperwork**

Name	Detail
Cycle 3 session plan and information (Appendix 6.15)	An overview of cycle 3's task – populating the session plans. Included the list of topics.
Draft populated session plans (sessions 1 and 8) (Appendix 6.16)	Between cycle 2 and 3, researcher had developed a draft populated session plan for session 1 and 8. This was based on the discussion in cycle 2
Topic list (Appendix 6.17)	The topic list, which was enlarged. Each topic was laminated. The blank session plans were also enlarged. The intention was for the co-researchers to use the laminated topic cards to place on the blank session plans. It enabled topics to be moved around as the discussion progressed.

The draft session plans for session one and eight (Appendix 6.16) were sent to the co-researchers for comment, prior to the cycle 3 focus group. Alice and Ellie

commented via email. Their comments were passed on to the other co-researchers and included within the discussion. At the start of cycle 3, I explained the task of populating the session plans. I showed the co-researchers the enlarged blank session plans and the laminated topic cards. These were placed in the middle of the table, so that everyone could reach them. The co-researchers moved closer together so that they could see and move the cards into place on the blank session plans. This focus group seemed to have much more energy and impetus – perhaps because it was acknowledged that this was our final meeting and we needed to get this done.

### **6.12.1 Themes**

As cycle 3 built on cycles 1 and 2 discussion results, only additional comments, insights, reflections etc. will be included here. Cycle 3 was a task-orientated, practical session. As such the themes of: framework and model; structure of workshop; and workshop education and content dominated the discussion.

## **Theme 3: Structure of Workshop**

### **The Session Plan**

The key task of cycle 3 was to populate the session plans. It was agreed that there would be eight sessions, with session one being an introduction and session eight a showcasing celebration:

*'I think that is an excellent idea because it makes the working sessions less pressured and more focused' (Jodie 27-8)*

Each session would have the same structure: to encourage familiarity; support typical concentration levels; and offer varied activities and levels of participation – hopefully making the workshop programme stimulating and enjoyable too. Each session had 4 parts and included reoccurring activities such as:

*'I took it from you about having something before the break and after the break as being the main [activities]. So in every session we have got housekeeping, check-in, icebreakers and a recap. And at the end checkout. So I've stuck those in as standard' (Sam 33-6)*

Each session would also have an introduction and the opportunity to discuss participant reflections (from between sessions – it is likely that some participants will work on narratives outside sessions). The other parts of each session would be taken up with the theoretical and learning activities and the active ‘doing’ activities (work on narrative, listen and share), which will occur across sessions:

*‘What I’ve got is I’ve got all these points on here laminated so we can move them around. For example, what is recovery? That is on the lamination so we can move that around. The more educational stuff about boundaries and information stuff which is the main points on there, but we have also then got the doing things, for example work on the narrative, listen, share’ (Sam 73-7)*

#### **Discussion Thread 6.9**

- ‘So you could frame that as lots of different ways of doing narrative and we are going to explore this over the workshop’ (Maggie 161-2)
- ‘That leads them to the peer story or the peer’s perspective as an example to lead from’ (Peter 163-4)
- ‘I’m very keen when people are doing their narrative and sharing their narrative that we are drawing on people with lots of different examples, not just written narratives but there might be people using photography’ (Sam 165-7)

There was a sense that deciding on topic order in the session plans was arbitrary and in practice will likely be determined by the characteristics of each group. We were, in effect, trying to make an amorphous thing into a structure that would be able to be reflected in the session plans, but with the inherent flexibility for local needs and conditions. This needs to be reflected in the framework:

#### **Discussion thread 6.10**

- ‘You are quite right though that different people will be at different stages and you might find that the narrative of the group as you are working with them might lend it to have week four in week three or might be that you can push it further back. It can be almost plug and play whichever week you want to go ...’ (Peter 971-50)
- ‘And that is the syllabus facilitation. We are trying to make an amorphous thing into a structure’ (Sam 976-7)
- ‘In my head, if we have got a lot of topics to cover it will feel from a delivery point of view you can feel yourself being rushed to make sure you cover all of them. As long as it is all spaced out, when you are delivering at a pace that you are comfortable with it comes across with the students, the people receiving it, and participating in it. Sometimes it will go ... again, it is down to how many people. If you have got four people there is a minimum size, then it can go both ways. It can go really slow or really quick, but when you have got lots of people ... say six to eight, which is the maximum size group, then you will want a bit more room to spread ...’ (Peter 981-9)
- ‘And also a bit of space to play with’ (Sam 990)

Thus linking theoretical content with process and doing activities and therefore building the whole picture of the process of narrative development and creating a seamless flow:

**Discussion thread 6.11**

- 'Yeah, and maybe the focus of the second one could be more on why I believe in the power of the narrative' (Jodie 190-1).
- 'And then that could lead into drawing into how the students themselves can then use it. So it leads in to do things that lead to another thing. Not doing right we have done that bit and now we are going to do this. It naturally moves onto the next thing so that your different parts link with each other' (Peter 192-5)
- '... actually it is about building the whole picture and it all flowing' (Sam 198-9)

**Learning Outcomes**

All topics were taken from the developed scheme of work (Appendix 6.18):

*'The aims and objectives of each session, which I haven't put in here, are going to be pulled from the scheme of work. Because the scheme of work has got the aims and objectives. And I'll be able to say in this one we are looking at this, where does that match the scheme of work? And that can be that will link into this. If you imagine each of these sessions have got a front page with aims and objectives. But that will come from the scheme of work. Because none of this is new to us now, it has come from our discussion that put the scheme of work together. We haven't added anything different here, so I will be able to go back to the scheme of work' (Sam 1183-92)*

It was important that the session plans were not merely a listing and ordering of topics. Each session plan was supported by session aims and learning outcomes which reflected the session content (Appendix 6.19). The supported learning aspect of the workshop programme is crucial:

*'If you have got access to the computers, maybe a tape recorder, or whatever, then you can have people go off and watch a You Tube video on their own, or whatever. But, again, it is the supported element of doing things. So they might not be physically generating work but they are learning or getting in a supported environment the knowledge to then take away' (Peter 1121-5)*

It was decided that the criteria to measure success of the learning outcomes would be differentiated by:

*'you want a learning outcome from an educational point of view, you need learning outcomes to say this is what you want to achieve at the end of the session' (Peter 1151-2)*

By the end of the course:

- **All** participants will be able to....
- **Some** participants will be able to....
- **A few** participants will be able to....

#### Discussion thread 6. 12

- 'Again, using the Recovery College models that I have seen, we have a three tier approach to cover different people's ability and willingness to participate. You have a minimum criteria where you are expecting 100% of people to do it. The minimum thing is at the end of the course someone can tell you what the narrative is. And that would be it. So say that someone can tell you what a narrative is and the benefits or pros and cons of it. They don't have to say whether they want to do it or whether they think it will benefit them, it is just that they understand the principle of why they have come on this course, the narrative is this and it does that and it does this for other people or for some people. But then the second one would be someone has understood it a bit further and has looked at different versions of narrative and may consider it for themselves. The third tier is someone who is engaged in it, says I understand about narratives, these are the benefits for me, I am in the process of ... or this is what I have done. That would be your three levels. So if you have got somebody who has stood up, sat and listened, not necessarily participated much but said one or two key words, or hasn't done anything, has gained something from it because they know what a narrative is. But the other end of the scale is someone who has done the whole whistles and bells. It also means there is no pressure to achieve any of these things because the danger with putting in an objective and aim is people feel they have got to achieve it' (Peter 1211-31)

- 'Sometimes those aims and objectives are for the facilitator to keep ...' (Sam 1232)

- 'So we know have we wasted our time the past eight weeks?' (Peter 1233)

- 'Everything needs to be qualified in any educational thing. Whichever organisation, whoever is running it will want to know the benefits so they can then warrant putting the resources into it. Because at the same time, whatever this does, just one course and the paperwork, the resources involved in it, it depends on how deep and how simple it is, can cost a fair bit of cash. And you have got to sell this to somebody and say well it does work' (Peter 1235-41)

As Peter suggested, course evaluation measured by the learning outcome measures and participant feedback is important. It will allow facilitators to evaluate the programme and determine any changes that may need to be made in the delivery of further programmes. This also has resource and funding implications.

As a document the session plan is vital. It allows the facilitators to plan effectively, keep on track and ensure that everything is covered. Yet at the same time, it allows flexibility, fluidity and creativity (if the facilitators want it to be so – although often this requires experience and confidence to do so):

#### Discussion thread 6.13

- '...when you sit writing these things you work out enough minutes how it goes but when

you get in the room the flow of it with the groups you are mentally binning we are covering that by talking, the conversation is taking us down the path we wanted to go down naturally. And it quite often will organically lead itself to where you want it to go. It is just for yourself from the delivering point of view of being able to have the way markers to say we are still on track. It is not suddenly rambling itself out of a spinning world, oh where are we now?' (Peter 200-07)

- 'So we have got six sessions of instructional, educational type topics around what narrative is and some of the aspects of narrative, which are all on this sheet. It is actually do we formally put them in sessions? I would hope, as Peter suggested, that whilst there is a formal structure it will be flexible to go with the flow as well. So this is the sense that we will have a structure but this gives us the stability to move off piste' (Sam 218-23)

- 'And also some weeks you don't cover as much and there is space in the six weeks for that for things to move' (Jodie 224-5)

If the session plans and running order are overly prescriptive (often by determining how facilitators should deliver the content - including outlining specific activities), this could create difficulties for local facilitators. As a result they may choose not to run the programme:

#### **Discussion thread 6.14**

- 'Just putting my teacher hat on, would it be better to start with what you want the participants to get out of each session, a learning outcome? And then you can work out in a really flexible way So if I'm picking it up for somebody who is going to join my workshop I'd go 'oh okay this section is all about getting them to blah, blah, blah.' Or it says here I can do this with photography, I might know somebody who is a photographer. This session is about getting them to cut out a magazine. It is your learning objectives' (Maggie 564-71)

- '..on that particular session it is down to the people to utilise their resources specifically' (Peter 566-7)

#### **Workshop Introductory Pack**

A workshop introductory pack was not something that had been considered by the researcher. However it had been discussed in cycle 1 and agreed to be beneficial. It will let prospective participants know what the programme is and is not, allowing them to choose whether to participate or not. It actively encourages agency. It needs to include relevant information such as: aims of programme; number and length of sessions; and content:

#### **Discussion thread 6.15**

- 'in cycle 1, James suggested it is a good idea that I produce a decent outline of it all so we can have all the session numbers and whatever the name is....give everyone the full picture' (Sam 704-9)

*'That is what you can do in the intro. If we have got a title for each week we can give the title and then say these might be the sub-headings that we will cover each week' (Peter 710-2)*

It needs to be clear on who the intended participants are (open without formal assessment and referral), and to emphasise that the programme may be therapeutic but not therapy. This will be an important part of the pilot phase, to be developed prior to participant recruitment.

### **Sharing and listening to the narratives of others**

Whilst it is important that the co-facilitators share aspects of their personal narrative, it is important that participants get to hear different types of narratives, which may use a variety of media:

#### **Discussion thread 6.16**

- 'Going back to the other thing we have started talking about is how we use people's experience and using stories. Maggie was saying about how do you get that story in if you haven't got people to do it, do you bring somebody in? What I was thinking is the whole way through you could do case studies or a person's already written down examples. But where you can replace a pre-defined example with a lived live narrative then you have got both avenues covered' (Peter 547-54)
- 'Also you have got things like digital stories you can use... is an important part of this is to be immersed in other people's narratives to hear what ... and for me it would be really beneficial that it is not all things that have been developed by written word. But I get your point that if we are saying that we want a photographer there or this there, that is ... in many ways, when you are developing a syllabus or scheme or work, you put in a lot of ideals in and you say in an ideal world we would want this, this and this. But I think now there is a lot of You Tube stuff that people tell in their narratives' (Sam 555-63)

This 'doing' and the 'time to do' was incorporated into both the scheme of work and session plans:

*'...We have got three blank weeks because that is working on, working with them, and people might want to do the narrative more than once, and giving us plenty of time' (Jodie 805-807)*

*'And you think if you have got people's voices who were abusers as well in there, it is a really important ... but I think if we keep these fairly blank in terms of instructional output, that gives us time and space' (Sam 857-9)*

It is important to get the balance right between theoretical and educational input and the space to 'do':

#### **Discussion thread 6.17**

- 'I think from my experience here of working with people to develop the narratives, one of the criticisms would be that it is too top heavy with that kind of stuff and not enough ...' (Sam886-8)
- 'That is why I was saying moving them around because I'm thinking that we are waiting until this week before we get any doing. I would be happy getting stuff doing here. But it is in the context of how you get the doing going. And it has got to be relevant doing for the sake of doing' (Peter 889-92)
- 'People will start to do. This is the listening, sharing, working is the doing' (Sam 893)

#### **Discussion thread 6.18**

- 'That is the key to the two and a half hours and the key to ... so you don't load too many other sections up because then it does get bogged down with the theory, the thinking stuff and the information side of it. It is the doing, doing, doing. I think that is the key' (Peter 1095-8)
- 'I think a lot of these information ones are quite succinct. They might look in terms of the titles, oh my god we could talk for months about this. But really if we think of this as an introduction to narrative work because, to me, narrative work is a lifelong process. These things might look like huge things but actually within each session there is a lot of time to listen and to share. Because otherwise we might as well just run a lecture' (Sam 1099-1104)

#### **Theme 4: Workshop Education and Content**

Cycle 3 discussion was characterised by much debate as to: what topic went in what session; what topics went together; the balance between 'theory', 'doing' and 'reflecting'; and the flow from one session to another. The laminated topic cards were positioned and positioned again. This continued until all the topic cards were placed on the blank session plans and the co-researchers were in agreement that the overall order and balance was satisfactory. It was clear that the topics were interrelated and were considered to all be important factors in narrative development work (Figure 6.4 topics to include in session plans). Whilst a particular topic may be introduced in a specific session, it was acknowledged that it would continually be revisited and built upon throughout the programme.

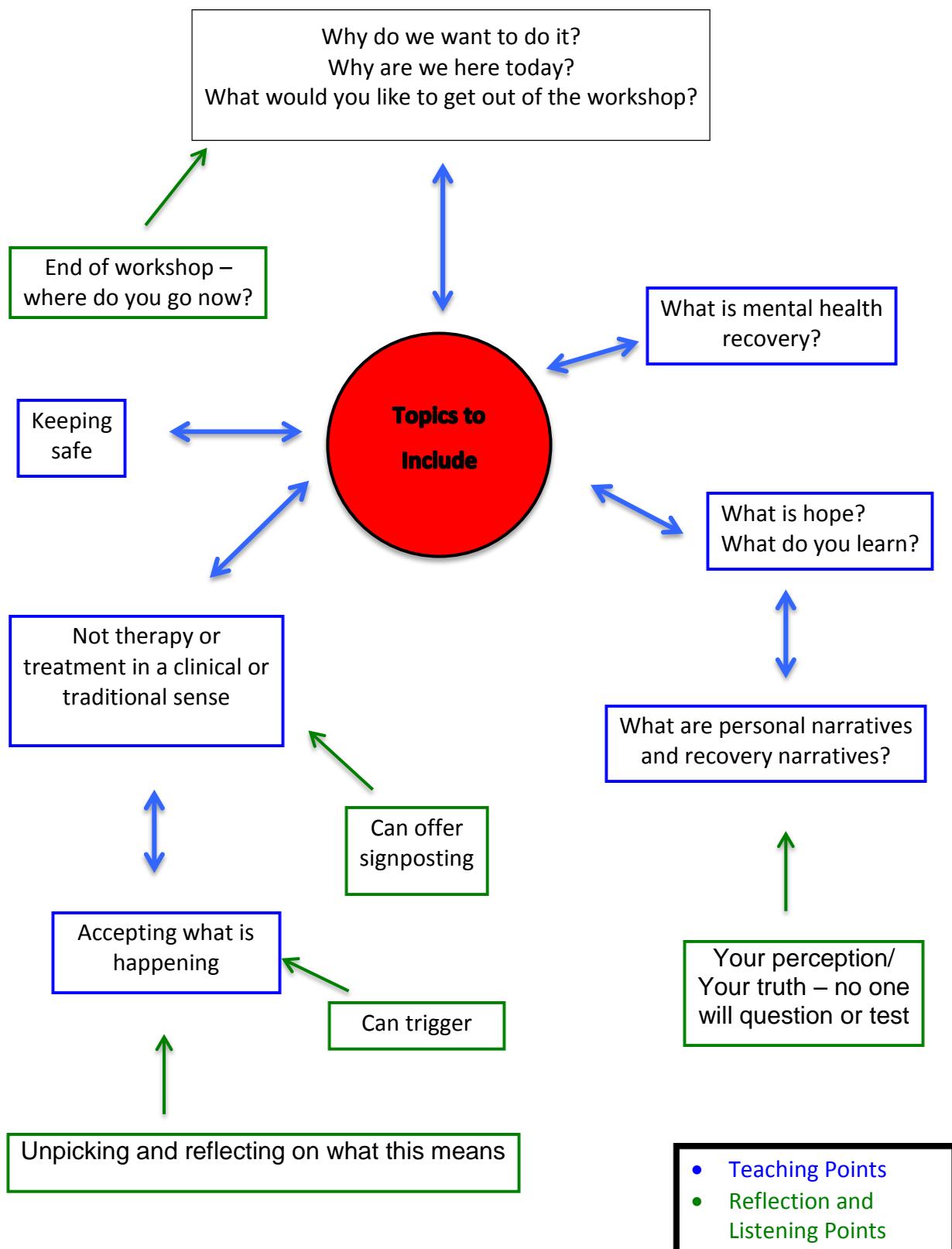
In turn, each session was reviewed. Session names were debated and chosen. Session aims and learning outcomes were matched to the session content.

Throughout this process, the co-researchers were mindful of working towards the underlying considerations:

- What were we trying to achieve in the eight-week programme?
- Would our programme support the development of an individual's personal narrative?

These considerations will be initially tested and evaluated in the pilot phase. Table 6.11 provides an overview of the completed session plans, including session titles, reoccurring activities and topics. The full session plans (with aims and learning outcomes) are in Appendix 6.19.

**Fig 6.4 Topics to include in session plans**



**Table 6.11 Brief Overview of Session Plan Content**

Session Number and Title	Content
<b>Session 1</b> <b>Introduction and Getting to Know Each Other</b>	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• Introductions and house-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker (e.g. how did you get here today?)</li> </ul> </li> <li>• Overview of the Workshop Programme <ul style="list-style-type: none"> <li>▪ Background</li> <li>▪ Introduction to the content of the course and what will happen in the sessions</li> <li>▪ Who and role of co-facilitators</li> <li>▪ What the programme is and what it is not (not therapy or treatment)</li> </ul> </li> <li>• Ice-breaker (Building Trust)</li> <li>• The Group Agreement <ul style="list-style-type: none"> <li>▪ Discuss the importance of Trust, Keeping Safe and Boundaries</li> <li>▪ Develop the group agreement</li> </ul> </li> <li>• Discussion - Initial consideration of why participants have signed up for the workshop programme – why are they here today? <ul style="list-style-type: none"> <li>▪ Expectations, hopes and concerns</li> <li>▪ Any questions?</li> </ul> </li> <li>• Check-out</li> </ul>
<b>Session 2</b> <b>Why Bother Creating a Narrative?</b>	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• House-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker</li> </ul> </li> <li>• Recap from session 1</li> <li>• Introduction to Session 2 <ul style="list-style-type: none"> <li>▪ Discuss what is hope and what is recovery?</li> </ul> </li> <li>• What is a personal narrative and a recovery narrative? <ul style="list-style-type: none"> <li>▪ What is the difference?</li> <li>▪ Who is the narrative for?</li> </ul> </li> <li>• Sharing Narrative <ul style="list-style-type: none"> <li>▪ Co-facilitator (or peer) shares their personal narrative</li> </ul> </li> <li>• Discussion – what did it feel like to hear the personal narrative?</li> <li>• Consideration of the possible benefits and difficulties of developing a personal narrative</li> <li>• Check-out</li> </ul>
<b>Session 3</b> <b>Mechanics of the Narrative 'bits and bobs'</b>	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• House-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker</li> </ul> </li> <li>• Recap from session 2</li> <li>• Introduction to Session 3</li> <li>• Discuss different media in personal narrative development</li> <li>• Introduction to different narrative development frameworks (e.g. drawing a time-line, storyboard or Tree of Life)</li> <li>• Sharing narrative <ul style="list-style-type: none"> <li>▪ Co-facilitator (or peer) shares their personal narrative (preferably showcasing range of media)</li> </ul> </li> <li>• Discuss the advantages and disadvantages of using different media</li> </ul>

	<ul style="list-style-type: none"> <li>• Consider individual choice, interest and expertise of participants</li> <li>• Check-out</li> </ul>
<b>Session 4</b>  <b>'Plain Sailing and Stormy Seas' – the ups and downs of creating and sharing your personal narrative</b>	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• House-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> </ul> </li> <li>• Ice-Breaker Recap from session 3</li> <li>• Introduction to Session 4</li> <li>• Exploration of the advantages and disadvantages of sharing their personal narrative with others <ul style="list-style-type: none"> <li>▪ What might it feel like?</li> <li>▪ What are their initial concerns?</li> </ul> </li> <li>• Discuss important considerations in sharing their personal narrative <ul style="list-style-type: none"> <li>▪ How much to share?</li> <li>▪ What is included and what is left out?</li> <li>▪ The voice of others within their personal narratives</li> <li>▪ Who is the audience and why is this important?</li> </ul> </li> <li>• Playtime – Start to have a go at developing their personal narrative</li> <li>• Check-out</li> </ul>
<b>Session 5</b>  <b>'Playtime' – doing it!</b>	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• House-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker</li> </ul> </li> <li>• Recap from session 4</li> <li>• Introduction to Session 5</li> <li>• Listen to a peer personal narrative</li> <li>• Explore the process of the peer in developing and sharing their personal narrative</li> <li>• Work on personal narrative within a supportive environment</li> <li>• Check-out</li> </ul>
<b>Session 6 'Tinker Time' - Continue working on personal narrative</b>	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• House-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker</li> </ul> </li> <li>• Recap from session 5</li> <li>• Introduction to Session 6</li> </ul> <p>Participants are in the process of developing their personal narratives and are possibly starting to think about sharing their personal narratives with others</p> <ul style="list-style-type: none"> <li>• Discuss and re-evaluate their experience of developing their personal narrative and the possibility of sharing it with others: <ul style="list-style-type: none"> <li>▪ What it might feel like to share their personal narrative?</li> <li>▪ Have any of their initial concerns been realised?</li> <li>▪ How much to share?</li> <li>▪ What is included and what is left out?</li> <li>▪ The voice of others within their personal narratives</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>▪ Who is the audience and why is this important?</li> <li>• Work on personal narrative within a supportive environment</li> <li>• Check-out</li> </ul>
<b>Session 7</b>  <b>'Show and Tell'</b>	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• House-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker</li> </ul> </li> <li>• Recap from session 6</li> <li>• Introduction to Session 7</li> <li>• Sharing and listening to personal narratives (or parts of)</li> <li>• Sharing and listening to personal narratives (or parts of)</li> <li>• Check-out</li> </ul>
<b>Session 8</b>  <b>'Reflection and Celebrating'</b>	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• House-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker</li> </ul> </li> <li>• Recap from session 7</li> <li>• Introduction to Session 8</li> <li>• Discussion of individual's process of developing and sharing their personal narrative: <ul style="list-style-type: none"> <li>▪ (Could include discussing aspects such as: developing their own voice, acceptance, gaining a better understanding of themselves, improving confidence, identifying with others, reduced isolation and de-stigmatization)</li> <li>▪ What was it like to begin to share your narrative?</li> <li>▪ What was it like to hear the narrative of others?</li> </ul> </li> <li>• What to do with the personal narrative now? <ul style="list-style-type: none"> <li>▪ Different ways to use narrative (e.g. sharing for training purposes)</li> <li>▪ Signposting</li> </ul> </li> <li>• Feedback to each other – what have I learnt from other people?</li> <li>• Programme feedback</li> <li>• Show-casing</li> <li>• Check-out and group ending</li> </ul>

In cycle 3, it was very apparent that the group was more purposeful and task orientated. As a result, there was less need for facilitator direction. The fact that this was our last scheduled meeting may have helped the co-researchers to focus on populating the session plans. It felt a more cohesive group, but this may be because the group was moving towards a practical outcome (which coincided with my needs as the researcher).

## Populating the Session Plans

Sessions one and eight were '*pretty much filled in [cycle 2] because we discussed that didn't we*' (Sam 29-30), with session one being the introductory and programme overview. As a session it can stand-alone and will enable participants to choose to continue or not:

*'might be that people would want to come the first one and think actually I'm not ready for this yet... overview to the workshop programme...what is this going to be? ...Introduction to the course and what will happen in sessions... the role of facilitators...what are their expectations, hopes, concerns...what the programme is and what it is not because it is not therapy or treatment – Alice suggested that she would like that in the programme right back at the top...' (Sam 23-44)*

Session one would offer a clear, factual statement of what the programme is and is not. This is intended to give clarity for anxious participants and provide an opportunity for focused questions. The session title, '*Introduction and Getting to Know Each Other*' will re-enforce this:

### Discussion thread 6.19

- 'I like that idea because I come in, I may be nervous, I don't know anybody and you never know quite what to expect and it is made quite clear this is what this is about. I like that. It gives me clarity' (Jodie 46-9)
- 'And if you think you are coming for therapy you could actually say thank you very much and leave' (Sam 49-50)

Given that developing a personal narrative is a process that is not benign – there is a potential for an emotional reaction, it was decided that issues such as confidentiality, boundaries, keeping safe, and the group agreement needed to be discussed in session one. Hopefully, this would engender a safe and supported environment in which participants could start to build trust and therefore be more willing to share with the group:

#### **Discussion thread 6.20**

- 'to say from the start that we don't discuss specific medications or clinicians or anybody by name' (Jodie 62-3)
- 'one of the things is the group agreement and it could be part of that' (Sam 66)
- 'The other problem is if we are in a group and someone shares the name of a specialist someone else might think oh I know you outside of here. But it is the what goes on in Vegas stays in Vegas type agreement of share it in the room but please don't share it outside' (Peter 68-71)

It was hoped that the session names would be seen by participants as fairly light hearted (to reduce anxiety), but at the same time describing the session content and proposed activities. Session two, '*Why Bother Creating a Narrative*', initially concentrated on unpicking terms such as hope, recovery and narrative. It was agreed that these terms have a collective and common understanding and usage in our western culture, but we were not sure if participants would be aware of their meaning and usage within the mental health world. In particular, the term mental health recovery is about living a meaningful life with/without on-going symptoms (Anthony, 1993) (Chapter 1). It should be noted that not all participants will agree with the term 'mental health recovery' or believe that it is possible for them. Equally, this study has chosen to use the term personal narrative rather than the more common recovery narrative or 'story' because recovery narrative suggests developed for other people's benefit not their own. Finally in mental health 'story' has the potential to be disbelieved (Chapter 2). It was important that as a group, the participants would be able to explore what these terms meant to them at an early stage of the workshop process:

#### **Discussion thread 6.21**

- 'You have got things like what is hope, what is recovery, as generic topics. You have got trust, boundaries, keeping safe as another. You have got different medias. What is personal narrative, benefits of it. And then aspects like who is the audience, how much to share, what do you include? What do you reckon? In terms of session two, so it is our first working session, we have got the ... and there is that flow between as well. We have got people coming that don't ... we live what is recovery and what is hope' (Sam 587-93)
- 'Where do you see that fitting into what we are doing?' (Peter 594)
- 'So if we turn it into one ... would you like a session where by the end of the session people have explored what is hope and what is recovery?' (Maggie 595-6)
- 'I have grouped them...The first thing to me is what is recovery, hope and what are a personal narrative and a recovery narrative? They, to me, group together. Then the

benefits of developing a personal narrative, and that may well come at the next session because it gives people time to think about it. So what are the benefits, how do you keep safe, who are we speaking to?' (Ellie 601-606)

- 'Priority rather than session. So recovery, hope and what are they, personal narrative and recovery. That is one. Then I would say the benefits of developing a personal narrative' (Peter 608-10)
- 'So we don't want the boundaries and keeping safe and trust? (Sam 611)
- 'Not yet no' (Ellie 612)
- 'I would have them first [session 1]' (Maggie 613)
- 'Oh the boundaries is the group agreement, I thought we had already done that' (Ellie 615-6)

The above negotiation about the content of session two was a good example of PAR in action - the interplay between co-researchers that was necessary to reach each and every consensus-driven decision. Similar negotiations occurred for every session plan. This process was time-consuming (and at times frustrating) but that is an important characteristic of PAR and allows the balancing of power between researcher and co-researchers. The result is greater than the sum of each person's input.

Session three '*Mechanics of the Narrative 'bits and bobs'*' focused on the use of different media to develop narrative. The advantages and disadvantages of each medium were fully explored in Chapter 2. The value of session three was to suggest that anything is possible:

*'Individual choice, interest and expertise. That is encouragement saying we don't all have to be doing this the same way. I don't think it needs to be any more than that. It is giving people permission to ...' (Sam 810-13)*

Emphasising choice encourages agency and decision-making. It also nods to skills and interests – the person rather than the illness (Slade, 2009). These are important factors in recovery (Leamy et al., 2011, Bird et al., 2014). Some co-facilitators may need encouragement to pursue non-written media because it is likely to be easier to promote the written word (it also has resource implications).

Session three also focused on helping participants get started by offering examples of different narrative techniques including: drawing a time line (Figs 4.1-3);

storyboards; and Tree of Life. Different techniques may be useful for different people:

*'Because this is the introduction to different kinds of ... so this would be here and that would be there. In some ways you want to get people to be having a go and maybe doing a timeline or something' (Sam 794-6)*

*'I think this should be the working. We can hand a storyboard out here for people to start jotting things down as things about their life come to them' (Jodie 894-5)*

### **Listening and sharing**

Listening and sharing were considered to be key elements of the workshop programme - for participants to be immersed in the narratives of others – to be offered the sense of hope and what was possible. It was hoped that participants would have the opportunity to: listen to a variety of personal narratives (hopefully developed using different media); listen, explore and reflect on the process with others; consider the benefits and difficulties that others have had when developing their narratives; and begin to share their own narratives with others in the group.

*'if we were able to get someone to do their narrative and actually talk about how they impacted other people... so say this is the stuff that we are going to cover and it would be really useful to not only hear a part of the narrative, or whatever, but actually then that person say it was really hard writing about my mother or talking about myself as a mother and the impact it has had on my children. So you bring in through the narrative listening here, these are the delivery aspects and then actually so how was it? So what was it like doing it that way – if we have got someone here doing it with a different media? If we just listen to someone's story that is just listening to content. We get a lot out of it in terms of we are not alone or oh you have had that sort of experience. So you get that learning but then they can sort of say well this week's session is around voice of others or using different media, can you just bring into your discussion a bit about that. So you are reinforcing' (Sam 914-927)*

Delivering content can be process too. It is suggested in session two that the first narrative heard is one of the co-facilitators:

*'What Elllie said is she looked at the topics and this, which I said to you all, and she wondered... whether the starting point should be someone's personal narrative, a facilitator or something. Because she suggested we are powerful and inspirational in the beginning (Sam 79-84)*

*'I really feel that the facilitator's story should be on the first [working] session. Because it is the thing that humanises you, brings you on the same level. That is the hook that connects us with people and that is when they identify. It is the first thing that people want to hear' (Ellie 92-5)*

As Ellie suggested, it might help to humanise the co-facilitators and it will model the importance of the peer model. It might also allow the participants to feel able to start to share aspects of their developing narrative.

Chapter 2 concluded that listening to and sharing narratives were considered to be key processes in supporting mental health recovery. It emerged from phases 1 and 2 that the decision to share their narrative was not always a straightforward one. Session four '*Plain Sailing and Stormy Seas*' – the ups and downs of creating and sharing your personal narrative - focused on key issues (positive and negative), and the possible emotional impact that participants needed to consider when deciding if and when to share their narrative:

#### **Discussion thread 22**

- '... so what do we want for the outcomes for plain sailing then?' (Sam 840-1)
- 'It is about considering whether you are sharing or not and who you are sharing with" (Sam 842-3)
- 'Because it might just be for yourself. You might be doing this to keep it for yourself and not want to share it yet' (Maggie 844-5)
- 'I think the voice of others is very important' (Sam 846)
- 'Even if you are keeping it to yourself there are still others in there' (Sam 847)
- 'And thinking about other people in our narratives' (Sam 848)
- 'I think the thing is as well if you don't want to share it you don't have to, and that is really important because some people are really nervous, but then they naturally start to share anyway' (Harri 849-51)
- 'And you think if you have got people's voices who were abusers as well in there, it is a really important ... but I think if we keep these fairly blank in terms of instructional output, that gives us time and space' (Sam 857-9)
- 'Because you can feel pretty scared and exhausted' (Sam 861)
- 'I'm always drained' (Jodie 862)
- 'It brings up all sorts of emotions doesn't it. And sometimes you are not expecting it because you have shared it before and another time when you share it again and somebody else might reflect with you and then you are like oh and take it in a different direction' (Harri 863-6)

One of the key issues to emerge from phases 1 and 2 was an issue that in practice is often not considered, but is likely to have a significant impact on the narrator, their sense of self and on their on-going relationships – 'the voice of others within our narratives'. Chapter 3 explored the relational ethics (Ellis and Bochner, 2000, Ellis, 2004, Ellis, 2007, Ellis, 2009) and technical considerations of sharing aspects of the lives of others within our own narratives. As part of the programme, it is crucial that

the ‘voice of others’ is considered. Participants could reflect on what to include in their narratives (at this point), what to then share and with whom. The intended audience is an important factor here, as is the underlying factors of keeping safe, confidentiality and trust. As the conversation above showed, there is an emotional impact of including and then possibly sharing the lives of others when we share our narratives of our own lives. This is equally true of listening to the narrative of others. Listening can effectively act as a mirror into our own lived experiences. It can lead to feelings of shame and guilt, because we may all tackle things differently. For example, I am, now able to talk about my role as a mother, Alice is not. Listening to others can be uplifting, inspiration and offer hope. They can resonate so reducing the sense of aloneness – but there is always an emotional cost. As Jodie states *‘I am always drained’ (862)*.

This exchange highlighted the importance of time and space to develop, share and reflect on their narrative. Sessions five – seven focus on this. Sessions five *‘Playtime’* – *‘doing it!* and six *‘Tinker Time’* – working on personal narrative is planned so that participants can work on their narrative in a supportive and safe environment. Session seven *‘Show and Tell’* is the opportunity to share their narrative (or parts of) with the group and to reflect on the process:

*‘what I have got here is so they have shared it, you have listened. A discussion of individual ... what was it like to share it and to hear the narrative of others? So very much a reflective piece’ (Sam 1003-6)*

Session eight with its emphasis on *‘Reflection and Celebration’* is an important point to complete the workshop programme. It is acknowledged that participants may have been on an emotional rollercoaster in developing their personal narrative. It is important that they have the space and time to: collectively reflect (if they wish) on the process of developing and sharing their narrative and the impact that it has had on them; and to celebrate their achievements and those of others in the group. These are important factors, which may support the reframing process and therefore recovery.

Phases 1 and 2 emphasised the on-going nature of narrative development, so signposting of what to do next, where participants may access further support to continue the process and opportunities to use their narrative in public arenas if they so choose, are important. This support and opportunities are likely to differ depending on local resources and peer involvement.

Feedback is important. Session eight aims to gather feedback in two ways:

1. To offer participants the opportunity to provide positive feedback on each other (e.g. highlighting an individual's growth, developing confidence etc.), which can have a positive effect on sense of self.
2. To provide a programme evaluation, which can be used to make changes to further workshop programmes.

### **Theme 1: Why Develop a Personal Narrative?**

An underlying consideration of developing the workshop programme was whether individuals needed to produce a personal narrative for their participation and the programme itself to be deemed successful? This all or nothing stance is not conducive to recovery. It is likely that many aspects of the process of participating and the subsequent emotional responses will be beneficial and contribute to recovery. The workshop programme has been designed to build trust, confidence and reduce anxiety through the use of icebreakers. It is hoped that, as well as learning from each other, participants will feel less socially isolated because listening and sharing narrative supports bonding and reconnection. The programme also promotes growing agency. Individual's are not referred, are not from a specific group of service users and choose whether to participate or not, what to include and whether to share their narrative or not:

*'we need to establish that people are doing it for themselves and not with the intention of having to share it' (Jodie 698-9)*

They may also choose to work on their narrative outside the sessions and some will already have had ideas and developed aspects before participating in the

programme (in phase 2, Tina had written poems but wanted help to make them cohesive).

The peer-led programme model also supports the development of agency, through a more equitable distribution of power. In the pre-programme information and session one, potential participants are informed about the content etc. so that they can make an informed decision. At least one of the co-facilitators will be a peer and will share their narrative with the group, so reducing the distance between 'them and us'. The programme is built on the ethos that knowledge is held in the room and not necessarily only with the co-facilitators:

*'One of the key things, one of our mantras at the Recovery College, is just because I'm at the front doesn't mean you're the one that is learning. It is shared learning and I'm learning as much as you are learning. I'm not the only one with the knowledge in the room. The person sat next to you can have as much information and ideas as the person delivering the course' (Peter 1106-10)*

At the same time, acknowledging that each narrative is unique can contribute to sense of self and the split of the 'it/me' (Slade, 2009). A narrative can reframe lived experience and promote movement from 'it - I am the diagnosis' often characteristic of the early 'chaos' narrative (Frank, 1995) towards a more rounded 'me – I experience difficult times, but I am also....' (e.g. my autoethnography, Appendix 4). Supporting the use of different media may allow an individual's creativity to be re/discovered: '*people are incredibly creative*' (Jodie 127-8). This was true for me – at a time when my language and processing skills were poor, discovering art opened up a whole new world. It had also been acknowledged that 'states of readiness' were likely to differ and it was agreed that participants might need to go through the programme (or parts of it) or follow-up groups more than once. The key point is that narrative development is an on-going process (Robertson et al., 2017):

*'to me, narrative work is a lifelong process' (Sam 1076-7)*

The workshop programme is designed to be delivered in a supportive environment and be facilitated by empathetic people. Aspects such as boundaries and confidentiality, keeping safe and looking after oneself are integral parts of the

programme, which will be continually reinforced throughout. This safety net is crucial because it is acknowledged that '[developing a personal narrative] is not a benign process' (Sam 739-40). For example considering and including the voices of others, may lead to reliving difficult experiences (Robertson et al., 2017):

*'It brings up all sorts of emotions doesn't it. And sometimes you are not expecting it because you have shared it before and another time when you share it again and somebody else might reflect with you and then you are like oh and take it in a different direction' (Harri 863-6)*

Whilst listening to others may encourage participants to share, listening can also have a negative impact too:

*'I can feel that way when I was in a ward all day yesterday talking to service users. When I come home I'm absolutely shattered. It is not only doing your own but it is viewing others. And that is something that they need to be warned about. When you are sharing each other's stories it does impact you' (Jodie 867-71)*

### **Discussion thread 23**

- 'The only thing I'd say is that when people often think they have to reveal everything and it can be over-distressing for them' (Jodie 946-8)
- 'So get some of the elephants in the room out there early' (Sam 849)
- 'This is about what a narrative is. Also, your narrative develops as you get more confident' (Jodie 950-1)
- 'That is what I mean about using those ones because then you can decide who you are talking to afterwards' (Peter 952-3)
- 'But it might equally impact on when you are developing it. If I want to go down this path and if I was to share this with my family I can't go down that path' (Sam 954-6)

The value of developing their narrative within a supportive group setting is important. Participants may be able to draw support from each other:

*'...you might have two very confident or very keen participants who want to show and tell, and you might find that after the break two other people who weren't as confident suddenly go oh and talk to the person in the break – oh you said that, oh I didn't realise. Then the other person will probably go come on you can do it. And they say well I didn't think I was ready but this is what I brought with me and then the facilitator says it is what you have got that is important. If you feel you can share it that is your opportunity. And then the group can give them help' (Peter 1136-43)*

The group process is the key:

#### Discussion thread 24

- 'The group themselves generates its own aura. And you would get a good week and a bad week and you will get a mixed week and I will come back and there is the feedback element with the other person at the end of it. Okay, we did this two weeks ago and was it me, was I off today or was it the group? Did we have a difficult group? And the person would say no it was the group. We were on form, the group itself came in in a bad mood, or the group didn't gel so well' (Peter 1350-6)
- 'And that is a really important component because you could say we do this work on a one to one. What I got out of phase two was actually the group process is key. In some ways it would be easier to do it one to one but it is the process' (Sam 1357-60)
- 'It is the shared knowledge and what we were saying about these weeks having Maggie supported and supervised, the safety net of someone being there as well, but sitting there and someone knows they can come along on a Wednesday and go oh we want to do playtime, if they aren't communicating externally with people and can only do it when they meet up they are coming in with their bit. They might not want to come and see us to talk about this but they might know another person in the group who would go oh I'm glad you are here, what do you think of this? Because they found a little person they trust' (Peter 1361-9)

#### Theme 5: Participants

It was decided that participation should be open to any service users and others with an interest in mental health and developing their narrative. No referral from mental health services was necessary. The key is not to exclude people:

#### Discussion thread 25

- 'Right back to phase two we didn't want it to be taken over by therapists and becoming a clinical intervention that it was all taken away and people who would be allowed to do the workshops would be determined by therapists and clinical assessment. I think that was what we didn't want because it becomes a therapy. I can see this in a therapeutic setting, it is perfect therapy...' (Sam 306-12)
- 'So when you think about the pack, when you think about how it is going to be written up and it lands on somebody's desk or somebody hears about it. You need a clear description of who it is being delivered to. So it is thinking about what that description would be. I think that is important because that will then impact on how you run these sessions. And going back to the point ...' (Maggie 313-7)
- '... personally there is always somebody worse off than me, and somebody better off than me. I would never put a value on anybody's experience. If you wanted to come to this workshop, as far as I would be concerned you have lived experience and this can be as equally valid to carers. Even though they might not have been in services it is of equal value to carers and we would be precluding experiences and things to share, all sorts of things. It is about people who can and are able to effectively share their experience' (Jodie 318-25)
- 'In the group Recovery Community in Portsmouth, they work on the basis that they don't exclude anybody. If you want to do this, you have mental health issues, interest in ... because there is an awful lot of service avoiders as well. I don't want to get into this we are only open to secondary service users who have been sectioned because then we might as well go down the therapy route' (Sam 326-331)
- 'Because further down the line I would like to see this everywhere' (Sam 333)

However it may be necessary to discuss with potential participants their readiness to develop their narrative (but this will be done in partnership with the co-facilitators).

### **Theme 7: Choice of Media**

It was important that participants be able to choose the medium/media that they wished to use (although this might have resource implications). Built into the workshop content is the opportunity to use different techniques (e.g. storyboards), watch and respond to digitally produced narratives (e.g. YouTube and digital stories) and listen to the narratives (and reflect on their process) of others that have been developed in a range of ways:

#### **Discussion thread 26**

- 'So the people know what we are going to be doing for the next six weeks is not just going to be talking about doing a written one because if people leave the first day assuming it is just going to be written and they are not aware of all the possibilities, they might not sign up for it' (Peter 161-4)
- 'So you could frame that as lots of different ways of doing narrative and we are going to explore this over the workshop' (Maggie 165-7)
- 'That leads them to the peer story or the peer's perspective as an example to lead from' (Peter 168-9)
- 'I'm very keen when people are doing their narrative and sharing their narrative that we are drawing on people with lots of different examples, not just written narratives but there might be people using photography' (Sam 170-2)

In Chapter 2, research suggested using different media could have different effects and emotional impacts. For example, photography and art may allow a greater emotional distance; which could enable some participants to develop their narrative. There were a number of concerns with just emphasising narrative development using the written word (cognitive and concentration difficulties, English as a second language and learning disabled). Equally, some media such as art and poetry can be off-putting because people think that they are not good at them. So it is important for participants to be able to use their agency and choose a medium that they are interested in, may have expertise in and potentially already have the equipment to use.

### **Theme 9: Workshop Facilitation**

Good and flexible workshop facilitation is the key to the successful delivery of the workshop programme:

*'I wouldn't really want it to be so prescriptive that you lose the creativity of the individual facilitators' (Sam 1133-4)*

The facilitators will link theoretical content with process and 'doing' activities. Good facilitation creates the pace and the flow of the sessions. It requires skill and subtlety to: keep the session plans on track; allow for deviation when necessary; to provide balance between being directive and enabling supported organic learning; and sometimes to just be there:

*'But I spent a lot of time as a facilitator in the later stages of just sitting next to somebody chatting and they would take me through their storyboard, or whatever. So it is doing with support and time and not feeling rushed' (Sam 1091-4)*

Good facilitation requires working with the participants that are in the room:

#### **Discussion thread 27**

- 'to me every time you run a group you are running it differently because if all the knowledge is in the room...' (Sam 1312-3)
- 'it is about the people that turn up' (Peter 1314)

Especially at the beginning of the programme, facilitators are potentially inspirational and powerful role models (hence importance of sharing their own narratives). They may also be seen as 'holders of the knowledge' and therefore more powerful than the participants. It is the role of the facilitators to model balanced power by modelling co-delivery and reinforcing that 'the knowledge is in the room'. Throughout the course of the programme, the facilitators will also support the development of trust, confidence, agency, sense of self, whilst providing a safety net. All are important factors in contributing to recovery (Slade, 2009, Leamy et al., 2011).

As this study is concerned with the development of the workshop programme, the training programme for the facilitators (Train the Trainer) will be developed as part of the implementation of the workshop programme (Post doctoral):

#### **Discussion thread 28**

'Yes there will be facilitator training. It is not part of this but I wouldn't dream of asking someone to facilitate this without some guidance and training' (Sam 494-5)

'I think to deliver it you would probably have to do the equivalent of the train the trainer thing. But that is not for us' (Peter 496-7)

'Train the trainer will come later' (Maggie 498)

'Don't you see as well here the importance of good facilitations in terms of the training package further on' (Sam 708-9)

#### **Theme 10: PAR Process and Facilitation of Focus Group**

In cycle 3 the key task was to populate session plans. The PAR process of negotiating, debating and placing each topic on the blank session plans highlighted a number of factors. As co-facilitators, we made decisions for topic placement. The content placement debate showed that the placement for some topics was fairly arbitrary. This process emphasised the co-researchers': motivation, skill and effort; judgement based on experience of developing our narrative, group facilitation and lived experience. This level of debate and negotiation for each decision highlights how the PAR process can slow everything down:

#### **Discussion thread 29**

- 'I think from my experience here of working with people to develop the narratives, one of the criticisms would be that it is too top heavy with that kind of stuff and not enough ...' (Sam 886-80)

- 'That is why I was saying moving them around because I'm thinking that we are waiting until this week before we get any doing. I would be happy getting stuff doing here. But it is in the context of how you get the doing going. And it has got to be relevant doing for the sake of doing' (Peter 882-5)

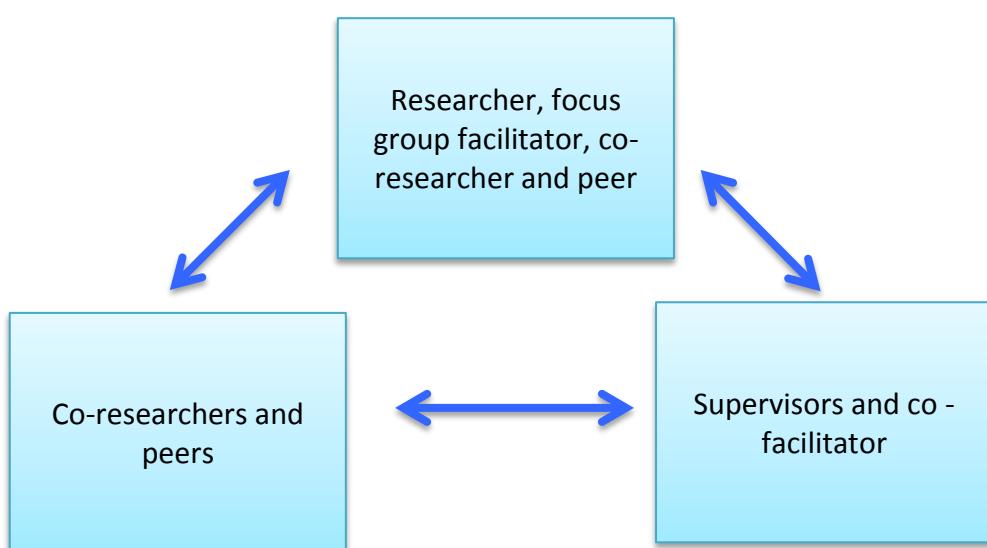
- 'People will start to do. This is the listening, sharing, working is the doing' (Sam 893)

- 'I think this should be the working. We can hand a storyboard out here for people to start jotting things down as things about their life come to them' (Jodie 894-5)

The PAR process produces additional richness to the output, but is balanced by the slower process of achieving it. Even here, there is a modelling parallel - participants will need time and space to develop their narratives. Yet, at times, I as the researcher and the focus group facilitator was having difficulty allowing the co-researchers time and space to explore what they were being asked to do (including deciding on the underpinning philosophy and framework of the programme) and the decisions that I wanted them to make (and the need at times to be pragmatic), 'we

*are not on about participation, this is delivery' (Sam 356).* In retrospect, part of my struggle was having my supervisors in the room and taking part, because I was aware that they had their agenda – they wanted me to achieve my output requirements so that I would have enough material to write up for my PhD. All these individual tensions and motivations interlinked (and were separated from the task of the required output).

**Fig 6.5 Possible interactions in the focus group**



Yet the output, my growth as a researcher, a facilitator and as a peer was richer for it.

The PAR process throughout phase 3 highlighted other strengths of the methodology too. In cycle 3, Alice and Ellie were unable to attend, but offered their comments via email. Jodie had been unable to attend cycle 2, so was brought up to speed at the start of cycle 3:

*'What we did do Jodie was originally we said we were going to have six sessions but in the last focus group session we decided that we wanted eight. One was very much an introductory one. Because we were sort of saying that it might be that people would want to come to the first one and think actually I'm not ready for this yet. It very much was a stand alone, this is what it is about. And session 8 was very much a where do we go from here, and do some showcasing'*

*and some celebrating' (Sam 17-26)*

The sense of participation not having to be 'all or nothing' is particularly important in mental health – allowing co-researchers to contribute and attend when they were able is important modelling for recovery. All contributions were equally valued. It also modelled what we were trying to achieve in the workshop itself. There were no criteria for how much individual co-researchers should participate or contribute. The focus group process was important for the co-researchers. Some of the co-researchers were socially isolated, so the regular meeting helped reduce this sense of isolation. Building each session, by putting together learning outcomes and topics (attempting to make sense and develop consensus) helped to promote growth in self-esteem (being a part of something that was important). Group discussions were characterised by negotiation, bouncing ideas around, agreement and confirmation of ideas and opinions. There was also disagreement concerning topic placement and the use of volunteers as co-facilitators. In particular, Jodie felt very strongly about it:

#### **Discussion thread 30**

- 'The minute you mention volunteer I'm out' (Jodie 532)
- 'I was just using that as an example because you were saying that you can't always get the people to run the groups. Sometimes if you haven't got two people to run it, sometimes a volunteer will step in and say I will do that for you for this moment until ...' (Harri 533-6)
- 'But your volunteers are service users aren't they?' (Peter 537)
- 'Yeah' (Harri 538)
- 'That is the key bit. They are not a random volunteer coming in off the street. I started as a volunteer' (Peter 539-40)
- 'I started out as a volunteer myself so of course when anybody else says to me can I volunteer I am like oh yeah you can, and then I'll help them to move on and do different things as well' (Harri 541-3)
- 'Can I suggest we come back to that' (Maggie 544)
- 'I think in a way that is really important. But if we don't have this [session plans] we have got nothing anyway' (Sam 545-6)

As the researcher, it was important that I informed the co-researchers what was planned for the implementation part of the workshop programme and how I intended to write up the material for phase 3:

### **Discussion thread 31**

- 'I envisage after my PHD that the post doctorate work will be around the pilot and in terms of you are starting to develop the package that goes with it, the training, and trying this out. That is what the pilot is about, and actually putting ... now we have got some bones it is putting the meat on in that thing' (Sam 1242-45)
- 'It will be a final part of the PHD, we can close the PHD with a really clear description of what goes on and the future plans and we will bring it to an end' (Maggie 1256-8)

One of my tasks as the researcher was to explain that this study was the first part of the developmental process – that the workshop programme will evolve over time:

### **Discussion thread 32**

- '... we may have got a bit side-tracked on the last session in terms of we were looking at things maybe phase ten, phase eleven, thinking about WRAP – they are still developing WRAP 20 years on and it went through various incarnations and focus groups and all that sort of stuff. And actually whilst trying to focus on the perfection we have got to get to the perfection and it is going to be a number of ...' (Sam 1302-7)
- 'I think it always has to evolve because of society and the environment they are in. We will look at how services have changed and things like that' (Maggie 1308-9)

Whilst the co-researchers acknowledged this, it was still apparent that they wanted the framework, scheme of work and session plans to be complete now - to include everything, to cover all angles and eventualities, having decided on key factors such as location (in/out of NHS settings), co-facilitation issues etc. This was impossible and undesirable without further development and trialling. At the very least, the pilot should highlight what worked well and what needed tweaking. Whilst the peer-led aim underpins the programme, exactly how it will be implemented is for the next stage.

### **Theme 2: Framework and Model**

The discussion of the underpinning workshop model and framework continued in cycle 3, with the final consensus agreed by the end of the cycle. The model is the underpinning philosophy of the workshop programme – peer-led, co-produced, co-delivered and (eventually) co-attended. The framework reflects the key aims and essentially the practical elements of how the workshop programme should be delivered. The decisions made throughout phase 3 (Table 6.12), form the

framework principle, that overarches the scheme of work and session plans (Box 6.4).

**Table 6.12 Summary of Framework**

Theme	Principles	Rationale
<b>Structure of Workshop</b>	<ul style="list-style-type: none"> <li>- Follow the underpinning principles but be flexible and not too prescriptive</li> <li>- 8 sessions (2.5 hours long)</li> </ul>	<ul style="list-style-type: none"> <li>• If the workshop programme is to be rolled-out after the pilot and its evaluation, it is important that the programme is flexible enough to support local conditions, facilitation and resources</li> <li>• Session 1 is informative and allows people to make a choice whether to continue. Session 8 is a celebration and showcase. Sessions 2-6 are the working, developing a personal narrative ones</li> <li>• 2.5 hours (including a break) allows enough time to cover the content and activities without being too onerous</li> </ul>
<b>Workshop Education and Content</b>	<ul style="list-style-type: none"> <li>- Follow the aims and objectives of the developed scheme of work and the session plans</li> <li>- Therapeutic not therapy</li> </ul>	<ul style="list-style-type: none"> <li>• Both the scheme of work and the session plans have been developed to provide a balance between: gaining understanding and knowledge of the issues and practicalities of narrative development; and the time and space to develop and share their personal narrative within a supported environment</li> <li>• Be clear what the workshop programme is and what it is not</li> </ul>
<b>Participants</b>	<ul style="list-style-type: none"> <li>- Open approach – no referral, formal assessment or formal diagnosis needed</li> </ul>	<ul style="list-style-type: none"> <li>• Issue of who decides what mental health is and who is mentally ill? Working together as co-facilitators – in the spirit of recovery and increased agency, the peer and clinician can mutually navigate and support participants to develop their personal narrative</li> <li>• The workshop programme was not designed to be used as an assessment tool or a diagnostic intervention</li> <li>• Referral and/or formal assessment close off access to the many. It is important that if individuals consider themselves to have mental health issues and are interested in developing a narrative then the workshop programme is open to them</li> <li>• Covers service avoiders</li> </ul>
<b>Timing</b>	<ul style="list-style-type: none"> <li>- When participants consider themselves ready to participate</li> </ul>	<ul style="list-style-type: none"> <li>• Participants can choose when they feel ready (because everyone is different)</li> <li>• On starting the programme, a participant may need to stop and come back at a later date and/or redo sessions</li> </ul>
<b>Choice of Media</b>	<ul style="list-style-type: none"> <li>- Participants should be able to choose the media for developing their narrative</li> </ul>	<ul style="list-style-type: none"> <li>• Each medium has advantages and disadvantages. Choice of media should be based on expertise and individual interest</li> </ul>

<b>Workshop Facilitation</b>	- Peer-led and co-delivery	<ul style="list-style-type: none"> <li>● At least one peer co-facilitator</li> <li>○ Should not preclude co-facilitators with professional standing</li> <li>○ Preferably both have lived experience (e.g. as a carer/partner/child of/parent of etc.)</li> <li>○ Both will have an interest in mental health, narrative development and peer support</li> <li>● Working with a clinician can add a different perspective and richness</li> <li>● Reduces the 'them and us' separation</li> </ul>
<b>Location</b>	- Preferably not exclusively tied to a healthcare authority or specific organisation	<ul style="list-style-type: none"> <li>● Working in partnership has benefits (resources, venue and support staff). Equally there is a concern about compromising the integrity of the workshop programme and/or the organisation imposing their objectives. Any organisations that express an interest in delivering the workshop programme will follow the framework and supporting documentation as set out</li> <li>● Ideally community based</li> </ul>
<b>Why Develop a Personal Narrative?</b>	- The process contributes to mental health recovery	<ul style="list-style-type: none"> <li>● A personal narrative is 'personal' and unique to the individual</li> <li>● It should not be prescriptive or its content and structure determined by anyone other than the individual</li> <li>● Individuals will have differing motivations for undertaking the process but it should be for the benefit of the individual</li> <li>● The process of developing a personal narrative is not benign. There is likely to be a strong emotional impact from the work, which should be supported within the workshop programme.</li> </ul>

### **Box 6.3 The underpinning framework principles for the developing a personal narrative workshop programme:**

It is believed that the process of developing a personal narrative can contribute to mental health recovery. The key aim of the workshop programme is to facilitate individuals to develop their personal narrative in a supported environment.

The workshop programme will be **peer-led, co-produced and co-delivered**. At least one of the co-facilitators will be a peer who has experience of developing their own narrative. It is expected that the second co-facilitator (e.g. a peer, a professional and/or carer) will have an interest in mental health and narrative development and may also have lived experience.

It is hoped that the workshop programme will be **community located** rather than being exclusively tied to a healthcare authority or specific organisation. It is hoped that this will encourage participation from a wider range of individuals.

The structure of workshop should follow workshop programme but be flexible and not too prescriptive. The workshop programme will be made up of 8 sessions (each 2.5 hours long). Workshop content should be based on the aims and objectives of the developed scheme of work and the session plans. Whilst the workshop programme can be considered to be therapeutic, it is not clinical therapy. Participants should be able to choose the media for developing their narrative, thus supporting expertise, interest and agency.

There should be an open approach to **participation** in the workshop programme. Participants will not need to be referred by mental health services or be formally 'labelled' as service users. It is hoped that the workshop programme will eventually be **co-attended** too. The workshop programme has not been designed to be formal assessment or diagnostic tool.

There is no formal '**timing**' requirement for participating in the workshop programme. For example, individuals do not need to be free from services or accessing services to participate. The timing principle is when individuals consider themselves ready to undertake the process of their personal narrative development.

**Table 6.13 Final Workshop Documents**

Name	Detail
The underpinning framework principles	The underpinning framework principles developed as a result of the work undertaken in all three phases of this study (Box 6.3)
Scheme of Work (Appendix 6.18)	Full Scheme of work developed from the discussions and decisions made in Phase 3
Session Plans (Appendix 6.19)	Fully populated session plans (including learning outcomes) developed from the discussions and decisions made in Phase 3

## 6.13 Further Reflections

### 6.13.1 Multiple Roles

In phase 3, I had multiple roles:

- Study researcher and author (e.g. determined the aims, objectives, workflow of the 3 cycles and what was written up)
- Focus group co-facilitator (organised and supported the other co-researchers)
- Focus group co-researcher (took a full part in focus group discussions)

This triple role had an impact on me and possibly how the focus group cycles were run. The competing demands of multiple roles required considerable reflection.

Being the study researcher meant that I had an overall perspective of the study as a whole. I had ideas on the direction of travel for phase 3 and the potential output that I hoped to achieve. I was aware that there was limited time (3 cycles of 2.5 hours over a three month period) and a limit of what I should expect from the other co-researchers. As co-researcher, I contributed equally to discussions. Yet as the co-facilitator for the group as a whole, I was responsible for keeping the focus group on task so as to achieve some output that would contribute to the development of the workshop programme (decisions regarding framework model, scheme of work and individual session plans). I also had to work with any ensuing group process, including supporting people to have their say. I was aware that as a result of my PhD research and previous teacher/trainer experience, I had considerable knowledge on narrative and workshop development.

This raised the issue of how equal co-researchers can be, when there are inherent power imbalances. Whilst PAR was chosen as a methodology because there is an attempt to have more equal power dynamics, the reality does not always match the aim. Although the overall aim of PAR is to involve and empower individuals through modelling a more democratic co-produced workshop programme, the approach can be criticised as still maintaining imbalances in power. Often these underlying power dynamics are not explicitly explored and discussed (powercube.net, 2018). In this study, I relied on my position as an 'insider' to reduce any power imbalances (including knowledge imbalances) as much as possible. On reflection, a discussion of possible power and knowledge imbalances might have been beneficial, bearing in mind that the reality of existing (if, unwanted) power imbalances were apparent and led to tensions for both my co-researchers and myself.

Given that I inhabited different roles within this study, my position in relation to power was very complex and oftentimes unresolved. This reflects the messiness, lack of clear boundaries, imperfect knowledge and power differentials that existed in this study and in real life. For example, in phase 3 cycle 2, the co-researchers wanted to continue the discussion about the underpinning philosophy. As the researcher and group co-facilitator, I felt the need to move the group forward. It was important to discuss the session plans content. I was aware of my tension and expressed it to the group; that without the session plans there was no workshop programme. I was also aware that my supervisor felt similarly (there were time constraints and that I needed enough data to be able to move the study forward). My supervisor suggested that we put some content ideas on a flip chart so that we could plan the sessions. I felt that if I did not show 'good enough' leadership, I was letting her down! Equally, the co-researchers need to be 'good enough' for me (e.g. Peter and Harri) was apparent. At the end of cycle 2 and 3, Peter asked 'if I was happy with the group's output?'

My status as researcher and academic (including my expectations for the study), and holder of the 'knowledge of narrative' ensured my socialised and internalised power was a key factor in how phase three progressed.

As the researcher, I controlled the workflow between cycles. I worked with the discussion material from each cycle and then produced the framework, the scheme of work and the session plans from it. I produced a coherent product from each cycle, which I then sent to the other co-researchers for comments. In effect, I was adding to the work of the focus group, outside of the focus group. This was in accordance with the PAR procedure that was set out for phase 3, yet there is a question of how equal I was within the process as a whole.

There was a conscious attempt to manage the co-researchers inside and outside the focus groups. For example, in the focus group discussions there was a sense that the other co-researchers were less pragmatic and realistic in terms of the workshop programme (especially in the early stages of delivering the programme). The discussions were often ‘blue sky’ thinking – everything possible should be in the scheme of work and it should aim to be relevant to all service users. Developing the workshop programme involved the interaction and discussion of practical issues layered with process issues layered with expectations of participants and co-facilitators. Whereas the reality is that this study is the first stage of a longer development process. Eventually, the workshop programme has the potential to go beyond mental health (because narrative development is a human need) and could therefore be marketed as a mental wellbeing tool.

My position as the study researcher, focus group co-researcher and co-facilitator reflects the real world messiness of using an ‘insider perspective’, working with co-researchers that I know and are known to each other. It adds depth and richness to the material but it is not without cost. Often there is concern in the literature about working with ‘vulnerable adults’ (Tee and Lathlean, 2004), but the ‘wounded researcher’ (Robertson et al., 2017) needs to be considered too.

#### **6.14 Chapter Summary**

Fundamentally, the workshop programme involves two key narrative processes:

- Developing a personal narrative
- Sharing personal narrative with others

Phase 3 was focussed on the development of the underpinning model, framework principles and supporting documentation to provide the structure for the workshop programme. As a result participants would be able to develop their personal narratives within supportive peer-led community settings.

The method for carrying out phase 3 was clearly outlined and explained, including the procedure that was followed to develop the themes and issues from each cycle that was analysed and then used to develop the documents for the workshop programme. Given that there were 3 cycles of the PAR focus group (with the resultant emergent data, themes and issues) and that each cycle built on the work of the previous one, it was important that the workflow plans (Fig 6.2) and the focus group attendance and participation (Table 6.1) for the 3 focus group cycles, was clearly outlined.

Having 3 cycles of co-researcher participation highlighted ethical concerns, such as how much should be expected of co-researchers? There were also noticeable tensions within my role as researcher, focus group facilitator and co-researcher that resulted in questions of PAR as a process, equity and power imbalances. These issues were reflected on (although not necessarily resolved) within the chapter.

This chapter was the culmination of the 3 phases of the study that resulted in the development of the framework (Box 6.4), scheme of work (Appendix 6.18) and session plans (Appendix 6.19) for the workshop programme. Its implementation and pilot will be the focus of post-doctorate work.

## CHAPTER 7 DISCUSSION AND FINAL THOUGHTS

### 7.1 Introduction

The aim of this study was to explore the process of developing a personal narrative and its possible contribution to mental health recovery. This final chapter provides a review of the study and its impact. The three phases of the study are summarised, outlining the journey that culminated in the development of a personal narrative workshop programme. This chapter reflects on the importance of this work in terms of the unique and innovative design (different methodologies allow emergent and generative data, where each phase builds on the work of the preceding one).

The application and positioning of this research in terms of previous research of narrative process and mental health recovery will be considered. Thus allowing the important theoretical, pedagogical and practical contribution of this study to the field to be acknowledged.

The strengths and limitations of the study are discussed in terms of its: practical and clinical application (the importance of a peer-led, safe and supportive workshop environment); theoretical understanding around the research process where both the researcher and the co-researchers are ‘wounded’ and ‘vulnerable’; the importance of a sound ethical basis; and the promotion of autoethnographic research within the Faculty of Health Science.

Reflexivity is at the heart of this study. The research question demanded, it as did Inhabiting my different positions within his study - as researcher, an ‘insider’, a co-researcher, a co-facilitator, a peer and a supervisee. Reflexivity adds to the richness of the emergent data; the connection between my co-researchers and me as the researcher; and ultimately the participants who will attend the workshop programme to develop their personal narrative. The need for me to be continually reflective throughout this study is a key strength – yet it also came at a price. This will be examined.

From the point of view of the service user and the clinician, translation of the workshop programme into practice is arguably the most important contribution of this study, in terms of mental health recovery. The future work needed to implement the workshop programme is outlined and discussed. Finally, dissemination of this study is reviewed (including planned publications).

## **7.2 Why I Chose my Research Question**

A recent addition to mental health service provision is the implementation of recovery colleges (Perkins et al., 2012). Using an educational (rather than medical or clinical) approach to mental health care (Sussex Recovery College, 2017), recovery colleges co-develop and co-deliver a range of 'recovery-based' courses which are co-attended by service users, carers and staff. Recovery colleges operate within educational environments (located in partner college campuses and non-clinical community settings). Courses are taught (not treatment) and attendees are students (not service users, carers or clinicians) who choose to study at the recovery college. Their aim is to: support understanding of mental health conditions; provide skills/tool development (e.g. WRAP (Copeland, 2013)); social connectedness (Slade, 2009); and a possible reduction in mental health service use.

*'Developing your Recovery Narrative'* is a course offered by local recovery colleges. As a recovery college trainer (in my previous role, outlined in chapter 1), I co-developed and co-delivered this course (2012-3). Using a version of the 'six-part storyboard method' (Lahad, 1992), the main aim of the course was to support people to think about their recovery journey (e.g. what helped and hindered) and to then consider sharing their narrative with others. The perceived rhetoric that informed the development and delivery of this course was that developing a recovery narrative had a positive contribution to recovery. It was how many of my co-facilitators and I had been trained to think about our own narrative development (which we were required to do as part of our role). The focus tends to be on developing recovery narratives in order to share with others to help improve hope around recovery. Also, recovery college students tended to be 'generally well' and therefore able to take part and attend the college. So their recovery narratives

tended to be positive with a sense of hope. It was, in some ways a self-fulfilling loop.

I was aware this perception that narrative development supported recovery (in the form that we taught) was based more on anecdotal evidence (myself and colleagues' personal experience – held up as testimonial models of recovery (Frank, 1995)) rather than a theory evidenced by formal research. In delivering the course, I realised developing a recovery narrative was not a benign process – there are potential positive and negative emotional and practical implications to people's lives (as phases 1 and 2 evidenced). These are discussed in my recent paper (Robertson et al., 2017).

This study was developed in response to these issues. To ensure that narrative development would contribute to recovery, the workshop programme was developed based on existing literature, narrative theory and the evidence that emerged from phases 1 and 2. Further, the workshop programme was developed appropriately following the principles of co-development (Lewis et al., 2017) (which was achieved using PAR methodology). This is evidenced by the resultant peer-led model, framework, scheme of work and session plans (from phase 3).

### **7.3 Where does this study fit with existing knowledge**

A narrative inquiry perspective was used as the over-arching methodology for this study. The research process and strategy were emergent and formative. There was an underpinning pragmatic rational for the design and methodologies chosen – autoethnography and participatory action research (Chapter 3) – to explore the process of developing a personal narrative. The desired output was a practical workshop programme that supported individuals to develop their personal narrative (Chapter 6).

The key concepts underpinning this study were the processes of narrative development and supporting recovery. It was clear from the literature review (Chapter 2) that there was very limited previous research on the process of

narrative development. This included studies that analysed recovery themes determined from narrative content rather than process (Wisdom et al., 2008, Holm and Severinsson, 2011, Scottish Recovery Network, 2011, Kalathil, 2012). The literature that looked at narrative development processes appeared to consider the process at the same time as when the development of the narrative itself took place – effectively within the same timeframe (Lysaker et al., 2010). As a result there was little time for reflection afforded by the distance of time.

A similar criticism could be levelled at phase 1, as I wrote my autoethnography and then analysed both the content and the process. However, I had significant experience of developing my personal narrative in different formats and to a range of audiences. Also my analysis was carried out over a period of nine months. This allowed a significant opportunity to reflect on the process (and I continue to do so). Equally, the majority of my co-researchers had developed a full narrative and had been using them in a number of settings and to different audiences. This allowed for a greater opportunity to retrospectively reflect on their process and how it might have contributed to their recovery. This study has shown that distance and time for reflection were two important narrative process factors that emerged from the three innovative phases of this study and were incorporated into the workshop programme. The emergent themes were an important contribution to the body of knowledge of the process of developing a personal narrative and its potential contribution to recovery.

In terms of implementing the workshop programme, recovery tools such as WRAP (Copeland, 2013) and Recovery Star (Mental Health Providers Forum, 2013) provided examples of different programmes used by services to support aspects of recovery. Alongside developing community links, these tools promote improving and gaining valued social roles and developing self-management skills. Both are predominantly used in clinical settings and are seen as clinical tools.

Given the important benefits of narrative development evidenced in this research, there is a scarcity of interventions that support individuals to reframe their

experiences through developing a personal narrative. Apart from the 'recovery story courses' in recovery colleges and their inherent weaknesses (e.g. lack of therapeutic support and focus on benefits to others, not self), current service provision does not directly address this potentially crucial task of recovery in a systematic and consistent way. This is what this study has attempted to rectify. There has been some recent interest in Narrative Therapy as a therapeutic intervention (White, 2014, Avon and Wiltshire Mental Health Partnership NHS Trust, 2014) but it appears to be very limited and dependent on individual practitioners offering it as part of a 'toolbox' of interventions. Recovery Star and successful peer-led delivery of WRAP training suggest that the narrative workshop programme can and should be implemented.

In conclusion there was limited previous research on the process of developing narrative with/without consideration of its contribution to recovery. There appeared to be limited therapeutic and clinical narrative work taking place, and the basis of the existing 'recovery story courses' in recovery colleges appeared limited and not specifically linked to the current underpinning mental health recovery theory and evidence (Conceptual Recovery Framework (Leamy et al., 2011, Bird et al., 2014) and Slade (2009) Personal Recovery Framework, which this study draws on.

With the limitations of existing research within the literature, it was important to fully understand narrative as a theoretical concept by exploring seminal narrative literature and narrative critique (Bruner, 1987, Kleinman, 1988, Polkinghorne, 1988, Bruner, 1990, Frank, 1995, Craib, 2003, Chase, 2013). This enabled a sense of the 'what?' 'why?' and 'value?' of narrative to be fully understood and incorporated into all aspects of the study: design – the importance of the 3 phases; analysis; evaluation and reflection. Fundamental processes of narrative development (not limited to mental health) were evidenced in the data that emerged from this study.

Both Frank (1995) and Kleinman (1988) provided a framework for understanding 'illness narratives' (such as my own). This knowledge was used to analyse narrative development processes and to consider the importance of narrative development in the separation of the 'it/me' characteristic in the recovery journey (Slade, 2009). Their work supported my understanding, 'teasing-apart', analysis and reflection of my continued tensions between: my recovery journey (the complete set of vignettes); my illness identity (vignettes 15-26); being well and then unwell (vignettes 35-49); and the re-emergence of my identity as Sam (vignettes 49-54) – my separation of it/me.

Likewise, Craib's (2003) critique on 'narrative truth' was fundamental in the consideration and analysis of narrative process, such as narrative voice, relational ethics (Ellis, 2009) and the methodological issue of verisimilitude (Ellis et al., 2011). Narrative voice and relational ethics emerged as important processes that affected the development of a personal narrative. Developing one's voice, especially one that had been silenced through mental illness, can be affirming and contribute to recovery. Unsilencing one's voice is especially important in developing a personal rather than a recovery narrative, because the process is about the individual rather than for the benefit of an audience. The presence and impact of relational ethics (the voice and role of others within our own narratives) was a surprise. At the time I developed my vignettes, I was not aware that each was developed from the voice of another (Robertson et al., 2017). I had not consciously appreciated (nor had the co-researchers) the voice of others and the implications that it had on on-going narrative development and intimate relationships. In teasing this out through my analysis in phase 1 and the focus group discussions in phase 2, we were able to ensure that these issues were incorporated into the workshop programme.

An important aspect of developing a narrative voice and the willingness to talk about others within our narrative is the need to be believed – it is the individual's truth. Whilst it is correct to acknowledge Craib's (2003) difficulty with 'narrative truth' (such as omissions, embellishments, mis-remembering etc.), verisimilitude and the value of developing a personal narrative to the individual's recovery

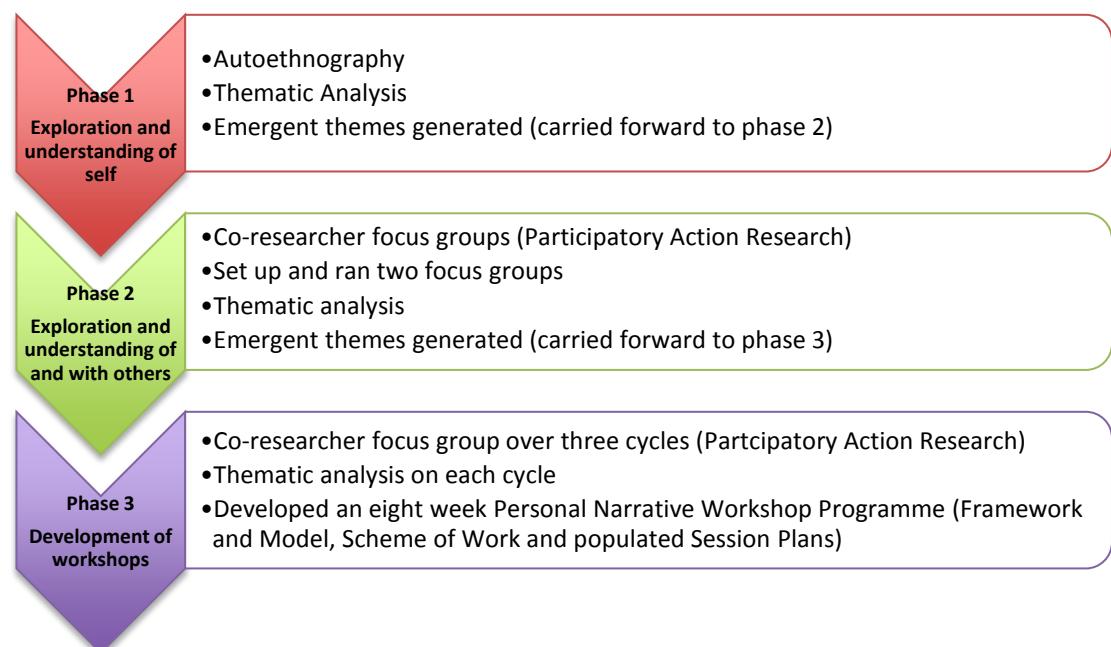
outweighed a theoretical and unrealistic consideration of any universal narrative truth.

### 7.3.1. Three Phased Study

Traditional mixed methods approach in health research integrate quantitative and qualitative data collection and analysis (O'Cathain, 2010, Bowling, 2014). Therefore benefiting from the strengths attributed to the different paradigms (and mind-set) including: increased confidence by triangulating and increased comprehensiveness. This study has taken a pragmatic approach, using two distinct qualitative methods (autoethnography and PAR) to explore the process of personal narrative development and to then practically develop the workshop programme.

The three phases of this study require a pragmatic approach, which enabled an exploration of the process of narrative development and the emergent themes to be translated into a practical workshop programme. Phases 1 and 2 were fundamental building blocks for the translation of narrative and recovery theory, co-researcher lived experience of narrative development into developing the phase 3 workshop programme that will be piloted in phase 4.

**Figure 7.1 Phases and Methodologies used in this study**



The design of this study was novel and creative. Using both autoethnography and then participatory action research (in focus groups and then in a three cycle focus group), I was able to explore and build upon the process of narrative development from an initial introspective position (autoethnography), to one that involved a group of co-researchers who had previously developed their narratives. This knowledge and insight was used to jointly develop the narrative workshop programme. As a result the locus of interest, spread naturally from introspection to confirmation with other experts by experience to developing a workshop programme for people earlier in their recovery journey. Using the phases as building blocks, I (and my co-researchers) lived the principles of both methodologies (verisimilitude, democracy, given voice to, reducing power imbalances etc.) and were able to model how we expect the workshop programme to be delivered and facilitated - as co-produced and peer-led. Equally this involved me as the researcher inhabiting different roles, which was not always easy, but was necessary to get the richest data from each phase.

Phase 1, the further development of my personal narrative, generated themes and considerations (e.g. the multiple voices within our narratives, the visceral impact and the on-going nature of development), which suggested that, whilst narrative development contributed to my recovery, it was not a benign process. The emergent data was used to inform and add to the discussions of the focus groups in phase 2. Co-researchers (who had already developed their narrative) reflected on their process. This emergent data was carried forward to phase 3, where it was used to generate an innovative solution in terms of developing the eight week workshop programme to support personal narrative development. This was a practical and novel implementation that was designed to fill this important gap in service provision.

My autoethnography was written with the expectation that any data that emerged from it would be used to inform the development of the workshop programme. This might suggest that my autoethnography was therefore written in a particular educational context. This was not the case as my vignettes were developed as a

stand-alone piece of personal narrative development. I had attempted to do this previously, but abandoned any attempts because the timing was not right. At the time of writing my autoethnography, there was no conscious consideration of how the vignettes would be used. The vignette content stood for itself as a reflection of my lived experience. They were about rebalancing and reframing my lived experience; regaining my voice; making explicit what was implicit; and regaining ownership and agency. I used the implicit knowledge that I had acquired (in terms of the mental health world, loss, power and stigma) in my time as a service user to help separate the me/it (Slade, 2009). I became Sam again.

However, I was aware, that I was developing my vignettes as part of a PhD, with a specific research question, aims and objectives. This work was being carried out within a particular research environment (Health Sciences). Therefore the vignettes would be used for a purpose. The vignettes needed to be analysed and situated to ensure academic rigour. The content of the vignettes and my process in writing them, were then used to inform phases two and three of the study.

Undertaking my autoethnography within Health Sciences (where mainly empirical research is undertaking) was probably the most novel and challenging part of the study. Initially, I had little understanding of the methodology, other than having read other service users' autoethnographies, which I had found fascinating. Having developed and shared my recovery narrative, I felt that it was worth pursuing. I was also aware that by developing my personal narrative, I would be modelling what I was asking people to do in the workshop programme. I would potentially experience some of the emotions that they might go through. As a result I developed a case to counter criticism of the methodology (Richards, 2008) and to show how autoethnography would be the foundation for all subsequent work.

As previously detailed, there is growing literature on autoethnography ((e.g. philosophy, methodology and examples of autoethnography across a range of disciplines (for example, Deegan, Ellis, Tilmann-Healy, 1996, Sparks, 2002, (Scott, 2014). In a critique of the representation of human suffering (individuals'

narratives) in cognitive behavioural literature (which reduced the narrative to fit in with the needs of the CBT model), Grant (2011) argued for more attention to be paid to listening and incorporating the individual's narrative into therapeutic practice: Listening to what service users want to say (and consider the value of sharing this), rather than only the parts that fit with the treatment plan. This, he stated could have implications for mental health nursing practice in terms of enabling a better therapeutic alliance. Yet, apart from the publication from this work (Robertson et al., 2017), there appeared to be very limited literature on the process of autoethnography development within mental health recovery (Sharma, 2014, Fixsen, 2016), or physical health recovery (Langridge, 2017, Parke, 2017). Without explicitly discussing their process of autoethnographic development, they acknowledged key process themes that also emerged from both phase 1 and 2 of this study: recovering and rediscovering identity; reclaiming a sense of self; distancing self from the medical illness identity; and developing and strengthening a sense of agency. Themes that this present study incorporated in the workshop programme design in phase 3. The literature used their autoethnographies as an end in themselves. There appeared to be no literature that used autoethnography to develop practical applications to support people to develop their narratives. This highlights the importance of this current study in adding to the literature.

### **7.3.2 My Varied Roles – the Importance of Reflexivity**

This research was undertaken within an 'insider perspective' (Richards, 2008), as I (the researcher) have lived experience. I knew and had worked with the majority of the co-researchers (as a trainer and as a peer). I had background knowledge that was not discussed in the research room, so was not a part of the emergent data, yet I was aware that this information affected the co-researchers' individual process. I had the potential to be the voice of another within their narrative and certainly within the analysis of their narrative development process. As such I was continually mindful of the relational ethical issues involved in my work as the researcher who had the responsibility to write up and analyse the data. I made the decision to only work with the data offered by the co-researchers within the research meetings.

Reflexivity (and the need to be continually reflective) is at the heart of this study. The exploration of the narrative development process is a reflexive process in itself. It is strength of this study. Yet the practice of being reflective is not without its difficulties. Being an insider and using three different research phases, required continued reflection, as each phase demanded a different research position, with differing tensions to be acknowledged and negotiated.

Phase 1 (my autoethnography) was an introspective and reflective description, analysis and contextual commentary of my personal narrative. In phase 2, I facilitated the focus groups – I ensured their smooth functioning without contributing to it. I supported the co-researchers to have a voice and to consider their narrative development process. In phase 2, my role was traditional (facilitating, observing and recording data in the focus groups. In phase 3, I had different, yet often competing roles. I was still the researcher, a full co-researcher (fully involved with the co-production of phase 3 output) and the focus group facilitator (with considerable teaching and facilitation experience). Within this role, I modelled how I hoped the workshop programme might be delivered. Finally I was a PhD supervisee – this added a tension of staying true to the democratic PAR process and producing the necessary data to develop and write-up the workshop programme.

Using an insider perspective left me vulnerable in terms of the impact of my introspection and working with others. It forced me to question who I was (given the multiple hats that I wore, which at times felt artificial), my on-going relationship with others (my family and co-researchers) and the value of my research. Its impact is still felt a long time after completing the study.

#### **7.4 Strengths and Limitations**

The over-arching strength of this study was the design itself. The three-phase approach was adopted with the practical aim of designing a narrative development workshop programme. The design was both creative and pragmatic. In developing this three-phase approach (especially using autoethnography as a methodology), I

gained experience of negotiating, discussing and defending my decision-making process.

In retrospect, my autoethnography was fundamental and added to the richness of the emergent data used in phase 2. Many key factors came to light as a result of writing and analysing my vignettes – important considerations for both phase two and three. For example, I found the writing visceral as I relived each experience, emotionally and physically. I felt despair, emptiness, fear, loneliness, loss, confusion, anger and aggression. At times I was unable to feel expected joy and happiness. This brought additional trauma. It was a deeply difficult and emotionally exhausting process (Robertson et al., 2017). I had not expected this. As an experienced ‘narrative performer’ (I had delivered different elements of my narrative as a teacher, trainer and conference delegate), I was used to deciding what to share, maintaining emotional distance and looking after myself.

Verisimilitude is the guiding ethical principle of autoethnography – work that is evocative, connects with others, believable, possible and coherent (Ellis, 2004):

*work is ‘judged in terms of whether it helps readers communicate with others different from themselves or offer a way to improve the lives of participants and readers or the authors own life’ (p. 12)*

The principle of ‘relational ethics’ - ‘do no harm’ – is a crucial dimension of autoethnography as a method, thus underpinning verisimilitude (Ellis, 2007). Reliving my trauma through my writing, and then analysing my process of reliving my trauma for the purposes of this study, caused me distress. Whilst, I had a support system (my husband, my academic mentor, my supervisors and my care-coordinator), this was only used because I had the tools to recognise (from years of therapy) and my husband had the awareness that my mental health was suffering. Within my Faculty, there was not a requirement or tradition that autoethnography needed any ethical committee input. Using autoethnography as methodology was novel and ground breaking within the Faculty.

Unlike phases two and three, there was no official ethical guidelines, boundaries or safeguards in place to support me in carrying out this work. As a result, I did not

consider the possible impact of this work. As Wolff (2009) suggested, ethics and 'relational ethics' are at the heart of autoethnology.

In my autoethnographical process, I did not look after myself. Reliving the trauma in order to write about it was not a conscious decision. I did not expect it to happen. I had assumed (perhaps naively) that I would be able to write dispassionately, from a distance that time, self-awareness and knowledge had afforded me (the reconstructed and reframed Sam). Yet the writing process transported me back to each and every experience. I became the toddler, the frightened child, the new mother, the challenging service user etc. I re-inhabited my surroundings, relived the emotions and interactions, and the physical sensations within my body. This re-enactment was addictive and I felt unable to stop – I needed to continually punish myself. To not look after myself added to the self-punishment downward spiral.

My husband supported me to stop writing and re-evaluate my autoethnography. He helped me to realise that I only wrote about difficult and traumatic experiences, which was not a reflection of my lived experience. As a result I added the positive vignettes. I am uncertain how an 'official' ethics framework and safeguards would have been helpful because I wrote from a position of verisimilitude. Perhaps though, I would have given more thought to relational ethics prior to starting the writing. In reality though, the writing highlighted the difficulties and tensions of relational ethics and the visceral nature of writing evocative autoethnography. As a result, I have discussed and presented on these important ethical issues. I have added to the debate about ethics, organisational support and systems and the unique needs of autoethnography.

I realised that in developing their narratives, individuals would be potentially reliving and going through further trauma too. Support for the individual and the peers that facilitated the workshops would be needed. Discussing issues such as: potential emotional benefits and consequences of narrative development; keeping safe by considering boundaries; the value of distance; what and how much to share;

and using support networks, were built into the scheme of work and session plans. Narrative development is not a benign process, so in implementing the workshop programme beyond the pilot phase, consideration needs to be given to ensuring facilitators are properly trained and supervised and that adequate time and resources are given to the workshop process. Each element of the workshop programme has been carefully considered and based on the emergent themes from phases 1 and 2. It is important that these elements are not lost due to time and resource expediency.

Ensuring that all workshop participants are supported to undertake this difficult work in a safe and ethical environment was a key consideration in the workshop development process.

Further, my narrative contained the voices of intimate others. This raised the issue of relational ethics and being considerate and respectful of the voices of others within my narrative and supporting others to do the same (within the workshop setting). I had no idea that in my previous narrative performances, I left out a key part of my lived experience – my role as a mother - which was/is fundamental to my mental health, recovery and who I am as a person, yet I unconsciously never talked about it. In phase 2, it was clear that others had similar difficulties: both Alice and Sunflower felt unable to describe and/or reflect on their lived experience as mothers. As part of developing my understanding of this issue: I conducted a narrative ethics literature search; attended a conference on relational ethics; presented on it at various meetings; and published on the subject (Robertson et al., 2017).

Developing my autoethnography and discussing their process with the co-researchers brought this major omission to light. Through my autoethnography, I realised that there are on-going tensions in my relationships with intimate others, which are complex and not readily resolved. It is hoped that the workshop programme will help others to explore these crucial relational ethical issues and the possible implications of including the voices of intimate others (e.g. family members

and even abusers) within their personal narrative. Including the voice of others (and therefore parts of their lived experience) or leaving their voice out and unsaid (and consequently omitting important parts of the developing narrative) are important considerations. In *Revisions*, Ellis (2009) suggested that the key intention of 'doing no harm' should be the guiding principle in what to, (and therefore, who to) include and what to leave out.

Providing a safe, supportive narrative workshop environment to reflect and discuss what all this means in reality is a priority for the workshop programme. One approach to supporting participants to consider the possible implications of including the voice of others, would be to use an adapted reflective tool such as Gibbs' Reflective Cycle (mindtools.com, 2018):

1. **Description** – Whose voice to include? Why? What?
2. **Feelings** – How did you feel? The original experience and/or relationship...  
How do you feel now?
3. **Evaluation** - How do you feel about possibly including this within your personal narrative? Positive and negative emotions.
4. **Conclusions**
5. **Action** – Come up with a plan e.g. how to include the voice of others: e.g. as composites, fictional or co-productive dialogues; asking the permission of the 'other voice' to be included or to provide feedback; and what to do if permission is denied.

This anticipatory reflective process could help the development of a reasoned and balanced decision and could support the workshop participant to better deal with the consequences (if any). Within the workshop programme, there is space for individuals to share their (already developed) personal narrative and process in developing it (e.g. how did their narrative process impact on their on-going intimate relations? Would they still make the same decisions on what to include and exclude?). Their knowledge and experience could further enhance the workshop

participant's anticipatory reflections. This will be considered and finalised as part of the post-doctoral phase 4 work.

Inhabiting such diverse research roles was another strength of this study, because it enabled rich emergent data to be generated at every stage of the study. This was both unique and innovative. The 'insider perspective' was crucial in all phases. Richards (2008) discussed the possible tensions of being both researcher as agent and researcher as the research object. In my evocative autoethnography, I wrote the vignettes (researcher as subject) and then critically examined and explored the processes involved in writing them (researcher as object). This was both a tension and a further strength of this study. Being the 'insider' and 'outsider' within my own story, required continual reflection and realignment. Unlike content analysis (in terms of much of the literature on mental health recovery), process analysis required a significant level of further process and reflection. This was also relevant in phases 2 and 3. Given that I had worked with/knew many of the co-researchers prior to the study, a level of trust existed that added to the honesty, the quality of discussions and the generative, purposeful contribution of the focus groups. This relationship impacted on how I represented their lived experience and narrative process in the analysis. I have continually reflected on my role as autoethnographer, peer, co-researcher, researcher and co-facilitator (such reflections are a contribution to the body of knowledge).

These strengths, give rise to possible study limitations too. Verisimilitude (Ellis et al., 2011) and 'narrative truth' (Bochner, 2002), rather than validity and reliability should be used to judge this work, although many of the emergent process themes generated from this study were supported by recovery theory and current recovery frameworks (Slade, 2009, Leamy et al., 2011, Bird et al., 2014). If as originally intended, my autoethnography had been a three-way dialogue with my sisters (both significantly older than me) focusing on our different interpretations of my mental health journey, the autoethnographical content and analysis may have turned out differently. Yet the key themes of 'others' voices', the importance of

sharing, the emotional impact of narrative development etc. would likely be similar. They are key themes that have been embedded within the workshop programme.

Another strength of this study was the underpinning consideration of health advocacy. Pinder (2010) questioned disability research (including mental health):

- To what extent research helps/hinders the lived experience of the individual?
- Who owns this research?
- How objective can or should disability research be?

In retrospect these concerns have been at the heart of this study in terms of design and delivery – the insider perspective and working with service users as co-researchers. For Pinder (2010), reciprocity and translating research into practical outcomes were key factors in promoting health advocacy through research. The reflexivity of each phase, and the inclusion of James's voice (who rejected the notions of recovery, the personal narrative and the view of mental illness as a pathology to be corrected) offered a counterview to the underlying assumption of this study that developing a personal narrative contributes to recovery. Equally the explicit acknowledgement that the co-researchers owned their contributions to the study and agreed that their work could be used in dissemination offered a more equitable sense of ownership.

In phase 3, the co-researchers effectively co-produced the workshop programme through the PAR cycles, although in reality there was a pragmatic need to develop practical outcomes, which did impact on the free-flow of discussions. Usually, service users are treated as vulnerable adults and therefore as vulnerable participants (Tee and Lathlean, 2004, Lathlean et al., 2006, Tee et al., 2007). This possible vulnerability was acknowledged by ensuring that the focus groups were properly facilitated but it was important not to infantilise and patronise either. Respect was important. Also it was recognised that the co-researchers were active in service user involvement and had used their narratives to train and work with others. Promoting the co-researchers' growing agency (contributing to recovery)

was important in this study. There was an ethical limitation linked to this. Co-researcher anonymity was required by ethics, even though the co-researchers wanted to be named in the research. There was concern for a continuing loss of voice, which PAR as a methodology was trying to promote.

The co-researchers in phases two and three were experts-by-experience (developed their personal narrative) living within a local county. This meant that there was a lack of ethnic diversity within the group, which was also a reflection of the reality of existing service users that fulfilled the inclusion and exclusion requirements (Table 5.1 Summary of Inclusion and Exclusion Criteria used to select Co-Researchers for Focus Groups). The study literature was circulated throughout the county within statutory, voluntary and educational (including the Recovery Colleges and the Universities) and gatekeepers were used to suggest referrals. This thorough recruitment strategy resulted with the 11 co-researchers in Phase two focus groups. To force the issue to ensure the inclusion of a BAME co-researcher (British English black, Asian and minority ethnic) could be considered 'tokenistic'.

The 11 co-researchers represented a diverse geographic, cultural and social mix. Within the group there were 3 male and 8 female co-researchers. There was a non-native English speaker, an Australian and an Irish – Catholic. Different UK regions were also represented, as were differences in age, marital status, familial structures, educational attainment and occupational status. The group was trans-diagnostic (e.g. lived experience of schizophrenia, bipolar, borderline personality disorder, major depression, anxiety, OCD and other complex conditions). They were also a mix of primary and secondary care service users, as well as some that had experience formal detainment within psychiatric services. In reality, it felt like there was a breadth of experience to draw upon within both phases two and three.

To ensure diversity and inclusivity in workshop delivery, it will be important to work with BAME community workers and groups (and others, such as local LGBTQ groups) to facilitate participation. Also the workshop programme and the information about the programme will need to reflect the variety of different needs

(both within the workshop content and in practical aspects such as access issues and times of workshop etc.). Local commissioners, stakeholders and workshop facilitators will need to ensure that the programme is adapted to promote diversity and inclusivity. This ability to be flexible is reflected in the underpinning framework and supporting documents of the workshop programme. It is envisaged that as part of the evolution and collaborative nature of the programme, there will be opportunities to test out different group settings and membership (e.g. women only groups, specific diagnosis, non-English speakers) too.

The creativity of this study design, with emergent data informing each new phase, offered the opportunity for real flexibility in the decision-making process – using PAR in this study really was enabling a solution to be found for a real world problem (le May and Lathlean, 2001). This flexibility was particularly apparent in phase 3 and it impacted on the final workshop programme. For example, initially the intention was to develop a ‘peer-led’ co-produced programme, which was located firmly outside the NHS (because this affected availability). Both co-facilitators would have lived experience as service users. There was a clear philosophical divide between services users and clinicians (‘us and them’).

The breaking down of artificial boundaries was an important strength of this study, because it had clinical and workshop delivery implications. The model allowed people to co-facilitate if they had lived experience and/or an interest in narrative development (and all would complete the workshop facilitation training programme). This would allow clinicians and therapists to contribute their expertise to the trainer team. An important factor that contributed to the ideas generated in phases 2 and 3 was the generative power of the focus groups – the sum was greater than its parts. Pragmatically, by opening up facilitation to stakeholders such as carers, clinicians and service users, would ensure a wider pool and thus a wider workshop programme – more participants could benefit.

## **7.5 Original Contribution to Mental Health Research**

This study demonstrated how the co-researchers had benefited from developing their personal narrative (Phase 2). The contribution to their recovery included growing agency, understanding, reflectivity, social connectedness and a separation of the 'it/me' identity (Slade, 2009, Leamy et al., 2011, Bird et al., 2014). As a result, the workshop programme has been carefully developed to support participants to develop, reframe their experiences (Frank, 1995) and potentially share their personal narratives with others.

At the study outset, the expected contribution to the body of knowledge was the production of the workshop programme (including underpinning Model and Framework, Scheme of Work and fully developed Session Plans). This workshop programme was an innovative and unique peer-led practical programme, aimed at filling an important gap in mental health service provision. This study has succeeded in developing the workshop programme. With the workshop model and framework incorporating service user and clinician co-facilitators (and other stakeholders), this has important implications to delivery of the workshop programme. It is more inclusive (unlike Narrative Therapy intervention) and should allow wider participation (because it will not be limited to therapeutic settings within secondary services). The lived experience, understanding and insight that emerged from my autoethnography and the co-researchers narrative process, was fundamental to the development of the workshop programme. The emergent data built upon the theoretical basis of narrative; its purpose and value. This combination, in addition to the workshop programme itself, is a significant contribution to mental health research.

This study has also made a significant contribution to the body of knowledge in terms of autoethnographic and PAR methodology. Key factors such as: 'loss of and regaining voice'; relational ethics (Ellis, 2004, Ellis, 2007, Ellis, 2009); the on-going nature of narrative development (Robertson et al., 2017); the 'insider' perspective and competing roles; the benefits and costs of reflexivity; and what we ask of co-researchers (especially in relation to PAR cycles), whilst adding to the academic and

research debate are all unresolved tensions and considerations. In raising, discussing and reflecting on these tensions, this study has not only added to the body of knowledge in terms of a greater understanding of the process of narrative development and the innovative development of the eight week workshop programme, but also contributed to discussion of the research process itself (especially as I could be defined as 'vulnerable' too (Robertson et al., 2017)).

Also, this study has added to the knowledge and understanding of autoethnography (as a method) within the Faculty of Health Sciences. There was limited understanding of autoethnography and its practical application within the Faculty, compared to other methodologies. Given my ground-breaking work (with the support of my supervisors), and the continual dissemination of my results and process reflections, it is hoped that there will now be a greater confidence to use autoethnography in Faculty PhD studies and in the wider mental health research world.

This work contributes to existing knowledge (theoretical and methodological). Given the subject matter (personal narrative development and contribution to mental health recovery) and the practical contribution of the personal narrative workshop programme, this thesis sits across different academic and research communities. Being situated within the academic and research fields of autoethnography, narrative development and mental health recovery (theory, models, practical implications, service provision and service user activism) is important, because these communities provide the rationale and on-going debate, development and critique. Being a part of these communities (e.g. the Brighton Autoethnography Discussion Group, Recovery Research Network, Mental Health Qualitative Research Network and Scottish Recovery Network) will also allow me to further my work and to collaborate with others (e.g. I have contributed to Slade's NEON study which aims to build a national repository of recovery stories).

The workshop programme has been developed using a collaborative peer-led psychosocial approach and would potentially fit within a non-clinical, therapist-led

setting; a guided self-help environment and/or a psycho educational setting such as Recovery Colleges, Wellbeing Centres or community groups (as long as key principles of a safe and supported group environment can be assured). It is not a formal educational programme and it does not fit within the traditional medical model - it is not intended as a tool for diagnosis, formulation or treatment.

### **7.6 Putting the Workshop Programme into Practice**

This PhD study was an exploration of the process of narrative development, which culminated in the development of the workshop programme. The rationale for the study was the apparent lack of provision for narrative development work within the NHS. However, as the study progressed (especially in phase 3), the needs of developing and implementing the workshop programme (both philosophically and practically) required a more balanced consideration of who could deliver the programme. It was acknowledged that clinicians could also have lived experience and service users could be clinicians too – and that both groups actually had so much to offer the programme (carers too). A crucial requirement was an interest in narrative development work. The key concern was location and ownership of the programme (fear that the NHS taking the programme over could affect participation and availability) rather than maintaining the ‘us and them’ boundary.

Translating research into practice is a NIHR research theme (National Institute for Health Research, 2017) with NHS Trusts actively encouraged to develop, deliver and translate research – to provide the evidence base that will deliver better and more efficient health care. Given the complex, interactive and organic nature of the NHS (Kitson, 2008), translation is not automatic and can take many years to achieve. Hayes et al. (2013) suggested that to ensure better translation, research needed to focus on the theoretical development, practicality and the fit with service users and clinicians. It can be argued that the breadth and value of this study: adding to the understanding of narrative development process and theoretical and methodological knowledge base; linking this to existing and clinically used recovery model frameworks; and developing the practical application of the workshop programme will lead to the translation of this study. The existence of recovery

colleges (Lewis et al., 2017) and third sector well-being centres provide the ethos, co-production culture and infrastructure to support translation.

It is intended that the implementation (including pilot), full evaluation of the programme and rollout will be carried out as post-doctoral research. The post-doctoral plan was detailed in Chapter 3 (Boxes 3.4 – 3.6). In summary:

**Box 7.1 Possible Post-Doctorate Research**

<b>Phase 4:</b> Develop the 'Train the Trainer' programme for co-facilitators
Deliver the initial training programme
Pilot the eight week Personal Narrative Development Workshop Programme
<b>Phase 5:</b> Evaluation of the Pilot
Evaluate the 'Train the 'Trainer' programme
Reflect on the experiences of the process of developing a personal narrative with the workshop participants
<b>Phase 6:</b> In the light of the pilot evaluation, further develop the workshop programme and 'Train the Trainer'
Run subsequent workshops

It is expected that the workshop will continue to evolve and develop.

For the post-doctoral stages of this research, funding opportunities will need to be explored. This will require involving all potential stakeholders (including service users, carers, clinicians, the NHS and 3<sup>rd</sup> sector) in developing the pilot protocol.

### **7.7 Dissemination of this Study**

Dissemination of this study has been very important. As well as regularly contributing to the Faculty's Mental Health Research Group, I am a member of a number of external research groups including: Recovery Research Network (RRN); Mental Health Mental Health Qualitative Research Network (MNQRN); Clinical Research Network (NIHR); Autoethnography Research Group (Universities of Sussex and Brighton); and National Survivors User Network (NSUN).

I have presented my work at various conferences and workshops, including:

**Table 7.1 Dissemination of Study**

Autoethnography Conference, University of Brighton, 2015
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14 <sup>th</sup> Lived Experience Reference Group Student Nurse Conference, University of Southampton, 2016
Autoethnography/ Participatory Action Research and the 'Wounded Researcher', Mental Health Qualitative Research Network, McPin Foundation, London, 2016
Keynote: Postgraduate Research Roundtable, University of Southampton, 2016
3 <sup>rd</sup> British Autoethnography Conference, University of Aberdeen, 2016
8 <sup>th</sup> Annual Conference, The Qualitative Report, Nova Southeastern University, Fort Lauderdale, January 2017

I have delivered a number of teaching sessions and workshops to all levels of the teaching programme and at the annual Service User/Carer Conference organised by the Lived Experience Reference Group. Recently I had my first paper published, *'From the Edge of the Abyss to the Foot of the Rainbow – Narrating a Journey of Mental Health Recovery' The Process of a Wounded Researcher* in The Qualitative Journal (Robertson et al., 2017). Planned future publications include:

**Table 7.2 Future Paper Plans**

Future Papers	Where
Overview of whole study	Mental Health Journals
A methodological paper on PAR and the process of co-production (with interested co-researchers as co-authors)	Qualitative Methodological Journals
Implications for practice of implementing the personal narrative workshop programme	Mental Health Practice Journals
Possible relational ethics paper (drawing on phases 1 and 2)	Qualitative Methodological Journals

### 7.8 Final Conclusions

This study was developed as a reaction to the prevailing model of 'evidence-based' and 'one size fits all' mental health service provision, which was inconsistent with current recovery theory that suggested each individual's recovery journey is unique, on-going and non-linear (Bird et al., 2014, Leamy et al., 2011, Slade, 2009).

In her Conceptual Recovery Framework, Leamy et al. (2011) identified three interlinked recovery domains (Tables 1.1 – 1.3). One, the key recovery processes: connectedness; hope and optimism for the future; identity; meaning in life; and empowerment (CHIME). Two, a model of change and the stages of change required in order to recover a life that is meaningful to the individual. Three, the characteristics of the recovery journey, such as: recovery is an active process; is a struggle; is aided by a supportive and healing environment; and can be achieved

without professional intervention. Bird et al. (2014) provided the empirical evidence to support this framework. In his Personal Recovery Framework, Slade (2009) emphasised four tasks of recovery: development of a positive identity; reframing the mental illness; developing self management; developing valued social roles. Throughout this study, the emergent data from all three phases has been analysed and considered using both recovery frameworks. The emergent data has supported the concept of recovery, its characteristics, processes and tasks within both frameworks. This has allowed decisions to be made and for the personal narrative workshop programme to be developed.

Slade (2009) emphasised the fact that recovery is non-linear. It is not a given that individuals will neatly move from one stage to another. It is on-going and hard work. Not every service user is willing and able to follow this process. Many are stuck in an illness identity (Kleinman, 1988) which is supported by low expectations of themselves and by others, and living within a benefits system. Getting better (and given that recovery is non-linear) is scary and takes a degree of desire and resilience to get started. Given that recovery is a lifetime process, recovery orientated service provision (both statutory and voluntary sectors) is strictly rationed and time limited. The reality is that the rhetoric of existing services does not have the required resources or political will to meet the needs and expectations of what recovery is for any individual.

However these recovery model frameworks and the underpinning philosophical expectation that recovery is possible and desired by every mental health service user, is problematic. The recovery movement is not a homogenised group with the same expectations of 'what a meaningful life and how it should be lived'. Many are opposed to the concept of recovery as it has been adopted, 'hijacked' and used by mental health services. James's view that mental illness was a symptom of societal and cultural malaise yet had been problematised as 'something wrong with the individual' and 'it is the gift of the individual to be recovered' (Slade, 2012). James's believed that it is acceptable to 'be mad' and 'live an unrecovered life'.

However, for many service users recovery as a concept is about living a more meaningful life despite the on-going difficulties of living with mental illness. This study was the exploration of how developing a personal narrative could support the individual to do this. A personal narrative is unique to the individual. My experience of: developing my personal narrative; the value that I attributed to my process of writing, reflecting on the narrative and sharing it; and working with other service users to do the same suggested that narrative development could have an important role in an individual's recovery.

Whilst narrative content is important (much of the literature has concentrated on this), exploring the process – what happens to the individual when they develop their personal narrative, was the focus of this study. Recovery models describe the characteristics of recovery in terms of increased agency, understanding and social connectedness. This study explored how these factors could be achieved through the process of narrative development: How reframing and making sense of lived experience; rediscovering one's own voice; being heard and sharing, contribute to an individual's growing sense of self. This exploration of narrative process was at the heart of phases 1 and 2. It fulfilled the core study aims (from Box 3.1):

1. Develop and analyse my mental health autoethnography
2. Explore the experience of service users who have already developed a personal narrative.
3. Explore the contribution that developing a personal narrative has made to their mental health recovery.

This study needed to go beyond this exploration of personal narrative and contribution to recovery – to combine the underpinning narrative theory, recovery models and personal experiences of the co-researchers to develop a tangible, practical solution (the workshop programme in phase 3), which would offer others the opportunity to develop their personal narratives. This was achieved (core study aim 4):

4. Utilise the resultant evidence to develop a personal narrative workshop programme, with the aim of supporting other mental health service users to develop a personal narrative

PAR, as a methodology was used for two main reasons. One, there was the expectation that a practical solution would be developed to support a real problem (lack of availability for narrative development within services). Two, there was the value of developing the solution with peers who were both service users and had developed their narratives. This was not only democratic because it gave a voice to normally 'marginalised' individuals, but the phase 3 co-production work, was richer and perhaps more meaningful because it was developed by peers with the relevant experience. This is important in the mental health world (evidenced by the increasing use of peer workers in service provision). The co-researchers have stated how much they gained from being a part of this study, in terms of their own continuing journeys. Many have expressed an interest in participating in the postdoctoral phase.

This study provides evidence that personal narrative development - and the process of reframing lived experience in order to make sense of what has happened/is happening, is an important contributor to recovery. Given this evidence, the peer-led, co-produced personal narrative workshop programme (with its underpinning Model, Framework, Scheme of Work and Session Plans) will be piloted and implemented in the post-doctoral phases.



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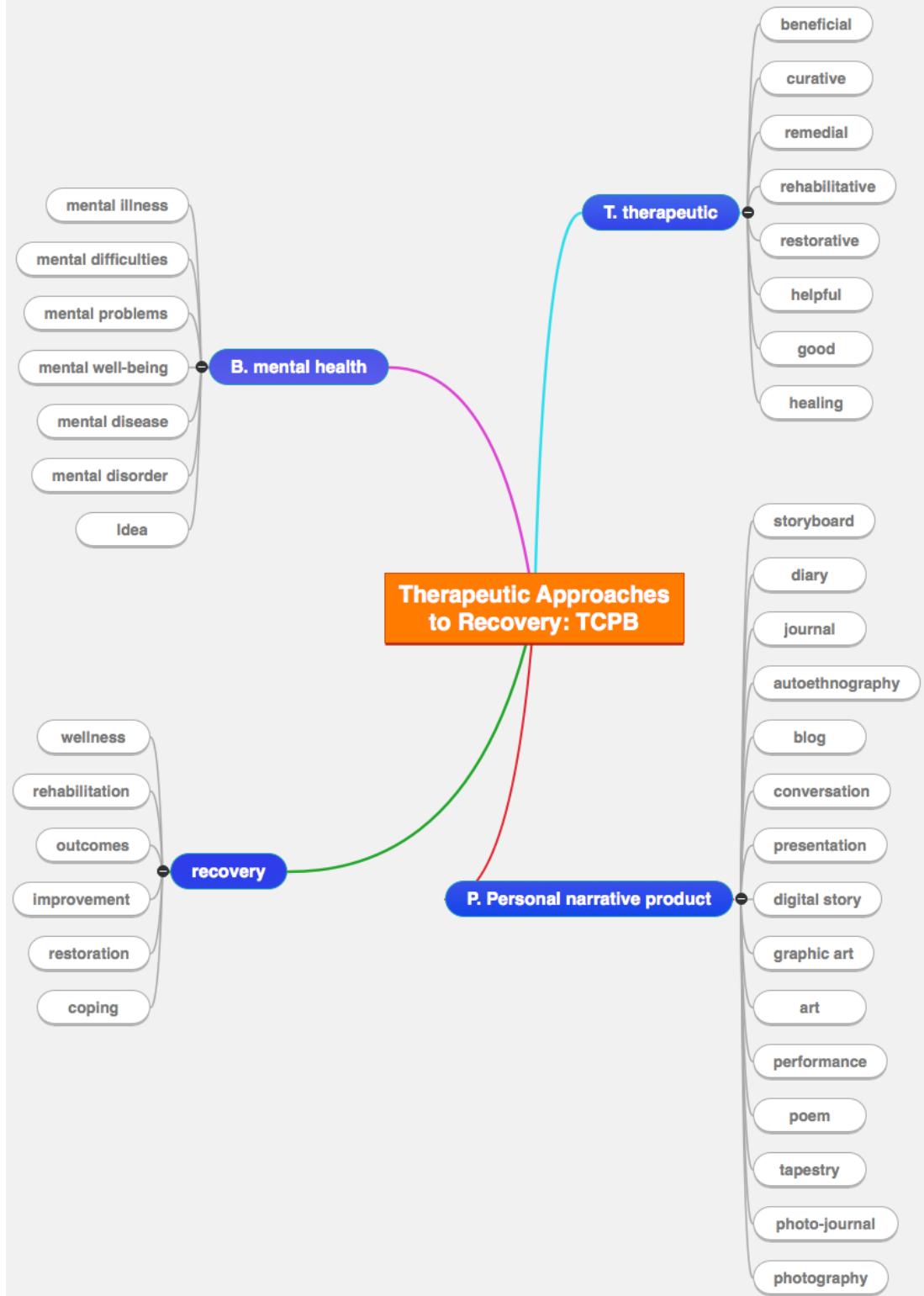
## APPENDICES

### Appendix 1.1

**Table 1.2: Recovery Model Studies used to map onto the trans-theoretical model of change (Lysaker et al., 2010)**

Study
32 Song L-Y, Shih C-Y. Factors, process and outcome of recovery from psychiatric disability the utility model, <i>Int. J of Social Psychiatry</i> , 2009, 55(4), 348-360.
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## Initial Mind map



## Search Recording Sheet: TPCB: Extract (Page 1 only)

## Appendix 2.2

Title: Therapeutic Approaches to Recovery					
Search engine/database: Delphis					
Concept T therapeutic	Concept P personal narrative approaches	Concept C recovery		Concept B mental health	
1 beneficial 2 curative 3 remedial 4 rehabilitative 5 restorative 6 helpful 7 good 8 healing	1 storyboard 2 diary 3 journal 4 autoethnography 5 blog 6 conversation 7 presentation 8 digital story 9 graphic art 10 art 11 performance 12 poetry 13 tapestry 14 quilting 15 "photo-journal" 16 photography	1 wellness 2 rehabilitation 3 outcomes 4 improvement 5 restoration 6 coping		1 mental illness (illness*) 2 mental difficulties (difficult*) 3 mental problems (problem*) 4 mental well-being 5 mental disease (disease*) 6 mental disorder (disorder*)	
12/3/14 No.	Search	Hits	Comments	Limits	Follow-up
S1	T AND P AND C	0			
S2	T (OR) AND P (OR) AND C (OR)	460			
S3	T (OR) AND P (OR) AND C (OR)	391		1990	
S4	T (OR) AND P (OR) AND C (OR)	243		English	
S5	T (OR) AND P (OR) AND C (OR)	243	• R4, R6, R41, R65, R76, R103-4, R116, R126, R141, R153, R167, R170, R192, R208, R212 are relevant	Re-run due to time out	16

**Search terms:****T – therapeutic****P – personal narratives****C – recovery****B – mental health**

Search	Search Terms	Records to follow-up
T AND P AND C	therapeutic AND personal narrative AND recovery	
T (OR) AND P (OR) AND C (OR)	therapeutic (OR) AND personal narrative (OR) AND recovery (OR)	
T (OR) AND P (OR) AND C (OR)	therapeutic (OR) AND personal narrative (OR) AND recovery (OR) (1990)	
T (OR) AND P (OR) AND C (OR)	therapeutic (OR) AND personal narrative (OR) AND recovery (OR) (English)	
T (OR) AND P (OR) AND C (OR)	therapeutic (OR) AND personal narrative (OR) AND recovery (OR) time-out rerun	16
T AND photography	therapeutic AND photography	
T AND photography	therapeutic AND photography (In English)	33
T (OR) AND photography	therapeutic (OR) AND photography	
T (OR) AND photography	therapeutic (OR) AND photography (In English)	3
T AND P (OR) without photography	therapeutic AND personal narrative (OR) without photography	
T AND P (OR) without photography	therapeutic AND personal narrative (OR) without photography (In English)	
T AND P (OR) without photography AND B	therapeutic AND personal narrative (OR) without photography (AND Concept B mental health)	
T AND P (OR) without photography AND B	therapeutic AND personal narrative (OR) without photography AND mental health	29
T (OR) AND P (OR) without photography AND B	therapeutic (OR) AND personal narrative (OR) without photography AND mental health	
T (OR) AND P (OR) without photography AND B	therapeutic (OR) AND personal narrative (OR) without photography AND mental health (1990)	6
T (OR) AND P (OR) without photography AND B (OR*)	therapeutic (OR) AND personal narrative (OR) without photography AND mental health (OR*)	4

R No.	Date		Description		Study Setting	Key Words	Follow-up
1	2013	J	Quilt making – process	UK	Culture	Preservation and restoration	
2	2013	J	Empirical. Post-op		Adults - physical	Healing plan - written	✓
3	2010	J	Art Therapy - Healing	Can	MH Adults	Aborigine. Historic trauma	✓
4	2011	J	Clay	US	MH Adults	Art therapy (AT)	✓
5	2008	J	Performance Therapy		MH Adults	Performance, healing, trauma rehab	✓
6	2000	J	Case study Art therapy	US	MH Adults	Post traumatic rehab	✓
7	2011	J	Art therapy and post modernism	Can	Review	Philosophy, current practices	✓
8	2010	J	Art therapy		MH adults	Substance abuse motherhood	✓
9	2004	J	Art therapy – developing the story		MH Adults Case study	Cultural feminist postmodernist framework	✓
10	2005	E	Creative methods		Theory	AT, drama, writing	✓
11	2008	J	oncology		Adults - physical	Healing quilts	✓
12	2009	R	Coping with death		Review	Adolescents, activities to work through grief process	
13	2005	J	Journal writing. Transactional model of stress, Adler		MH Adults	Support intervention	✓
14	2004	J	Mindfulness	US	Case study	rehab	
15	1993	J	AT, wounded female		Case study	Alcohol rehab	✓
16	2013	J	photography		MH Adults	MD, narratives	✓
17	2013	J	Reminiscence therapy		Older	Dementia, computer assisted	
18	2011	J	Photography		MH Adults	Life worlds	✓
19	1999	B	Photography		LD	Treatment and education	
20	2011	J	Photography. Brain injury	US	Adults – physical	Narratives, psychosocial,	✓
21	2011	J	Photography, breast illness		Adults – physical	psychosocial	✓
22	2009	J	Phototherapy, therapeutic photography	Fin	Theory	Review of conference	✓
23	2009	J	Re-enactment Phototherapy, therapeutic photography		Theory	Visual diaries and narratives	✓

**Photography/Phototherapy:**

MHA	Physical	Method Theory Review	Narrative	Life worlds	Psycho -social	Therapeutic	Visual diaries	Rehab SM	Evidence	Older person	Trauma	Digital	Re-enact
16	20	22	16	18	20	22	23	24	29	31	40	44	49
18	21	23	20		21	26		39				45	
26		27	23			27						46	
33		29	47			32							
41		32				33							
44		35				36							
47		36				41							
49		38				43							
52		43				44							
53		45				45							
		45				46							
		61				49							
						52							
						53							
						61							

**Performance/ Drama/Dance:**

MHA	Healing	Trauma	Rehab	Method Theory	Physical	Dance	Evidence	Review
4	4	4	4	10	50	57	81	84
81					57			
91								

**Phase 4: Papers for Inclusion in Literature Review: Extract (Page 1 only)**

**Appendix 2.6**

**Creative arts - photography**

Date	Authors	Area	Study Area	Description	Comments
2011 r1	Erdner, A	J	Scan	Photography –life worlds	
2011 r2	Lorenz, LS	J		Photo-elicitation in illness research = empathy	
2011 r3	Dennett, T	J	UK	Jo Spence anti-therapeutic survival techniques	
2006 r5	Glover-Graf, NM	J		Phototherapy –group therapy, SM	
2009 r7	Blank, BT	P		Art and photo therapy. healing	
2014 r8	DeCoster, VA	J		Therapeutic photo  Clinical social work: evidence based best practice This project systematically identified evidence-based interventions using photography in mental health practice. The initial search of the literature produced 4,929 hits, title reviews reduced this set to 225 possible studies, abstract examination refined this list to 81, and analyzing the articles determined that only 23 meet selection criteria for inclusion in this project: psychosocial-oriented intervention within the domain of social work practice with supporting empirical data. The majority of interventions involved assignments that included taking photographs or creating some kind of photographic product (e.g., collages, time-series of snapshots). Typically, these photographic activities were done in group or individual therapy and focused on social skills, coping skills, self-esteem, or identity for adults and adolescents. The empirical support for these protocols was usually from case studies or single-group design evaluations, all reported practical or theoretically significant improvements, and three produced statistically significant effects. This article will then discuss the implications of findings and direction for future research.	

## Sam Robertson

### From the Edge of the Abyss to the Foot of the Rainbow

#### A Mental Health Recovery Autoethnography



Freedom "Zenos Frudakis, Sculptor ©2000"

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- 38. 'Leave your service user hat at the door' (2013 Work)
- 39. 'You are a service user not a professional' (2013 A recovery college)
- 40. 'I think that I need to increase my meds' (November 2014)
- 41. 'Your pay grade isn't high enough to support you in doing a PhD' (June 2013 Work)
- 42. 'There's nothing that I can do for you' (May 2012)
- 43. 'It's alright for people like you' (December 2013)
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## THE HOPELESS NARRATIVES

### Part A: SOWING THE SEEDS - PAINFUL MEMORIES

#### 1. 'You've ruined my life' (Earliest memories)

*Mum – you've ruined my life I was getting my life back you father couldn't keep it in his pants no self control*

*Mum – what are you crying for – I'll give you something to cry for*

*Mum – take that smile off your face or I will take it off for you*

*Mum – go to the shops for a cane (to beat me or to threaten too)*

*Mum – I'll send you to the children's home*

No reply needed regular threats largely ignored exiled to good married sisters growing up youngest of seven running wild with the pack large council estate feral kids old old weary parents father ineffectual absent weak dominant matriarchal mother rules dominion running wild bully brother terrorises indoors hammer ever ready watchful don't upset him fucked up family wayward sister you might turn out like her no trust no debate fantasies real parents will find me this cannot be this is never wanted always known

#### 2. 'Take the rocking horse with you – she doesn't play with it' (Late 1960s)

It is the week after Christmas. I am 3 or 4 years old. I am full of cold – listless and lethargic. I have no interest in the toys around me. I just want my bottle and a blanket on the sofa. My main Christmas present is in front of the tree – a rocking horse. Wood, solid, shiny, inviting and waiting for me. My sisters had tried to interest me in it – lifting me up to sit on it – but I didn't feel at all well. I didn't want to play. It stands alone by the tree.

It is the week after Christmas. A brother and his wife come to visit for the day. He is a warrior. I don't know him. He's over 20 years older than me. He joined up before I was born. My mother was expecting me when he got married. His son is 3 months younger than me. I don't know them. They bring gifts off a market stall. They go home with my rocking horse. This pattern is continually repeated on a loop.

When my Dad dies. They visit and go home with half our furniture and Dad's car. They sold it straight away.

### 3. 'I think that me Dad is dead' (November 1976)

I am awoken. Footsteps overhead. Raised voices scared voices. Can't hear any words. I lay on the sofa in the front room; my Mum is in my bed. It is dark a thick winters dark. It's the middle of the night. Light is on in hallway. Steps on the stairs. The phone is picked up. I hear my sister panicked childlike voice

*Sister – hello ambulance please I think that my Dad is dead*

I hear no more. I rationalise. It's only a dream. I tell myself to go back to sleep and everything will be okay. I settle back down. Blanket pulled up to my neck comforting warm. Eyes shut shut out the world hear nothing back to sleep wake walk into the kitchen adults sitting holding tea mugs Aunty Lena is here it's still the middle of the night Mum turns to face me

*Mum – Your Dad is dead*

I am 10 years old. My life changes forever – from ignored to centre of her world. Wham bam.

### 4. 'All that I have invested in you' Part 1 (1976-79)

I like swimming. Hours of freedom with friends. Screaming, jumping from the high board. The water sooo cold. The jam sandwiches yummy! Endless summer – free. Laughing, making new friends. I can be me.

*Me – I like swimming. Can I join a club?*

Saturday and Sunday mornings – have to miss Swap Shop. Endless drills in the pool. Out of breath – getting better, faster, and more proficient. I can do this. Moving from beginners lane up to the bestest lane. Harder drills. Faster, longer, harder. Expectations rising.

Gala event – I win it all, take on all-comers. A Spitz-like moment. The coaches want me to move to a different pool – training before and after school. And so it starts. Dark, drizzly mornings, dark cold evenings – drill, drill, drill. Stop laughing this isn't a joke, this isn't for fun. Can't play hockey, no netball for me – endless drills, up and down, timed breathing, up and down.

I don't want to do this anymore. I hate it. I hate swimming. I want to do other things. I want to play hockey and netball for the school. Do athletics in the summer. Drills, drills and more drills. How do I tell her? She has just paid my fees for the year. She works so hard.....

*Me – I don't want to do this anymore*

*Mum – You ungrateful sod. I've just paid your fees. You will keep going. You will make something of yourself. You will not ruin your life like your sister – I will not allow it.....*

She doesn't talk to me for a week.

## **5. 'Where's the other 2%' (1976 – 1990 Mum's death)**

*Much loved teacher – she has potential*

*Mum - really*

Thanks for that. Expectations dreams hopes – hers not mine – pushing pushing pushing

*Me – I came top of my year in all my exams - geography I got 98%*

*Mum – where's the other 2%*

Expectations no time for friends worthy activities strive put on a show circus performer no down time no time to chew cud good job only law will do no romance they ruin your life striving displeasure ignore strive harder try to please automaton don't get it wrong there will be hell to pay don't leave me with her Sunday night bereavement who am I will I ever be good enough scholarship won my girl the star I'm her mum wow wow mixing with the big boys posh rich poor girl made good putting on posh voice do you know who she goes to school with no time for holidays you haven't done a days work in your life cleaning toilets rooming with royalty who the hell am I?

The years after Dad died. I became her world on her terms. Only good successful Sam was welcome. Scholarship won life saved. Escape nearly achieved. Poor lonely mum.

## **6. 'All that I have invested in you' Part 2 (1979-80)**

Mum. Uneducated. Bigoted. A snob. Sneering. Biting. Lost and alone in a constantly full crowd. A puppet master. Master manipulator. A toddler in an aging woman's clothes. An aged mother. A reluctant mother. An all-consuming mother. Destruction and debris in her wake. A desperate widow. Projecting her desires and regrets onto me – the child that ruined her life.

Works as a cleaner in a pub. She is the only real worker in this world. Detests those with soft hands. She wants me to have soft hands. She makes me work with her on school holidays – cleaning public toilets. She wants me to know what it is like to work – really work. She wakes me at 5 AM.

Borrows from Peter to pay Paul. Never enough money. Ducking and diving. Resents people on benefits. Shirkers. Those still in bed – those lazy sods. She makes sure that I know the cost of everything and the value of her sacrifice. I want for nothing – yet I want everything. I bury all my dreams and desires deep within me.

At 12, she gets me a job in the pub. Washing up. Pots that I couldn't see over. Hard, hard work. Sunday roast for 50. I start to earn my keep. I live within her ambivalence. She wants everything for me. Perfection in everything that I do – yet she wants to see my arms deep in crap – scrubbing catering pots – doing real work. Soft hands with the calloused scars of proper work.

I strive for perfection – it is my escape. Captain of school hockey and netball teams. 800m runner. Form captain – all round academic superstar. A swimmer. A dishwasher. It fills my world. I am only in her perfect orbit. She talks to me. I am her star, her living embodiment of what she wanted for her self. She doesn't know me. She knows the façade and all is good with the world.

I start a school newspaper. I am the editor, chief writer and distributor. I loved Superman. One evening after school, she says

*Mum – I've got you a Saturday job at the local newspaper as a cub reporter. One of the journalists comes into the pub and I told him that you wanted to be a journalist. You start on Saturday.*

My one lay-in of the week gone. Any interest that I may have had in journalism as a possible career gone. Ruined by her insistence to take over. Never allowed to do anything for fun.

I stuck it for a year. Another massive disappointment for her.

## **7. 'All that I have invested in you' Part 3 (Late 1983)**

I ring Mum from college – our regular Sunday evening call. I had made a decision about university and I knew that she wouldn't be pleased. I also knew that I would get a full grant, so she would not have to contribute anything. I had continued to work at the pub during all my holidays.

*Me – I am going to study economics at university.*

*Mum – I thought that you were going to study law – you wanted to be a barrister.*

*Me – no you wanted me to be a barrister and study law. I really love economics.*

*Mum – what are you going to do with it?*

*Me – I don't know.*

Her disapproval and disappointment dripped through the phone lines.

### **8. 'Don't worry she doesn't like anyone' (January 1984)**

The train pulls into the platform. The end of the line. Waiting anticipating dreading. You step off the train. I see you. We hug. We kiss. I feel whole again – your warmth – your strength – your humanity. We hold hands. Start to head for exit.

*Me – don't take it personally but she will not like you*

We head towards the ferry. It's a cold dank dull January afternoon. You are just about to meet my mother. My hero. My rescuer.

### **9. 'By the way, I've moved' (Easter 1984)**

There are only a few weeks to go until my International Baccalaureate exams at college. I am feeling vulnerable. I don't feel myself but I cannot explain what I am feeling or why. I know that I am sleeping poorly. I know that I am disconnecting from everyone apart from Don. I know that I am relying heavily on Don. I know that I am working incredibly hard – harder than I have ever worked before. I know that I am spending long hours in my carrel unit, snatching time with Don and then hiding under my duvet. My dorm-mates and friends are complaining. I know that I feel crap.

We have a long weekend leave over Easter. Don is coming home with me. Mum seems to have accepted that he is my boyfriend. He's good enough. He's going to a good university. He will have a good career. It is Thursday. I ring home to tell Mum what time our train is due in.

*Mum – By the way, I have moved house.*

She has moved house. I didn't know that she was even thinking about moving. She has moved from a two bedroom to a one-bedroom granny flat. She has packed up my stuff into 2 boxes – she kept what she thought that I would want and gave away the rest.

I slept on the sofa. My boxes in the cupboard. I had no home. I had no private space. I was stateless. She did this without telling me.

I went back to college – I am leaving here in a few weeks. I have nowhere to go back too.

### **10. 'I need you to be strong' (May 1984)**

Thank God that I have college. I have Don. I have my house parents. I love them both. I fantasize about them being my real parents. I am especially close to Jack. We have a playful, teasing kind of relationship. We can talk about anything. I wrote our yearbook entry for him. I respect and admire him.

Mum moving has knocked me for six. I can't understand why she has done it in the way that she did. I am confused. I feel bereaved – a feeling similar to what I felt when Dad died. The exams are creeping ever nearer. The teachers are piling on the pressure. I am still not sleeping. I am sleepwalking through each day. Don tries to contain me, hold me together. He is overwhelmed by the responsibility. I feel like I want to die. I look longingly at the training cliffs. I know that another student has died at the cliffs. It is not something that we talk about. We are trained to save lives. I am becoming more desperate. Don says that I must talk to Jack. I prevaricate. I cannot hide the despair any longer.

I ring on his doorbell. Can I speak to Jack? We go into his study. I try and describe how I am feeling. I am longing for him to rescue me. I am stunned by his response

*Jack – Not you as well. I rely on you as one of my strong ones. I need you to be strong. You cannot do this to me.*

He doesn't listen. He hasn't heard. He leaves me bereft, rudderless and homeless. I retreat further into myself.

I survive the next few weeks with Don's support. I pass my exams. I leave college – a plaster over the broken me.

## **11. 'All that I have invested in you' Part 4 (1988)**

*Me – I am applying to teacher training - I want to teach economics*

*Mum – You wanted to be a barrister. Anyone can be a teacher.... When I think about all that I have given you and you want to be a teacher.*

There is no pride or bragging rights if I become a teacher. A barrister, well that is something special. I have disappointed her yet again. A moral victory for me though. A further layer of Mum's expectations rubbed off – I've not given into her will and silence. A chink of Sam faces the light.

## **PART B: BEYOND DESPAIR**

### **12. 'I don't know who you are anymore!' (June 1996)**

We bump into each other awkwardly. In the doorway of our empty classroom. Miles scurries out, with the kettle in his hand. We look at each other. We have nothing to say.

No smile or laugh at the absurdity of the moment. The kettle in his hand says it all. Miles needs to escape. I say nothing. The moment elongates. Looking down at the kettle, Miles says quietly.....

*Miles - I don't know who you are anymore.*

He walks away. I sit in our cubbyhole of an office - alone bereaved racing thoughts no thoughts despairing empty silenced alone alone. The bell rings for afternoon school. Feeling nothing feeling everything. An automaton teaches afternoon classes watches the performance from some place else. The shell rushes off at a snails pace to pick up my son from where he was left that morning. No looking back.

Before my maternity leave lunchtimes were spent in our office together. Preparation for classes not yet taught. Marking. Planning - Ofsted was on the horizon. Seeing students. Chatting. Gossiping. Talking football. Content in our silence too. We were a team – had been for three years. Miles was my boss and he was my friend. We were tight. We shared a vision and a passion for our subject – Economics. We were frontiersmen, innovative and ambitious. I was fast-tracked, a spotlight over my head. I would go far. Everyone said so. Before my maternity leave.

*Me - I want to start my maternity leave at the end of October half term*

*M - We can't find a replacement for you.*

*M - Can't you wait until Christmas?*

*M - Can we send you some work to look at?*

*M - The exam season is approaching. When are you coming back? We need you*

My maternity leave ends. I know no better.

*Me - 'I don't think that I can go on with this any longer'*

### **13. 'I don't know if I can do this anymore' (October 1996)**

Slide down the radiator to the cold floor. Sightless. Disconnected. Don and John Doe – alien beings. I am the alien. I don't understand this world. I don't want to be in this world. Disconnected absent disorientated no thoughts racing thoughts no understanding. Each breathe a struggle. No momentum only inertia. Sliding onto the cold bleak floor. Don wants to get us out. Go into town. Have a coffee. Break this cycle. He talks in tongues. His lips move no sense comes out of him. I am mute senseless ashamed. I make no response. I am a lifeless lump of shit, sitting on the kitchen floor. Don steps across me, tries to lift me up. I am a deadweight. Inert lump of shit. He steps back. He says quietly to no one in particular

*Don - I don't know if I can do this anymore*

He is right. This descent into madness has gone on for months. The end is now in sight. He has signed my release form and my death warrant. I begin to make plans. There is light and hope. This too shall pass.

#### **14. 'I can't let you leave' (October 1996)**

Monday morning. 4 months later.

Do all the usual things act normal .... John Doe in my arms his bag over one shoulder school bag over other automaton acting dead inside planning planning planning lose thread start again think act normal.... walk towards front door nearly there escape close say goodbye focus appear normal be okay raise no alarm nearly there. He stands in front of the door barring all escape tall frightened unknowing knowing...

*Don – you are not going to work today*

*Me – yes I am, I'm fine*

*Don – you are not fine*

I crumple back to the wall slide down to cold floor dissolving into oblivion can't kill myself today so close so very very close non-entity existing the dissolution of Sam runaway train cataclysmic implosion impossible to stop no understanding separate empty walking dead so tired

.....This descent into whatever. I didn't understand it in terms of madness, mental illness or whatever. I had little experience of what was happening to me, to us. There was no language, insight, theories or solutions. Sam was disappearing before our eyes and we were powerless to stop it. We were ashamed, told no one, together and alone with our pain. We shut others out. Asked for no help. We were alone in a strange city far from family. We had no explanations. Both dying inside. The destruction of a teacher, wife, friend and mother. sam becoming nothingness. Better for everyone. Fresh starts. The decision made rational very rational place chosen the means squirrelled in my bag going to school and not coming home relief the automaton utterly focused

*Don – you are not going to work today*

### **BEGINNING THE LONG ASSENT NARRATIVES**

#### **ONE STEP FORWARD – ONE STEP BACK**

#### **15. 'Play the game – stop being challenging' (Feb 2003 In-patient in a psychiatric hospital)**

Choice – there is no choice. Comply or be dammed. Voluntary stay ha ha. Play the game Sam and you will get out of here. Show insight. Say the right things. Behave. Stop kicking off. Stop acting mental. Eat the slope. Paint by numbers. Go to sleep. Do yourself no harm. Be a good child. Don't mention the locked doors no drink after midnight the constant obs no connection waiting queuing for meds waiting to be let off ward. Do as told be good girl take your medicine – play the game – institutionalized but free. Ignore the screams the pointlessness the broken TV the forced restraints the locks the alarms the unopening windows no sharps bag searches. You are here to get better. Just play the game.

#### **16. 'Go kill yourself then' Part 1 (March 2003 In-patient in a psychiatric hospital)**

Early March. Sometime in the evening. Wandering along the corridor. Aimless. Preoccupied with suicide. Thoughts overwhelming. Sgt Steve Jones (don't know if he was ex-squaddie. Always introduced himself by his full name) Jones self-important pompous twat - stands in corridor. Us avoids him. No humanity pompous twat. As I pass by

*Me – I want to go to the garage*

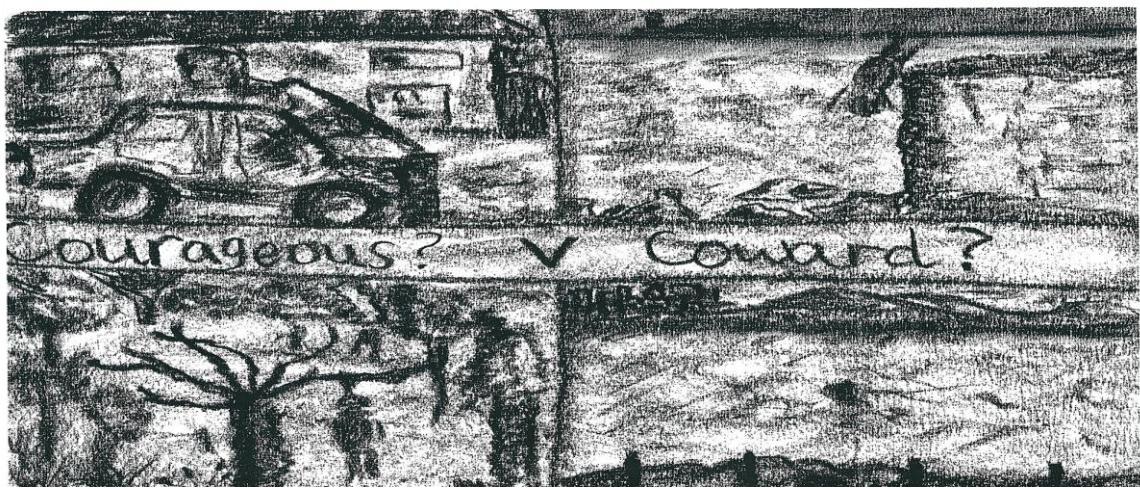
*Jones – Why*

*Me – To get some paracetomal I want to kill myself*

*Jones – Go on then if you want to kill yourself I cant stop you.*

Nothingness confirmed.

It's the middle of the night. Look around my ligature free cell. No ideas. I draw.



(Drawn with charcoal Feb 2003)

## **17. 'She's trouble – stay away from her' Part 2 (March 2003 In-patient in a psychiatric hospital)**

Later the same night. Us sit in chairs chuntering (there is a small common area at the head of the male and female corridors). Fucking Jones. Sally just back from A&E. Arms patched up again. Another failed attempt. Shall we go to garage. Fucking Jones. Do we have the energy? Ivy (a genial older Health Care Support Worker – the one who is usually on the ward) wanders by. Keys and alarm jangling on her belt. Someone catches up with Ivy.

*Someone – Did you hear what he (Jones) said to Sam*

*Ivy – No – stay away from Sam she is trouble*

Someone comes back to tell me

*Someone – I can't believe what she has just said*

I have no language. White-hot heat flows through my body. Incomprehensible emotions. I don't do emotions. Escape to my room. Throw things in my bag. I'm fucking leaving this hellhole. Frantic activity. Walk to public ward phone. Eyes down. No one around. Ring Don. Frantic, garbled, frantic.

*Me – Come and get me I'm coming home*

*Don – Okay I will be there as soon as I can*

*Me – I'm packed I'm waiting*

The open ward is locked. Pace outside the meds room stuff in carrier bags waiting waiting waiting kicking wall on my own kicking door waiting. Them say they have called the duty psychiatrist (a 10 year old on her 6 month rotation) blah blah blah no emotion overflowing emotion. Don arrives. He has had to find someone to sit with John Doe. It is now past midnight. Still I pace kick the bags the wall the door. Don persuades me to wait for doctor. He will take me home then. Waiting waiting waiting

She arrives. She is as predicted. Go into locked dining room. Only place to do this talks to me forever listens talks to Don listens

*Dr Pixie – I can't let you leave here, will you stay*

## **18. 'You have a lot of anger' (March 2003 Still in the psychiatric hospital)**

Emotionless. Kicking walls. Fists bunched. Red heat in back. Pacing muttering swearing this is not me. Don't know who I am not me shouting raging

*Nurse - You have a lot of anger*

Not me. Don't do emotions. Not allowed emotions. Emotions bad. Anger – don't even know what that is.

**19. 'How are you feeling today' – ward round (March 2003 Still in the psychiatric hospital)**

It's Wednesday again. Anticipation tension fear – I don't want to go home. I feel safe here. This is my home. Mustn't give too much away. I want to stay. Waiting all day until summoned. It could be first thing or just before tea. We all wait shuffling from room to dayroom to art room. If only I smoked. We are all fearful. Some want to go on remand – but they will be back! A support worker appears.... I am summoned before the judge and jury. I knock. I wait. I enter. In front of me is my consultant. I have no choice. He's who I got. I prefer the other one. The one with the wayward eye. He seems more human somehow. I scan the room. Upwards of 12 sitting in the shadows. All name tagged and pens ready. Mostly unknown. Many faceless. All sitting in judgement. I sit on a hard chair. All the comfy ones are bagged. I sit on my hands. Eyes down. Waiting.....

*Dr Judge - How are you today? How's the week been?*

*Me – Childlike voice – ok I guess*

*Dr Judge – How the sleeping the appetite the talking to others the therapy?*

*Me – shrug shoulders. Hang head in shame*

*Dr Judge – Scanning the room. Let's assess in another week.  
I am saved. I can stay another week.*

**20. 'Sam, you won't get into America again' (March 2003 In-patient a private psychiatric hospital)**

It is late morning. I sit on the edge of my bed in my Laura Ashley decorated room waiting waiting waiting. I repeatedly ask if there is any news – continuously as if on a loop. I ask anyone who passes by. No news yet. I sit on my bed, back to the headboard. Hunched up. Enveloping myself. Rocking back and forth. Red hot tension radiates up my back. Fear dread panic spreads. Don is sorting it out. I need to stay here. It is my only hope. No news yet no news yet no news yet.

*Them - There is a bed for you in the local holding pen.*

*Me – I want to go home I am not going back there I am going home to kill myself give me my shoes*

I search my room for my shoes. The nurse watches me from the open doorway, baring my exit.

*Me – where's my fucking shoes I'm leaving here going home what do you care you don't care where's Don give me my FUCKING SHOES*

More of them arrive. My doctor appears. I pace the floor of my cell. I will leave without my shoes. Emotions alien to me explode catatonic to raging inferno. Stand-off. Me in room. Them in doorway.

*Doctor – we can't allow you to leave*

*Me – who gives a fuck*

On a loop. One of them pulls away and steps towards me. She whispers in my ear

*June - Sam if they section you, you won't be allowed back into the States*

I sat down offer my hands up to them. I comply.

I had been an NHS patient in here for a week. There were no beds available in my local psychiatric hospital where I had recently spent 8 weeks. Then I was released only to be admitted to here 2 weeks later. Don was banging on doors trying to speak to local NHS managers to get them to agree to keep me in here. This place had a full therapeutic programme; in comparison the other was merely a holding facility.

At the same time that I was complying, Don got the agreement that I could stay. I was put on 24 hour observation.

## **21. 'If you don't behave, I will change your diagnosis to BPD' (private psychiatric hospital, 2003)**

It's 10 minutes in to our little chat. Patel (the posh consultant here – he travels a long way to do this private work) probes. Wants to know how things are. An omnipotent presence. Wonders whether I am ready for discharge. How the fuck do I know. I'm scared. Angry – don't know why. Don should be here. Patel, leans on the windowsill, arms folded, watching – he tries to engage me. He suggests that I sit. He lights the litmus paper.

I pace the room – the art room, the creative space. Agitated and angry. Fist clenching. Teddy in my hand, trailing by my side. Furious. A little bit of shouting. A lot of ignoring, of silence, eyes downcast. Walking out of the art room, down the corridor, down the elegant wide stairs, out the front door. It isn't locked. This place doesn't lock us in. Walking down the sweeping driveway, walking towards home. My teddy in my arms.

Furious. Where is Don? Why isn't he here? Fucking hate this place. Hate Patel – what does he fucking know about me? Walking towards the gate – the outside world, the sane world, the scary world, not my world. Stamp my feet, wait awhile. An eternity. Don still not here. It's a fair drive from home. Slowly walk back towards the ward. Baby steps, defiant steps, clutching my teddy. Sit on a bench below the big tree. Insignificant, frightened, disconnected, confused, holding my teddy.

Bend, look carefully at the ground. Looking for sharps, anything will do. A twig examined forensically. It will do. I start to scratch my arm, teddy at my side. Gentle probing strokes, gather intensity. Pinpricks of blood dot the lines. Press harder. It hurts. I have to punish myself. The arm is a bloody mess. I move on to the other arm. Repeat. Repeat. Repeat. I am a bad girl. This is all I deserve. I survey my work. It stings. The blood trickles are mesmerizing. The sane world disappears. I am here.

Don arrives. Looks at my arms. Hugs me. I pick up teddy. We walk back to the house. Patel is waiting. He looks at my arms

*Patel - If you don't behave, I will change your diagnosis to BPD*

I am damned.

## **22. 'There's nothing out there for people like you' (June 2003 in-patient discharge)**

Three months later. A whole heap of therapy later - broken down into component parts and sellotaped back together - tough exhausting bewildering exhilarating hopeful.... I am about to be released into the hands of my care-coordinator (community psychiatric nurse). My first one. I have always resisted. Better to be a dead person than labelled a 'nutter'. I sit in one of the posh meeting rooms, waiting waiting waiting.... She walks in – a stereotypical social worker. If I had been less broken, I would laugh. I register the thought. She sits, looks at me and says hello.

*Jermina – tell me about yourself*

*Me – Blah, blah, blah*

*Jermina – there is nothing out there for people like you.*

She might have just as easily punched me hard. I crumpled inside, didn't want the bitch knowing how this makes me feel. What was the point what was the fucking point? The work of the past 6 months gone wasted rubbish no hope what a bitch.

Jermina admitted that day groups were full of mentally ill people, drinking coffee, eating pre-chewed food ad infinitum. She didn't want that for me but she couldn't offer an alternative. She didn't recognise that at the time all I needed was to sit in the same room with others who were like me and drink coffee. She offered no hope.

### 23. 'You shouldn't have another baby' (2004)

My middle-aged psychiatrist – Dr Judge turns from my notes to face me

*Dr Judge – it is highly likely that if you have another baby, you will suffer a relapse. You really shouldn't have another baby.*

He turns to Don

*Dr Judge – what do you think?*

*Don – I think that you are probably right. What we have been through with John Doe, I don't think that I could do that again. It was so awful and we still struggle now*

He turns to face me

*Dr Judge – what do you think?*

I stare back. Silent. Taking the blows that are reigning down on my head. A fleeting memory of the euphoria that I felt in the hours that followed after John Doe's birth. Overwhelmed with awe and love. I wanted another two – bang bang bang.

I am being told that it would be unwise to have another child. In my heart, I know that they are right. I am only still on this earth because of Don's insistent watchfulness. I struggle to be a good enough mum. Unlike the other mums, glowing and selfless – motherhood has been a nightmare. Not John Doe – but all that surround him. I no longer know who I am. A lost cause, never good enough – my mother in my ear. Walk through treacle, always fantasising about my next sleep fix. I cannot cope. He would be better off without me. He is too young to remember me. Don will find a better mother. We limp though. Overuse of nursery. No family. Grandparents preferring to let us do it all by ourselves. Choosing not to hear the distress in Don's voice during the weekly call. Fucking crap mother. A nutter who always sleeps. John Doe too loud, too vibrant, too demanding. A walking zombie pretending to be a mother. Never good enough. I know so. Don is dad and mum to John Doe and me.

We couldn't do it again. I know this. But it hurts like hell to be told.

### 24. 'I think that you should take lithium' (2006 In-patient in a psychiatric hospital)

Feet up to my chest. Back to wall. She walks in. She may get me. She gives me the time. She listens. She waits. We've been doing this awhile now.

*Dr Brown – Sam I think we should try lithium now*

*Me – are you taking it too*

*Dr Brown – the other meds are not working blah, blah, blah*

Horrified. I've read Prozac Nation. I know the score. Stupefied zombiefied non-functioning automaton. I am now hitting with the big boys. My apprenticeship is complete. A fully paid-up nutter.

I am giving my first dose.

## **25. 'You have no choice' (from 2003 – 2012)**

A small impersonal consulting room. No photos. No plants. A desk. A computer. Three chairs. I sit on the lowest chair.

My notes open on the desk. He leafs through. Takes his time. Glances at me. How's the hair. Is she clean. Appropriately dressed.

*Dr Judge – how are you today*

*Me – side-effects really distressing walking through treacle no libido disconnected so so tired always sleeping always wanting to sleep never ending.....*

*Dr Judge – it's that or death – you have no choice – I'll see you in 3 months*

## **26. 'Hold Out your hands' (2003-2010 Friday Group)**

Friday again. Group again. Arrive a little late. People sitting in their usual places – chatting, reading the provided paper, playing dominoes (provided too) and drinking tea. Some sit alone, alone in their thoughts. We are allowed to make our own drink. Don't use all the milk. It's not for drinking. Some people colour in patterns or do crafty things in the other room. We wait. Wait until it's time to go home again.

As I enter, my thoughts noticeably dull. I leave Sam at the door. My language reboots to childhood. My step slows, shoulders hunch. A veil of infantilised unwellness descends. I become the part. I merge into the crowd. Lunch is prepared for us. Cheap, pre-chewed crap. Mum shouldn't have gone to Iceland. Yet we wait in glorious anticipation. I've got out of bed for this. The highlight of my week.

*Tina – LUNCH IS READY (she really does boom)*

Line up. Hold out our hands. Dollop of hand wash. Shuffle to food. Paper plate. Being watched. Always the same on offer. Don't touch food with hands. Being watched. Don't take too much. Naughty.

*Tina – YOU HAVE ALREADY HAD A PUDDING*

Loudly across the room. We freeze. Is she talking to me?

## **27. 'I've just seen in the paper that your sister has died' (2012)**

The phone rings. It is sister one. A friend has rung her and told her that she has read the obit in the paper (sister two has died).

We didn't know she was ill. We didn't know she was dead. The last time that we had seen her, she had turned up drunk at sister four's funeral. Sporadic sightings had been confirmed and attempted landings rebuffed – we didn't need her or want her in our lives. She was dead. Another loss that we had to process. Brother one had died the year before and we weren't invited to that funeral either.

Sister three phones our bereaved niece .... We are told that sister two didn't want us to know that she had died. I wonder why then put it in the paper – unless she wanted to punish us to get the last laugh. Sisters one and three were indignantly angry ...what right, bloody typical... a bitch to the end.... I (sister five) deeply saddened that she wanted to hurt us this badly. I also felt concern for the niece who was supposed to keep this a secret and could not then ask for our help or support.

It was an outer body experience. I looked down at the scene dispassionately, wondering at her motives – angry, misunderstood, malevolent, wanting to be centre stage. A puppet master's last performance. Three years on, sisters one and three are still angry. The result – a further chasm in our dysfunctional family. Interestingly, in both cases, I was excluded because of my supposed relationship with sister's one and three. When the shit hit the fan regarding brother one, I was a child. When the shit sprayed the room for sister two, I had lived away from the area for over 10 years. Mum had a lot to answer for. How long such heartache can continue, perpetuate and build. Mum has been dead 24 years, yet her influence lives on. I am alone in a large catholic extended family.

Anyways, more loss to add to my abandonment complex.

## **PART B: MOVING ONWARDS AND UPWARDS**

### **28. 'You are worth saving' (2004-2006 CBT one-to-one)**

Sitting in a small bare treatment room – a desk, a desktop, a desk chair and two low chairs. The room, coolish and darkish. The blinds drawn to shield the summer sun. The windows closed to protect confidentiality from the passers by. The anonymous room in the anonymous building. I wonder if the passers by have the slightest inkling as to what goes on in this building? I sit on a low chair, not facing Sylvia who sits in the desk chair – her the adult, me the child. Thirty months into a six week CBT course.... The conversation is uncomfortable. No eye contact. I swivel further in my chair away from her, looking towards the wall. I contemplate putting my hands over my ears. She wants

to talk about my achievements. I hold up my hand to obscure her face. I retreat further into the chair, folding myself into an envelope.

*Sylvia – The big black hole is there in front of you. It is bottomless and pitiless. You are heading towards it. You reach the edge. You can choose to jump in or you can choose to walk around it. Work with me to help you to choose to walk around it....*

*Me – Why*

*Sylvia – because you are worth saving.....*

## **29. 'You've had your moan, now let's get to work!' (c2005 Care Co-ordinator meeting)**

It's a warm summer's day. We are sitting in the garden. I am on a lounger and Jim sits next to me. He listens without interruption. He listens to my woes, my angst, my distress. He is with me in this moment. He is with me in my distress. I pause for breath, waiting for a response, for feedback for the usual platitudes – the usual soothing saccine comments that I am conditioned to receive but not believe. I need the comments so that I can throw them back in his face. It will not get better! I don't want to give it any more fucking time! Yadda, yadda, yadda. He sits quietly, aware of the conversation going on in my head, giving me space. Not adding to it. He gives me time. I'm pissed off with him. He is meant to help me. Yet he just sits, quietly serene.

He sits forward, closing in on me, invading my space. Ready to speak at last

*Jim – right you've had your moan, now it is time to work*

I look at him incredulously. How bloody dare him. In my head – my first reaction – fuck off Jim. I don't need you. You are like the rest of them. A bunch of wankers. I pause. I take a breath. Out loud I say

*Me - ok*

I didn't know it at the time but this was a turning point – an epiphany. I was being offered the choice to move forward with my recovery. I chose to do so, although I didn't know it at the time.

## **30. 'Keep the silence going' (2009-2011 Psychodynamic Therapy Group)**

I move my seat back from the circle. Need distance – my own space. Too intense. Jan surveys, her knowing eye. Takes us all in. She senses everything. She gives away nothing. She is power. She is God. She waits. We wait. I wait. Who will break the silence first? Amusement inside. I take bets. I can do silence. Silence is powerful. I am an adult.

We sit in a circle of sorts, intimate strangers 18 months into a relationship not of our choosing. Infantilized. No comms outside group. Verboten. Spill guts then walk away. Jan (the therapist) a blank canvas. Demands all gives nothing.

Silence. A glance at the clock. In my head 'it's your own time that you are wasting'. Wouldn't give her the satisfaction. Jan speaks.

*Jan – here are the dates when we will not meet. Okay.*

Jan passes around a sheet. I glance at it. Crumple it. Throw it back at her.

*Me – No it's not okay. You make these decisions unilaterally. This isn't a democracy. Why the pretence?*

I leave the circle and go and sit in the corner willing myself to sit under the table. I want to leave. I stay.

### **31. 'You have one of the best support networks that I have ever seen'**

We leave the consulting room. The care co-ordinator is pleased. They can tick their box. They don't need to worry I am well cared for.

*Don – what a load of bollocks*

*Me – what*

*Don – you..... all those people in your support network it's total fucking bollocks. Ok, you've got the names – your family (reels off names), my parents, a couple of friends but that is on paper. They are never there for you, for us, for John Doe. We do this alone. The only person who is supportive is Ruby. She's here she listens but up to a point..... the rest are fucking useless. We walk this path alone.*

Don hyperventilates

*Me – you never let them in*

*Don – when I am desperate I have asked – they didn't respond. I was lonelier than ever*

Realisation dawns – we truly walk this path alone.

### **32. 'You don't know the power that you have over others' (2012 Work)**

Often disconnected, little sense of self, a photographic negative. Rarely feel worthy to sit at the top table. Others better, more needy. Evidence of success or praise – talk to the hand – disassociate. It's not me. It's someone else. Never good enough. Mother whispers in my ear.

In supervision one day – I had been working in Trust for over 2 years (always waiting to be found out as an imposter) Lucy (my boss) casually remarked

*Lucy - When you enter a room everyone knows it*

*Lucy - You don't know the power that you have over others. People are drawn to you.*

Talk to the hand.

### **33. 'Mum you don't like wearing hats' (August 2012)**

Out of hospital, wobbly on my feet. Manic, loud insistent voice, vocalising a stream of consciousness. Rarely sleeping, laughing raucously – living every moment, joyous.....

*John Doe – she's not going to always be like this is she?*

*Don - no I don't think so*

Watching the Olympics – so important to me. Happy childhood memories. Have tickets – going to London – doctor said I could. I'll go in my wheelchair yeh – I will be a para-olympian!!!!!! Engrossed in the dressage. Concentrate on every movement – the rider and the horse are one. I am in love. Ideas run from my mouth. I shout to John Doe

*Me – I'm going ride in the dressage in Rio. There's plenty of time  
I ring my friend*

*Me - I'm going ride in the dressage in Rio. I need you to be my bagman, because I don't want to sweep up the shit myself. Will you do it? Will you come?*

John Doe rolls his eyes, deadpan he says

*John Doe – Mum you can't do the dressage. You don't like wearing hats.*

I had never ridden a horse before either.

Newly released from hospital. Lithium toxicity. Shouldn't be here. Blood work said that I had fatal level. Not sure how I survived. A good story to tell. Psychosis, complete loss of bodily control, green eruptions – liver shutting down. Missed the first half of the Olympics – but I had tickets!!! Don frustrated. Exhausted all the drinks in the Coop. This water tastes horrible. I'm not drinking it. Don cleaning up my mess. It is lucky that he fitted the loo next to the sink in the en-suite. I could evacuate at both ends at the same time. Liberal use of disinfectant. Waiting patiently until there was no more left to come up. Holding me up right in the shower. Forcing the lithium down my throat – the GP said that I had to continue taking it. Days of not eating, not drinking - it's only a stomach bug. Body jerking. Brain not connecting with body. Messages not getting

through. Help to go to bathroom. Can't do it by myself. Don pushing the lithium at me. Putting the tab to my lips. I dribble it out laughing. We play 'choo choo enters the tunnel'. He despairs. He is angry. I am not playing ball. He blames me. I am not helping myself to get better. Just drink and take your meds. I have no energy to laugh. I sleep. He wakes me to take a sip. I sleep. John Doe wakes me to take a sip. The Olympics playing on the radio quietly beside the bed. John Doe provides updates of the gold's that keep coming. The room smells of disinfectant. Don is on knees cleaning again. Time passes – it's been two weeks – it's been forever. I had tickets. A dream come true. I didn't care.

The GP arrives – I must be dead. Follow his finger. What finger. Whispered talking with Don. Ambulance called. Carried down stairs by two paramedics, bang, bang, bang. Away with the fairies. How was I feeling? Who am I? Laughing..... Trying to find a vein. There aren't any. They dig for gold, deeper, multiple sites. They all have a go – a junkie without the euphoria. They give me a break, then they try again. She is meant to be the best – she fails. Addictions ward. Own room. They still think there may be bugs too. A commode. Strangers wiping my arse. Waiting for strangers to wipe my arse. Hear voices in the night – they are coming to get me. Whispering, plotting, hunched over – they are coming for me. Behind the closed door. I want to move, to escape, to confront the voices. My body is not accepting messages from the brain. I just listen in despair. The night is so dark. So alone, so afraid. The addictions ward – from other inmates, there are shouts, attempted escapes, threats of the police. There is a look of disdain on the staff faces until they read my notes and see it is poisoning. Compassion appears – I am not a junkie, an alkie – I'm just unlucky. Don barely visits. He is angry. He can't go through this again. I am being watched. What I eat. What I drink. What I poo. Taken away and checked for consistency. I lay on my bed alone. Awake. Awake.

Listen to all the Olympic programmes. Draw comfort. A switch is turned on – from catatonia to mania. I am released into the care of my husband – care in the community.

I can go to the Olympics!

#### **34. 'I would prefer the teashop by the sea' (December 2014)**

*Sister three – I'm glad that you are feeling a little better – shall we have a coffee and catch up?*

*Me – I can manage meeting for a coffee in town*

*Sister three – I would prefer the teashop by the sea as I've not been there for months. Shall I invite sister one?*

Fuck off... I cannot believe it.... Do they ever think????????? The ever simmering volcano erupts. As usual Don gets the fall-out and as ever, he guides me through these hugely difficult, guilt ridden emotions. I want to ex-communicate them, escape to someplace else – new name, new identity. Effortlessly they drag me back into the black hole that is

my family. They throw a grenade without ever realising the emotional pain that results. I think that they think that I am just an incredibly spoilt bitch and perhaps I am. It suits them to lay the guilt on thick.

A simple meet up for coffee as equals, as sisters – sharing a common womb, a common sociopathic mother – yet worlds apart. I am sure that I was swopped with another baby in the hospital. We could not be more different – yet our commonalities are what causes me the greatest on-going pain, torment and torture. Often Don asks whether it wouldn't be better to just cut the cord. I have fantasies about this moment, yet I can't quite push forward enough to do this. The difference between the public and private persona in a nutshell.

Going to the teashop by the sea is a game changer. It ups the emotional stakes. It draws heavily on the resource bank. It takes time to recover from. A trip to the teashop by the sea involves obligations and expectations – the reincarnation of my mother – the reverting to the childlike state. I scream inside because I can't scream at them.

It's a trip to the teashop by the sea. It requires planning. The sisters revert to children to be picked up – to be taken – to be chauffeured. They would never dream of getting there themselves. I drive – just come out of your way, drive around town, pick us up – when we want you to – not a minute later – otherwise there is hell to pay and then do the same again in reverse after the teashop by the sea. A cup of tea in the teashop by the sea becomes a military manoeuvre.

Sister one has settled comfortably into her role of disabled victim – an elderly middle-aged woman – isolated and lonely – all of her own making. She basks in her illness narrative, childlike in her determination to dominate every moment with tales of her boils and bowel movements – happy to divulge whatever, whenever. Her superego has left the building. Low level racism, low rent criminal off-spring. Talks about nits and neglected grandchildren – she has no shame. Just a cup of tea in the teashop by the sea? Hell no!!!!!!

Sister one has never once come to visit me in my house in my town. We have been here for 16 years. Even when I have been at my worst, she has barely offered to help, look after John Doe... anything, ever..... yet she demands to be kept informed. A minute by minute account – to do what with – who knows because it has never translated into real support. This gnaws away at me. Always accusing, pointing the finger never offering an open hand. Just a cup of tea in the teashop by the sea? I don't think so.....

Sister three – her footprint on this earth vacuous. Another victim of her own making – getting off on being incompetent, uncomprehending and ..... Wanting everything to be done for her – she needs servicing – never contributing – always demanding in a passive aggressive way – so like Mum. Inconsequential, uninformed, disinterested. Doesn't even know who Obama is, doesn't care, doesn't concern her. Just a cup of tea in the teashop by the sea? She gorges at the teashop, long after everyone else is finished. Picks leftovers from other people's plates.... Never fed her kids properly... disgust and

revulsion. She will have indigestion later. Just a cup of tea in the teashop by the sea? Perhaps I really am the spoilt bitch that they think that I am.

This is all replayed on a loop, every time we visit the teashop by the sea. Add to this, I am just coming out of a period of severe clinical depression. And they want me to take them to the teashop by the sea? I wanted to say fuck off, don't you get it????? I said, obviously in a text

*Me – I can only manage coffee in town, perhaps we should leave it until after Christmas.....*

Meeting in town would involve for an hour. This is a big step forward. Still I seethe inside. So much left unsaid. Can't quite cut the ties yet. They probably think that they are bending over backwards to do what I want. Perhaps I really am the spoilt bitch that they think that I am.

## THRIVING NOT SURVIVING NARRATIVES

### PART A: LESSONS LEARNT – DOING THINGS DIFFERENTLY

#### 35. 'Look it up on the internet' (October 2012)

Don is on the phone to my consultant psychiatrist. The hospital has asked Don to inform her because it will be quicker than her waiting for my notes. She asks him why he is bothering her. He should be speaking to the GP. He tells her my lithium blood level. 2.7 – over 2 is considered potentially fatal. She relents. Agrees that it is very serious. Agrees to see me immediately.

We go to see her. I am walking with a stick. She wants to start me back on the lithium because it works. She can measure it. She can monitor it. Didn't do a particularly good job of that. Go figure. We agree to start again. Build it up. Weekly bloods. Attend lithium clinic. Talk about side-effects.

Six weeks later, it begins again. Toxicity is building again. Don rings the psychiatrist. Told to stop lithium immediately. She speaks to me

*Me – I am being sick again. Losing control of my body. Jerky like a Parkinson's.*

*Dr James – that is such a shame. Lithium works so well. I don't think that we should try it again. Here are your options - valproate or lamotrigine. You've already had carbamazepine. I suggest that you go away and do some research – because I know that you will – and then we meet next week to fully discuss your options*

I was being treated as an adult. I got the sense that she had the measure of me. Collaboration. I quite liked her. I looked them up. Neither looked like a good option but I didn't have a choice. This had been drummed into me. So lamotrigine it was.

### **36. 'Come back and end the group properly' (2011 Psychodynamic Therapy Group)**

I've had enough. The frustration and anger was building. Rationalise these raw emotions. Therapist hat on – it's transference and countertransference. Bollocks – I could still kill her – she's driving me mad. Her defence mechanisms, her unwillingness to share with the group, her inability to change – stuck and sinking in her victimhood. Oh how I despised her. She represented everything that I detested in weak, ineffectual women – God did she push my buttons!!!!!! I have put up with her for nearly 2 years – she has added nada apart from criticizing others and telling them how to live their lives. For the first year, she sat with her arms crossed and said nothing. Always arriving late – a sense of not committing to the group or that she was more important than the rest of us. Oh how I wanted to beat whatever it was out of her. She soaked up us spilling our guts, but added nothing to the mix. A blank sponge. Increasingly I wanted to scream at her. There were occasions of breakout aggression – forcing her to own her own stuff. She walked out of the group – not sure if she will return. I didn't like myself much for my behaviour. Control was hard. Resentment too long suppressed. Evidence of a very severe superego. Mother on my shoulder. Dr Jekyll and Mr Hyde. I was dealing with my own stuff and my incredible negative reaction to her..... and the group was coming to an end. Towering Inferno – at the mercy of the maelstrom of emotions – with a layer of knowledge and rationality to complicate things further.

I would leave the group – not her – how gracious and self-sacrificing was I? I would fall on my sword. The group was ending anyway. I could slink away quietly. My modus operandi intact. Normally I get away with this behaviour. I walk away, never to meet these people again and I move forward – ha bloody ha. I wrote the letter – I was allowing her to continue at the expense of moi – she obviously needed the group more – she was more fucked up than any of us. That's the end of that then!

I got a letter back. Would I come in for a one-to-one to talk this through?

*Me - Fucking hell Jan, can't you just let it lie? Fucking hell Don, do I have to go and see Jan? There's only a month left of the group and you know how it always knackers me.*

*Don – It will be good to talk it through and maybe end the group properly – say goodbye?????*

I went to the meeting with Jan. She listened – what's new. I talked. Shameful emotions – hating another vulnerable person – hating my barbed comments, my frustration, my anger. Punishing myself for being a bitch. Wanting to leave the group early because the emotion was too painful and raw. Never acknowledging that I could hurt so much – worthy to hurt so much. I wasn't worth anyone's time. Couldn't bear the group to end. Had to walk away first. My God, I was being laid bare by a silent mirror. Jan was doing

her job. The realisation of what was unconscious was excruciating. Jan patience personified. I was embarrassed to come back. Loss of face. What would the others think. I had acted like a spoiled brat. Humiliated, never gracious.

Together we worked out a plan for me to safely return to the group to end the group properly. To say goodbye to people who were so important to me – apart from her – I could still leave her – but I didn't want her to win either.

I went back – sloped in quietly, eyes down, waiting for the moment to apologise. I went back each week until it ended. I had said goodbye properly. I walked away with a hug and a smile. I was no longer the thief in the night. I walked out the room with pride – ten feet tall. I allowed myself to feel pride and it was ok. I felt liberated. I knew that things would be different from here on in – and they are.

### **37. 'You aren't doing too much are you' (2002-on-going)**

Choose any of the options below

- a) *I've been asked to be the Chair of Trustees at Mind*
- b) *I've got a job*
- c) *I am going to do a PhD*
- d) *Don and I are going travelling going to see friends going out twice in one week*
- e) *Blah blah blah*

Choose a response from those below all provided by the ever-helpful sisters one and three

- a) *You're not doing too much are you?*
- b) *What if it makes you ill?*
- c) *You are always pushing yourself?*
- d) *Why are you never satisfied?*
- e) *It will end in tears*

The sister's prefer me to be ill.... An introverted, disconnected automaton. Highlight of day/week/month to drink tea and listen to their inane incessant chatter about Corrie. I haven't watched it in years, but they don't care. They understand me when I am ill – I am one of them. I am monosyllabic – on a good day I can rise to two syllable words. They understand this. They think that my world becomes their world. They see me. They get me. They think that I am one of them. Myopic racists. Failed human

When I am ill, I scream within. I am empty, bereft of all emotion – yet I scream. Intolerable. This is no life I want more I need more. Stop colluding with my symptoms and drawing me into your world. Our worlds are not the same. We were born from the same womb but that is where WE end. I am ME and YOU are YOU. When I am hopeless I am more hopeful than the two of you put together. You will leave this earth with little

imprint of any contribution to humanity. Don't narrow my horizons to meet your own. I am more than our home town.

When I am well, we have even less in common. Soap chatter even less appealing, talking about people that I don't know, major outings to town. Asked no questions about my world. I retreat to the great world beyond. They see me less. I am in the world. I am thriving not just surviving.

Surviving is not in the plan. They don't get me. That's ok. I don't get them.

### **38. 'Leave your service user hat at the door' (2013 Work)**

*Me – why do I have to conform to the rules of working on the ward when I am the only person in the Trust that does my job? Why do I need to book all my annual leave a year in advance when I need flexibility to support my mental well-being? I am not a nurse who has to clock on and off.*

*Lucy – Because I cannot be seen to treat you differently. You have no more rights than anybody else.*

*Me – You recruited me because of my lived experience and that I also had professional skills and experience. This job can only be done by a service user. There are times that as a service user, I need some flexibility in order to be able to keep working. You know how motivated I am, the quality of my work and how hard I work. Sometimes though, I am a service user too. I didn't get the label for nothing... you cannot have one without the other. Why are you demanding more from me than non-service user colleagues?*

*Lucy – because your bar is higher. To prove that you are equal to professionals and worthy of a job in this Trust, you need to be performing at a higher standard than non-service user staff. You need to leave your service user needs at the door.*

She is an outed non-accepting service user. I left the Trust

### **39. 'You are a service user not a professional' (2013 A recovery college)**

I had been asked to become a peer trainer at a local mental health recovery college. I had met Anne (she was setting it up within a NHS Trust with a local FE college partnership) at a recovery conference and I had told her about my research. She wanted me to work on a narrative course.

I arrived at the start of the Two Day Train the Trainer course (I had already developed a similar course and had been delivering it for a number of years in another Trust. Added to this I was an experienced teacher, trainer and group facilitator). In the spirit of co-production, the participants were a mix of 'service users' and 'AMH Professionals'. Within this mixed bag, there seemed to be a number of service users newly out of crisis

(one guy kept falling asleep), totally inexperienced within this environment. This was true of the professionals too.

As the day progressed, I became increasingly alarmed at the overt demarcation between 'service user role' and 'professional role' within both the development and delivery of any course. Anne stood in front of the group outlining the 'professional role' and the 'service user role'. In horror, I realised that I was having my wings clipped – I was to perform under the service user ticket – to just tell my story. I was a professional too. Feeling anger rising. Weighted down with labels, disability, can't do..... attitudes, stigma, indignation of narrow perspectives... sense of all my work towards recovery and still thought of as inadequate.....just a service user. The sleeping guy across the room, reinforced the stereotype. I am more than my label – the moralising activist reared her indignant ugly head. I raised my hand...

*Me – Can I just check with you, I am here as a service user and that is the only part of me that you wish me to bring to the college? I am both. I am ..... Blah, blah, blah*

*Anne – yes, your role is as a service user – to essentially offer your lived experience. The AMH trainer will provide the theory/technical parts. There needs to be a clear delineation of roles – so the students are not confused.*

*Me – Life is not clear-cut. You don't want my knowledge and experience beyond my mental health label. You are effectively wheeling me out as a person who is brave and is doing well despite the odds..... where is the true role-modelling in this?*

I didn't want to be a part of this and that was okay. I will survive!

#### **40. 'I think that I need to increase my meds' (November 2014)**

Having just experienced the best summer for many years, my mood took a plunge – ever downward. This was the time for thriving not surviving. Triggers and warning signs duly noted. Public face stronger, private person fading. Disconnection, suicidal thoughts, insomnia, nightmares, clothes unchanged, toothbrush dry. Still working, ploughing on – need to get finished in double quick time. Hiding behind earphones, cut off from the world, not communicating. Same old, same old. Acknowledging that this was not right, knowing that I had to do something...

*Me – I think that I need to increase my meds to support me to be able to use my tools. It's a really difficult time. Christmas is coming up. I think adding in meds will hopefully halt the decline. I will make an appointment to see the GP to keep her in the loop. I am also going to increase how often I see my mentor.*

I am doing things differently. Taking charge. Being in control. Being an adult. Acknowledging that I have choices. Using my agency. Using my tools. I am still thriving in the midst of surviving. I keep working. I am resilient. I am mindful. I am making connections – reaching out.

#### **41. 'Your pay grade isn't high enough to support you in doing a PhD' (June 2013 Work)**

My monster of a manager calls me into her office for another bollocking.... I've been told that although I am working very hard, she can see that my heart isn't in it... she is fighting a war of attrition that recently has gathered momentum into a full assault. I know that she sees me as a threat. She wants me gone. She wants me out. She hates that I am being reasonable and not rising to the bait.

I know that I need more. I don't want her job. I am enjoying the project management work – it gives me a buzz. The desire to do a PhD is taking hold. I really think that the time is right to go for it.

I get the bollocking. I know that it is not about me. It's all about her. She then gets on to the PhD stuff. She lands the final blow. Previously I had asked her if there was any mileage in the Trust supporting me in someway to do my PhD in recovery.

*Lucy – I've spoken to Liz (Director of Operations) and we've agreed that your pay grade is too low to support you. Also we don't feel that we will get any benefit from you doing a PhD*

*Me – ok*

The meeting continues – she wants to see me making the appropriate effort and blah blah blah. I ask for a copy of her notes from the meeting.

I leave the office. I will not give her the satisfaction of knowing how this makes me feel. I make a cup of tea and then go home. She has made the decision for me. I will do my PhD. I know that I will.

I hand in the resignation letter. She becomes my best buddie. Can I hug you? she asks. She is relieved. She has won and maybe she has, but it wasn't a battle worth fighting. I work my notice say goodbye walk out tall never look back no regrets.

#### **42. 'There's nothing that I can do for you' (May 2012)**

Sometime May 2012. The generic consulting room, behind locked doors. No privileged access - wait to be invited in. Their appointment, their schedule. Creating powerlessness before a word is uttered. My psychiatrist – I don't know her. I am a name on a list. She doesn't know Sam. She has skimmed Samantha's notes. Impasse. I bristle before a word is spoken – this all-powerful 5 year old sits before me. In a higher chair of course! She keeps me waiting and then she plays her opening gambit.

*Dr Barbie – So how are you Samantha?*

*Me – I'm doing really well*

*Barbie – Take me through your meds. What levels are you on?*

*Me – I am on a lot less than you think I am. I have been steadily reducing them (as discussed with Cat – care co-ordinator) and I feel really good. As you know, I am no longer on a mood stabiliser. The one (ends in GIN) after lithium didn't seem to be making any difference, so we agreed to try without it. And that has seemed to work.*

Barbie casts a glance at Don who is sitting next to me in the naughty chair.

*Me – So the Sertraline, I'm down to 50mg and Mirtazapine to 15mg nocta. And I feel ready to knock the Sertraline out all together. I sit further back in my chair and feel empowered.*

*Barbie – I thought that 'we' had agreed that this would be a managed withdrawal.*

*Me – I agree and it has been!*

*Barbie – But it has not been under my supervision. I want you to increase your dosages – back up to 200mg of Sertraline and 30mg Mirtazapine – then we will withdraw in a fully supervised manner.*

I cannot believe what I am hearing. I feel more agitated and angry. I will not be treated like a thick child. I sit forward. I glance to Don for support.

*Me – Are you listening to me? Have you heard a word that I have been saying... I have been withdrawing responsibly... I am using all my tools and I feel great... I am feeling emotions and working through them... I am not walking through treacle... I am alive... I see colours again... I will not increase my meds again just so you can tick your medical model risk adverse box that you are supervising my withdrawal. I am not saying I will never take meds again, I just want to live with the minimum that I can.*

Barbie turns back to my notes and makes some notes. I imagine 'challenging' comes up! She turns to face Don (pleading for support). He agrees with me.

*Barbie – So there is nothing that I can offer you. I am discharging you from my clinic - you will still see Cat.*

We all stand up and leave the office. The locked door closes behind me. I feel 10 feet tall. Discharge is not a fearful place of failure, scaredness and loneliness – discharge is a place of freedom and risk, of ownership and agency. Discharge is a brave new world and it feels good.

#### **43. 'It's alright for people like you' (December 2013)**

*A carer – I don't know what recovery means for us – it's alright for people like you*

*Me – eh*

*Carer – my son is a paranoid schizophrenic. He pees into bottles. He lives in a mice infested flat. He doesn't believe that medication or the services work. He doesn't trust us. I ring him – he screams down the phone. He doesn't answer the door. He is alone.....*

*Me – what do you mean that it is alright for people like me?*

*Carer – you are bright, articulate. You have Don. You are in the world. Services work for you. There is no comparison between you and our son. Recovery isn't possible for our son. There is no hope.....*

It's alright for someone like you bellows through my head. Deeply hurt, indignant, affronted, uncomprehending. Someone like me?

Don and I are running an 8 weeks course for carers around recovery and self-care. We are 5 weeks in. I have a feel for the 9 carers that turn up each week – know a little about them and whom they care for. Naively, I assumed that they got the concept of recovery, otherwise why were they coming on this course? Silly me. Carers are a different breed.

I acknowledge that I had certain derogatory pre-conceived thoughts and opinions about carers: power hungry, living their lives through the distress of others, an impediment to recovery, old, toothless moaners. They don't get us and we don't get them. I suppose that this view – and it is a deeply held disdain – is in part very much due to the sister three. She is my nephew's carer. He a paranoid bipolaroid, brought on by a drug induced psychosis when he was 17. He is now a 5 year old 31 year old man. Infantilised, living in a cocoon of his mother's making. He sits up all night smoking and hiding from the world. Jobless friendless meaningless – he was a gregarious teenager. He is alone living in a twilight netherworld of despair and hopelessness. She fears that he will go back on the weed. So protects him by shutting down all avenues of hope. Her limited horizons are his – and they shrink exponentially as each day passes. He is a lost soul who looks in the mirror and sees the face of his mother saying no.

So she does colour my view of carers. Anyway back to the story Ronnie. Tonight's class is on recovery. The carer's comments have knocked me. I am supposed to be doing my recovery narrative. I don't want to now. I feel all funny inside. I am not going to share my life with this carer. Don continues the discussion with the carer. I retreat into my head – a full blown confrontation with myself. I want to go home. The 'old me' would have just left – quietly during the coffee break. Course over you ungrateful bitch. I could do with puking right now. Don catches my eye – a slight movement of the head. He understands – I forget that he is a carer too. I decide that I will do my talk – mainly to show her that change is possible that there is always hope – even for people like her son.

Later when I reflect on this experience, I realise that I generally talk to people that get recovery, want recovery in their lives, and want to move forward. Her view pole-axed me. She is the kind of person that I need to get too. People who get recovery will move forward anyway – she wont.

I do my talk – I do the full in yer face description of living with suicidal ideation on a daily basis. The impact on our family. The loss – the catastrophe. Even for people like me. I told them what it was like – my relationship with Don as my carer and partner. When I finished she said

*Carer – I get what you mean now. You have given me hope.*

#### **44. 'Do you hide her meds?'**

*Dr Judge to Don – do you hide her meds and just give her what she is meant to have (I was also in the room)*

*Don – no if I hid her meds, she would find something else to use*

Unconsciously Don was expressing my agency – treating me as an adult, albeit a pretty messed up one at the time. He was right, how do you suicide proof a house? It couldn't be done. Admittedly I was very creative when it came to self-harm tools. If I could do it in a ligature free room on a closed ward in a psychiatric unit, what hope did he have?

Reflecting on Don as my carer and husband over the past 18 years, I have mixed emotions and a deal of ambivalence. Don has always been very clear that he didn't want to be my carer. He is my husband but for great tracts of time he has been my carer too. When the carer role dominates our relationship changes. Effortlessly we move from a partnership to one of parenting. In a parenting role he puts food in front of me and guides me to the shower. He is the good parent. I am the naughty child. I scream at him – often in silence, in my head – because I want him to get it right without telling him. I expect him to be in my head and understanding my needs totally – and those needs can change on a minute by minute basis as does how I want him to react and meet those needs. The ambivalence is here – I love him, I hate him, I need him, I wish that he would leave, he's a saint, he's a bastard .....

When I was in the private psychiatric hospital (2003), he said

*Don – if after all this therapy, you come to realise that you need something else, that there is no place in your life for me – I will understand. I want what is best for you*

At the time, I didn't understand what he meant – was he cutting me loose?

Another abiding memory I have – we are lying in bed. It's early. Very dark. Even in summer, it is always dark. Oppressively dark. He listens. He holds me. In a monotone, I talk of despair of emptiness and death. I beg him to release me, to let me go, to get on with his life, give John Doe a better future, let me go, this is worse than death, I beg you. He listens as I repeat on loop. He says that he will never give up on me that he will hold the hope for both of us. This scene is repeated every night for months and then again every few years. He turns grey. He starts to self-medicate with alcohol – he despairs. He believes in me.

In the past couple of years, Don has been in therapy too. He wonders if how we interact, especially in relation to his carer role has impeded my recovery. He has been able to consciously acknowledge that he is a people pleaser – always to his detriment – and that has allowed me to maintain behaviours that serve no good purpose – he has let me get away with murder. We have been working on changing our behaviours to each other – we are growing together. We are being more honest and authentic. We are starting to own our emotions and feeling less afraid to voice them. We are partners again.

Don is becoming who he wants to be. His has gone all pink and fluffy. His Dad remarked that he would be getting a tattoo next – he did that last year!

## **PART B: EPIPHANIES**

### **45. 'I bet that you are borderline' (2011 Work)**

*Her – I bet you are borderline*

I stand in my office doorway perplexed. Borderline moi? Headlines run through my head - untratable unmentionable – what signals have I been giving off?

*Me – what makes you say that*

*Lucy – well.....*

I'll Google it when I get home – an eureka moment – welcome to my world.

### **46. 'I wished that she had just killed herself' (2012)**

We sit in the car, looking out to sea. Good, hot coffee on the dashboard. We have just dropped John Doe off and decided that as we were already here, to get a coffee and enjoy the view. It's blowing a gale. Horizontal rain. So we sit in the car, chewing the cud, talking about this and that, a little bit of bitching, reminiscing, planning. We can eat veggie tonight as John Doe is out.... Yadda, yadda, yadda..... An old married couple, comfortable in the chat and the silence. Sipping coffee, glad that I'd got the nutty syrup.

A thought pops into my head. Out of kilter with our gossip. Abrupt but not unwelcome. I turn to Don, whisper

*Me – I wished that she had killed herself*

*Don – what*

*Me - I wished that she had killed herself. It would have saved us all a lot of heartache*

I had said it out loud. I had never consciously thought this before – and there it suddenly was. My mother should have just done the deed. There it is, loud and bold.

Acknowledging that she had her demons. She didn't deal with them. She made my life a misery. A dead mother by her own hand would have been preferable. We could have all grieved and then lived our lives – less damaged than we are now.

*Me – I can't believe that I've just said that. I know that survivors of suicide never get over it. This is why I am still here, but she really should have just done it.*

She would have set me free

#### **47. 'You've found your voice' (July 2013 Work)**

I've handed in my notice at the Trust. I'm leaving in three weeks time. Fuck her and fuck those who sail in her. Perhaps a bit harsh. Perhaps I could've gone for constructive dismissal but I wanted to leave on a positive and start my PhD adventure. Wounded but not defeated. I let it go.

I don't have to toe the party line anymore. I'm at a conference on the joint working between the Council and the Trust – looking at service provision for the next five years. Sitting at my table is James – my public school radical Marxist colleague and fellow survivor. He rages against the oppression of mental health services at every opportunity – and somehow he is allowed to get away with it. Is it his accent? Is it the fact that he is up in the North (the far reaches of our locality), so he can't do too much harm? Or is he a token service user to be tolerated? Anyway, I like him.

I make a throwaway cutting remark about the reality of services and the propaganda that is used. James looks at me and says

*James – Sam, you have found your voice again*

I am startled. Bloody hell, he is right. I had got the job partly as a result of my activism and leadership and then it had been wiped out, rubbed out as I slowly swallowed the corporate bollocks. I morphed into a suit. I became the voice piece of the ideal service user – not a dribbling, dirty, keys around the neck wreck – but an articulate professional who also happened to go mad in her own time. I became one of them. I ticked their box – I became an agent under their control with a license to beautify others. I was silenced. I suppressed opinion when I sensed injustice. I accepted that I should be grateful at being invited to sit at the same table as them. I allowed and participated in corporate tokenism.

I was ashamed. The suit did not match my core beliefs. No wonder I was struggling. Every day that I dragged myself into work was a slow death. Anger and frustration ever increasing.

I resigned. I could breathe again.

#### **48. 'Don't you know that I am borderline?'**

I have been a service user since 1996. A long long time. In that time, there has been huge lows, suicide attempts and long hospital stays – always informal with the threat of becoming formal never far away. There has been so, so many different drugs. Some made me aggressive, some catatonic – all made me sleepy and dead below the waist. I stumbled through life, mothered John Doe to a greater and lesser extent (depending where in the mood cycle I was) and was parented by Don for much of this period. I withdrew, disconnected, played a public Sam and more often than not the private Sam and Don and John Doe paid the price. Few could believe that I was a nutter. The mask was a fabulously elaborate, beautifully gilded one. The public Sam who sat on a pedestal often became the childlike catatonic unkempt nobody – only Don saw this. Even John Doe was kept at arms length during these long times. I was like a watered down version of the Incredible Hulk but in reverse. The public got the best of me, leaving only crumbs for Don and John Doe.

As the years of therapy bedded in and I started to use my tools, believe in myself and acknowledge and accept that I had my limitations, I began to grow. It is often said that people want to go back to who they were before a trauma or catastrophic event. And this was true for me for quite some time. Then something switched. I didn't want to go back to the person that I was before – the inauthentic Sam. In all the crap, I had been growing, gaining agency becoming more whole. As the capitalist dream became more unattainable (and to be honest, it was never my dream anyway – it was the expectations of others). Accepting that I would always need to manage my mental health that it was a tight line that I walked. I had become more human, more compassionate, and more open to new ideas, more resilient.

In the wilderness years, I paint a picture of desolation, pain and unknowing. And indeed it was. But it was also a time of success and creativity – of discovering new me's – skills and interests – walking a path that I would have never thought possible in the pre-John Doe days. I achieved academic success, work success and fulfilment, a return to my political activism, a deeper understanding with Don – a more deeply fulfilling life. I was back out in the world, actually living it and not mimicking it.

And so life went on.....

About three years ago two things struck me, both incredibly profound – both whilst I was driving home from work.

1. I had had a particularly good day at work. I can't remember what I had been doing. I could make it up and probably an older version of me would have done because of the need to be perfect, but it is actually enough to remember the emotion rather than what triggered the emotion. The sun was shining. The air felt warm. A song I liked played on the radio. I turned into my road. In that moment I had the thought

*'This is what it feels like to be happy'*

I felt the emotion and I could put a name to it. I don't think that I have ever been able to do this consciously before.

2. Similar scenario – returning home from work feeling happy. I could put a name to the emotion now. Looking forward to seeing Don and John Doe. I was driving across the Bridge (high above the river), looking at the horizon – feeling really good. A thought pops into my head uninvited, alarming...

*'This has been a good day... it would be a good day to check out.... Check out on a high'*

I imagined myself turning the wheel towards the wall and stepping hard onto the accelerator. My hand actually moved towards the seatbelt as if to undo it. I imagined hitting the wall and flying through the air towards oblivion below.

Then the moment passed.

Afterwards, I had many similar moments – utter clarity and ruthlessly rational. Always, in that moment, it seemed the right thing to do.

I suppose that I have had suicidal thoughts for much of my adult life. Even where I am now, I still have them almost daily. I idealise, I fantasize, I plan. I have a desire to self-harm – a desire that I have to work hard not to give into – because that way spells doom. I realised that I have suicidal thoughts and a deep over-whelming sense of emptiness even when I am not clinically depressed. I have suicidal thoughts and a deep over-whelming sense of emptiness even though I am married to my love of my life and that we have been together forever. I have suicidal thoughts and a deep over-whelming sense of emptiness even though I have a beautiful, happy son. I have suicidal thoughts and a deep over-whelming sense of emptiness even though to all outsiders I am successful, bright and can do what I want. I have suicidal thoughts and a deep over-whelming sense of emptiness because I do.

This realisation was an eureka moment. I DSM-IV'd the symptoms – Borderline Personality Disorder. I have a well-thumbed DSM-IV in my study. I ran a finger down the different behaviour categories – tick, tick, tick... I was coming home. Hello Sam – this is who you are (to a degree – I am not full-blown). The key thing, which helped to explain so much, was that I have a deep fear of abandonment. It coloured relationships, how I ended things (I could never say goodbye – I would just slink away). I have my fantasy of escaping to a place where nobody would know me. I did the abandoning to save myself from being abandoned. Even after 30 years together, I still have the daily fear that Don will abandon me for someone else. The 'other' is always better.

The sense of abandonment diminishes me. It can overwhelm – again leaving the frightened unloved child. However the realisation and knowledge of what was happening and what was triggering particular behavioural patterns was in itself deeply powerful and liberating. Both Don and I can recognise, discuss and laugh when 'my

abandonment issue' kicks in. This insight allows me to choose to react to it differently, although the emotions accompanying it are as intense as ever. The nightmares still happen, but the understanding that I was pretty emotionally unstable has had quite a stabilising effect. I feel quite the adult now. I see much less of the tantruming two-year old. It is liberating and so much less exhausting.

#### **49. 'The old Sam'**

I often prefixed sentences with 'the old Sam' suggesting that the old one would have done things differently. Someone once asked me, why I used this phrase so much. I had to think, to analyse to consider...

I was telling people that I am doing things differently – even telling people who didn't know the old Sam. I needed to remind myself that I was doing things differently. It is incredibly important and at times life-saving that I use the tools that I have developed in all the years of therapy – it makes all the wasted years worthwhile – to have gone through all the shit and not learnt anything – they might as well shoot me now. I acknowledge that I am intolerant of people who do not learn and apply to change their lives for the better – always cast as the victim, playing the victim role and taking a bow. I suppose that I need to acknowledge to myself and others that change takes effort and energy. Nearly 20 years into this sentence and the 'cant do scary impossible, weak, dependent – are often still my default positions. I have to work to turn it around. The old Sam – without the benefit of insight and tools - would have reacted and behaved differently, punitively and gravely – perpetuating disconnection and self-hatred. The new Sam said, did and felt differently. I suppose part of me was also showing off that I was doing things better, more appropriately, less toddler-like and that people were also benefitting as a result. I needed to be continually reminded of how far I had come. To move forward, to thrive and not just survive. The old Sam was surviving and often barely that. The new Sam is out in the world living, contributing, shouting from the rooftops. Yah!

I say the 'old Sam' less often out loud, but I have a wry internal grin when I think it. Oh I'm growing into an adult!

### **PART C: MOMENTS**

#### **50. 'Life is too short – bring only the best wine' (August 2014)**

A request delivered with love. Joy closely followed by dread. Will the wine chosen be the best – will I measure up? Will the Coop in the village meet this demand? Highly unlikely. Hey ho. I am in the midst of the summer of love, nostalgia, laughter – the clock

turned back 30 years – I am a teenager again. Back to where it had all began – our 30<sup>th</sup> reunion.

Scholarship girl from the backend of nowhere. Council house groupie going to a sink school. Always punching above my weight. Trying to wash the estate out of the girl. Double negatives no grammar education experiment – you can take the girl out of the estate but you can't take the estate out of the girl. Flying high – would go far. Teachers who believed but never taught to play the game. Punching above her weight. Scholarship girl – how could she possibly???????????

A castle in the sky. The girl has come home. So many are like here. Best friends forever. The handsome prince is spied, plotted against and caught. He's mine all mine forever. Work so hard, give of ourselves so much, grow ever upwards, love deeply, party like it's 1999. Soul mates found – deepest secrets shared. We were all escaping. We all left something behind.

It is all over. We scatter to the four winds of the globe. Angry that life outside the castle doesn't match up. University – they are all kids. Back to the council estate no privilege mum's demands. Don and I cling to each other – nurturing our souls with our memories. Renounced the castle in the sky and the people in it. Did it ruin our lives – life would never match up. Don't want anything more to do with it.

Letters start to arrive – book for the 30<sup>th</sup> reunion. I can't bear to think about it. I am a overweight nutter who has achieved nowt. Kings, captains of industry, politicians among our alumni. Why put ourselves through this torture. Gossip trickled in. A few tentative emails. Meeting up for coffee in London. Discovered other screw-ups – others who have lived and suffered and are still here. Realised that we did still like them – no realised that they got us.

We booked our tickets. Months passed. Clothes shopping. Does this make me look slimmer? Scared uber-excited. We walk down the driveway towards the castle. I ask Don to stop at the top to take in the view of the castle and the sea. I drag my feet. Take baby steps. I cling to Don's arm. Can we turn back? We walk slowly on, ever closer. If it is awful we walk away and never look back. The Tithe Barn is in front of us. Lots of people milling around. Recognition from a distance. I see my Chilean dorm-mate. She sees me. We walk towards each other and hold each other. Thirty years melt away. It was right to come.

The wine order comes the next day. Ric, Don's Chilean dorm-mate announces that the wine that will be served at the reunion dinner will not be good enough. He has despatched all the car drivers in our gang to buy the good stuff. We all do our best. We are all kids again – not sleeping drinking too much getting louder and more risqué. We are not the 50 somethings anymore. Responsibilities have been left at the Portcullis. We plot, we plan, we drink some more. We revisit old haunts, a little inter-dorm visiting. We recount 30 years of our lives. Our old gang back together again. We are fully human again, authentic and complex..... Chile, South Africa, Zimbabwe, Norway, USA, UK and Gosport....

We are going to do it all again in 2015 in Scotland.. then South Africa.... then Chile. I am living again. Thriving not surviving. They get me, diagnosis and all. They value what I do. We are all survivors but now it is our time again.

### **51. 'Sam you are so naughty' (November 2014)**

An impromptu house party in Manchester with old college friends. Sitting around late into night drinking red wine and talking Tolkien, inter-dorm visiting, Post Modernism, divorce, opera, kids, Talisker whiskey.... Friendship recently rekindled. We get each other, grew up together, escaped together. We are 18 again laughing planning being naughty being rude being loud being crude being earnest smoking cigars being us. Hugging and holding each other. Love and understanding that is real. Our time has come to be us again.

### **52. Getting Back on The Horse**

As I reflect on the time from 1996 – 2010, it is easier to concentrate on the horror, the despair, the sheer emptiness and waste – the black hole. It is easy to remind myself of the loss, the hopelessness – my constricted and constrained world. The mental patient – the nut job – the shirker, the lazy bitch... yadda, yadda, yadda. To relive these tortuous times in all their monochrome glory. Yet in this same time, I also achieved many things. I find it harder to remember or acknowledge these counterpoints. I had to be reminded by Don. As I think about them now, I am unable to put any of them into vignettes – only straightforward prose will do. A list of 'didn't she do well', 'not bad for a nutter'..... It is either this or leave them out.

At the point of when I was at one of my lowest points – early in my mental illness journey, when I was the walking zombie, the bad mother, the cold wife, I did two things, which on reflection were two very important things, which positively changed the course of my life.

1. I began and completed a psychology degree with the Open University. I fell in love with psychology. It helped develop new skills in me but also accentuated existing difficulties. I was awarded a first class degree and was a Bruner Prize winner – but I fought daily battles with being good enough to the point that I worked beyond the point of exhaustion and it precipitated a major breakdown.
2. I went back to teaching – working with young people but in a completely different way – holistically – working as an advisory teacher to support other teachers to work holistically with excluded young people.

Another important factor in my recovery has been by mental health activism and getting involved in running mental health services – essentially making a difference to the lives of others, which in itself has a profound effect on me. All done with small steps – a little

bit of volunteering, a bit of managing services, a bit of directing and finally a paid, permanent job within the enemy camp. Now I am doing a PhD in activism.

This continual movement and getting involved, trying new things and taking risks supported me in regaining a sense of self. Tenuous at times but growing in strength and confidence, giving me a sense that I can do things and be successful. All is not lost. I may be a mental health service user, but I am so much more. I am not my diagnosis – well not all the time anyway! It's much harder to joke and make light of success or the good stuff, but it is there. My recovery journey is light and shade, ying and yang – but I have to work much harder to remember this!

It highlights the public and private persona thing again. At home, I am often in PJ's eating my dinner off a tray watching TV. I watch crap. I watch crime dramas. I watch blockbuster and subtitled art house movies. I avidly follow sport. Go to games, drink beer and swear with the best of them. I enjoy good food and Crunchies. I go and see comedy and opera. Gigging from Blondie to Andy Williams. I talk about philosophy and nonsense. I have high hopes and am happy to just be. Walking the dog with Don by the sea is wonderful. Bickering about a question on Never Mind The Buzzcocks with John Doe -priceless. Reconnecting with long lost friends – life-affirming. Unfriending those who add nothing – liberating. I am complex, mask wearing, open and increasingly authentic. It has to be worked at each and every day.

### **53. 'That is why we are so attracted to you' (January 2015)**

Part of a personal email from a friend. We had been talking about recovery and writing these vignettes...

*Terri - ... You are inspirational you know!!!! I think it amazing on so many levels. One, the raw honesty with which you face yourself, and your experiences, and expressing them head on. It is so truthful and real. No masked prettying up of it and that must be key to recovery. Secondly, the never being the victim and 'not doing victims' a second key to recovery. It does not mean you do not do compassion it means no victim mentality. And I think you are incredible the way you forge the way ahead all the time through your own personal difficulties but at the same time inspire others. Truly amazing Sam!!! That's one of the reasons as to we are so attracted to you (that is apart from your obvious love of cricket and your wicket :) sense of humour etc.. ). I do admire you. I know it is tough. I know from my own journey. I find you more honest than I am about it.*

### **54. 'You are an inspiration'**

A person that I admire said this to me recently. Although difficult to accept, I said thank you. I knew that it was heartfelt. It left me wondering what it is about me that others see. Things that I still find difficult to accept or acknowledge out loud. Sentiments and attributes that leave me squirming. How do I inspire? What is it that I do? Is it by

example and role modelling or my values as a human being? I know that I want to make a difference. I know that I want others to see that one can do whatever they want whilst living with mental distress. Does this make me inspirational? I am just making my path by walking it.

## Autoethnography Vignettes: Thematic Analysis: Frequency of Codes

### Appendix 4.1

Code	Frequency
Ambivalence	6
Recurring Patterns	4
Juxtapositions	6
No regrets	1
Regrets	2
Memories	2
Reflections	20
Epiphanies	20
Knowledge	5
Understanding	20
Dates and times	20
Contexts	28
Places	3
Recovery narrative	6
Recovery journey	5
Positive emotions	7
Good behaviour	3
Activism	9
Work	16
Work at recovery	6
Recovery tools	4
Acceptance	5
Hope	14
Empowered	5
Positive change in me	20
Alex	7
Don	50
Family	26
Mother	46
Dad	5
Friends	9
Labels	11
Stereotypes	4
Roles we play	60
Public v private	13
Internal and external worlds	33
Cannot voice/no language	19
Sense of self	39
Core values	8
Default position	1
Good enough	9
What does recovery mean to others	1
Other's view of me	48
Expectations	38

Code	Frequency
Disappointments	5
External drivers	3
External decision makers	7
Bereavement	6
Abandonment	10
Endings	6
Escape	15
Aloneness	6
Collaboration	10
Relationships	24
Communications	17
Connections	6
Didn't want others to know	9
Comfort	6
Home	9
Safe	1
Symptoms	20
Negative emotions	46
Trauma	11
No hope	5
Punishing myself	9
Effects of mental illness	47
Waiting	15
Physical	31
Bad behaviour	24
Suicide	22
Choice and conformity	23
Power	42
Agency	2
Playing the game	15
Medication	12
Control	3
Collusion	1
Treatment	48

Recurring Patterns 4  
Ambivalence 6  
Juxtapositions 6

No regrets 1  
Regrets 2  
Reflections 20  
Memories 2  
Epiphanies 10  
Knowledge 5  
Understanding 20

Contexts 28  
Recovery narrative 6  
Dates and times 20  
Recovery journey 5  
Places 3

Labels 11  
Stereotypes 4  
Internal and external worlds 33  
Public v private 13  
Roles we play 60  
Cannot voice/no language 19  
Others' view of me 48  
Sense of self 39  
Core values 8  
What does recovery mean to others 1  
Good enough 9  
Default position 1

John Doe 7  
Dad 5  
Don 50  
Mother 46  
Friends 9  
Family 26

Disappointment 5  
Expectations 38  
External drivers 3  
External decision makers 7

Collaboration 10  
Relationships 24  
Communications 17  
Connections 6  
Didn't want others to know 9

Choices and conformity 23  
Agency 2  
Medication 12  
Power 42  
Control 3  
Treatment 48  
Play the game 15  
Collusion 1

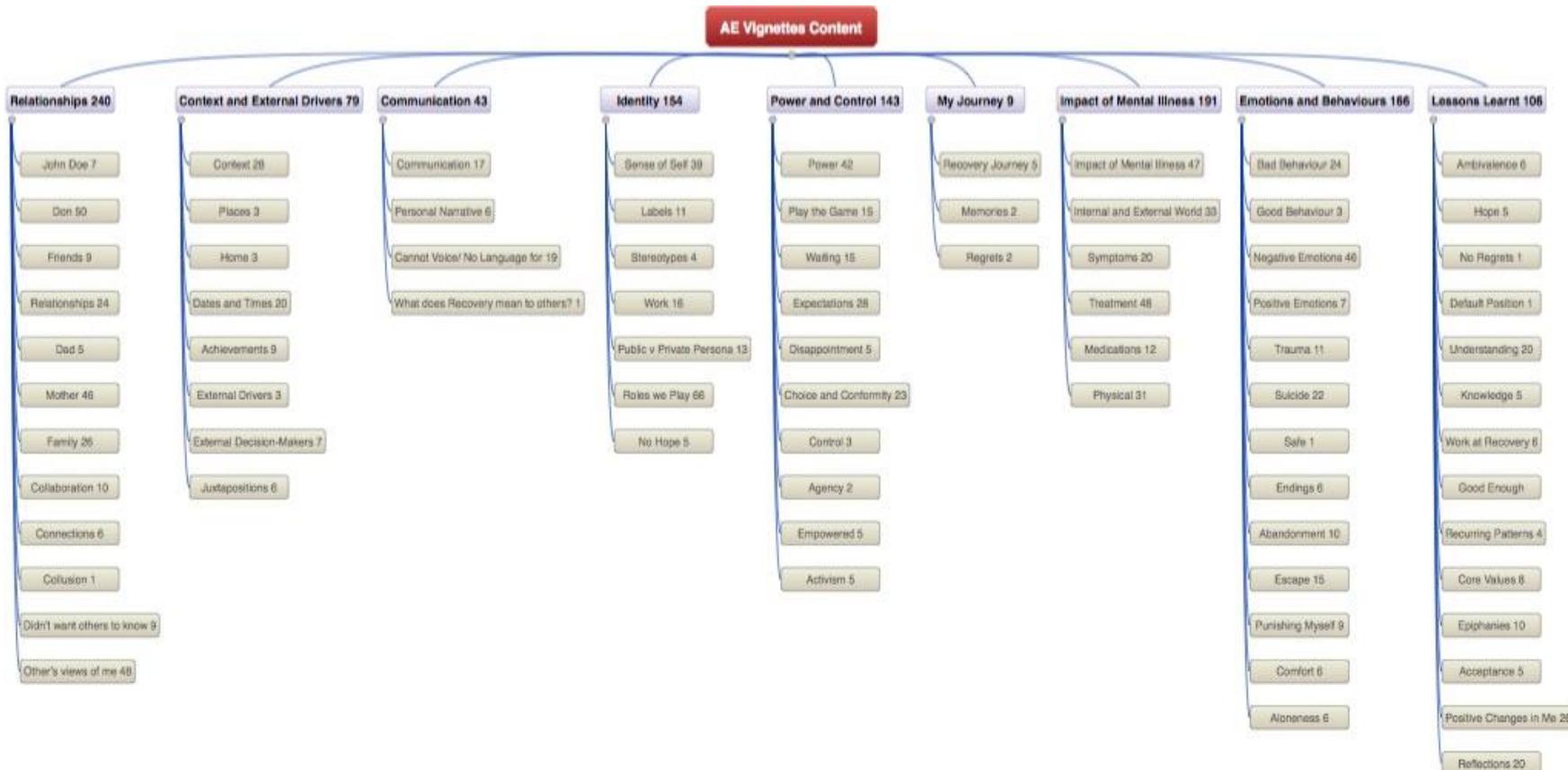
Comfort 6  
Home 9  
Safe 1

Bereavement 6  
Endings 6  
Abandonment 10  
Aloneness 6  
Escape 15

Symptoms 20  
No hope 5  
Waiting 15  
Physical 31  
Negative emotions 46  
Punishing myself 9  
Bad behaviour 24  
Trauma 11  
Effects of mental illness 47  
Suicide 22

Positive emotions 7  
Good behaviour 3  
Work 16  
Activism 5  
Work at recovery 6  
Acceptance 5  
Empowered 5  
Achievements 9  
Hope 14  
Recovery tools 4  
Positive changes in me 20

Relationships 240	Context and External Drivers 79	Communication 43	Identity 154	Power and Control 143	My Journey 9	Impact of Mental Illness 191	Emotions and Behaviours 166	Lessons Learnt 106
JohnDoe 7	Context 28	Communication 17	Sense of Self 39	Power 42	Recovery Journey 5	Impact of Mental Illness 47	Bad Behaviour 24	Ambivalence 6
Don 50	Places 3	Personal Narrative 6	Labels 11	Play the Game 15	Memories 2	Internal and External World 33	Good Behaviour 3	Hope 5
Friends 9	Home 3	Cannot Voice/ No Language for 19	Stereotype s 4	Waiting 15	Regrets 2	Symptoms 20	Negative Emotions 46	No Regrets 1
Relationships 24	Dates and Times 20	What does Recovery mean to others? 1	Work 16	Expectations 28		Treatment 48	Positive Emotions 7	Default Position 1
Dad 5	Achievement s 9		Public v Private Persona 13	Disappointment 5		Medications 12	Trauma 11	Understanding 20
Mother 46	External Drivers 3		Roles we Play 66	Choice and Conformity 23		Physical 31	Suicide 22	Knowledge 5
Family 26	External Decision- Makers 7		No Hope 5	Control 3			Safe 1	Work at Recovery 6
Collaboration 10	Juxtaposition s 6			Agency 2			Endings 6	Good Enough 9
Connections 6				Empowered 5			Abandonment 10	Recurring Patterns 4
Collusion 1				Activism 5			Escape 15	Core Values 8
Didn't want others to know 9							Punishing Myself 9	Epiphanies 10
Other's views of me 48							Comfort 6	Acceptance 5
							Aloneness 6	Positive Changes in Me 26
								Reflections 20



**Autoethnography Process: Source 1 (DR and SR discussion): Frequency of Codes**

<b>Code</b>	<b>Frequency</b>
Mindfulness	13
Emotions	2
Acceptance	8
Growth	12
All or nothing	2
Omissions	9
Time	17
Memories	31
Finding where things fit together	7
Realisations	19
Collaborations	18
Compliance	4
Choice	5
Internal drivers	2
External drivers	15
Work	5
Advocacy	2
Don	6
The Role of Don	8
Labelling and non-labelling	10
Public vocalisation	12
Adding things together	5
Recovery Narratives	13
Impact of writing stuff	7
Journey	1
Reframing	2

## Appendix 4.6

### Autoethnography Process: Source 2 (Supervision discussion): Frequency of Codes

Code	Frequency
Thematic Analysis Methodology	6
What am I going to ask other's to do?	7
What goes in?	4
Medication	1
Stigma	3
Diagnosis	3
Timespan	6
Omissions	4
What I have learnt	3
Reliving Trauma	3
Mother and Family	11
Choice and conformity	2
Suicide	1
Internal drivers	13
External	4
Collaborative working	1
John Doe	1
Don	5
Labels	1
Private v Public	1
Recovery Narratives	9
AE	9
Recovery Journey	10
Breaking things into parts	5

**Autoethnography Process: Source 3 (Process Diary): Frequency of Codes**

Code	Frequency
Default thinking	5
Emotions	5
Acceptance	4
Doing things differently	12
Trauma	3
Diagnosis	1
Timeline	1
Core values	1
Putting myself out there	1
Activism	1
Motherhood	4
Compliance and Choice	3
Family	16
Internal drivers	10
External drivers	5
Working	5
Other's perceptions	12
Don	5
Labels	11
Private v Public	2
Connections	1
Recovery Narratives	12
AE	22
Recovery Journey	20
Recovery	10
Process	37
Talking about very difficult topics	11
Reflections on the process of others	10
Theory	4
Supervision	19

1. Finding where things fit 7  
1. Impact of writing 7  
1. Breaking things down into parts 31  
1. Omissions 9  
1. Collaborations 18  
1. Adding things 5  
1a. Reframing 2

1. Internal drivers 2  
1a. Emotions 2  
1. Realisations 19  
1. Acceptance 8  
1. Mindfulness 13  
1. Growth 12  
1a. All or nothing 2

1. Public 12  
1. Labelling and non-labelling 10

1a. Journey 1  
1. Time 17  
1. Memories 31  
1. Recovery 13

1. External drivers 15  
1a. Don 6  
1a. The role 8  
1a. Advocacy 2  
1a. Work 5

1. Compliance 4  
1. Choice 5

Recovery journey 10  
Autoethnography 9  
Recovery narrative 9

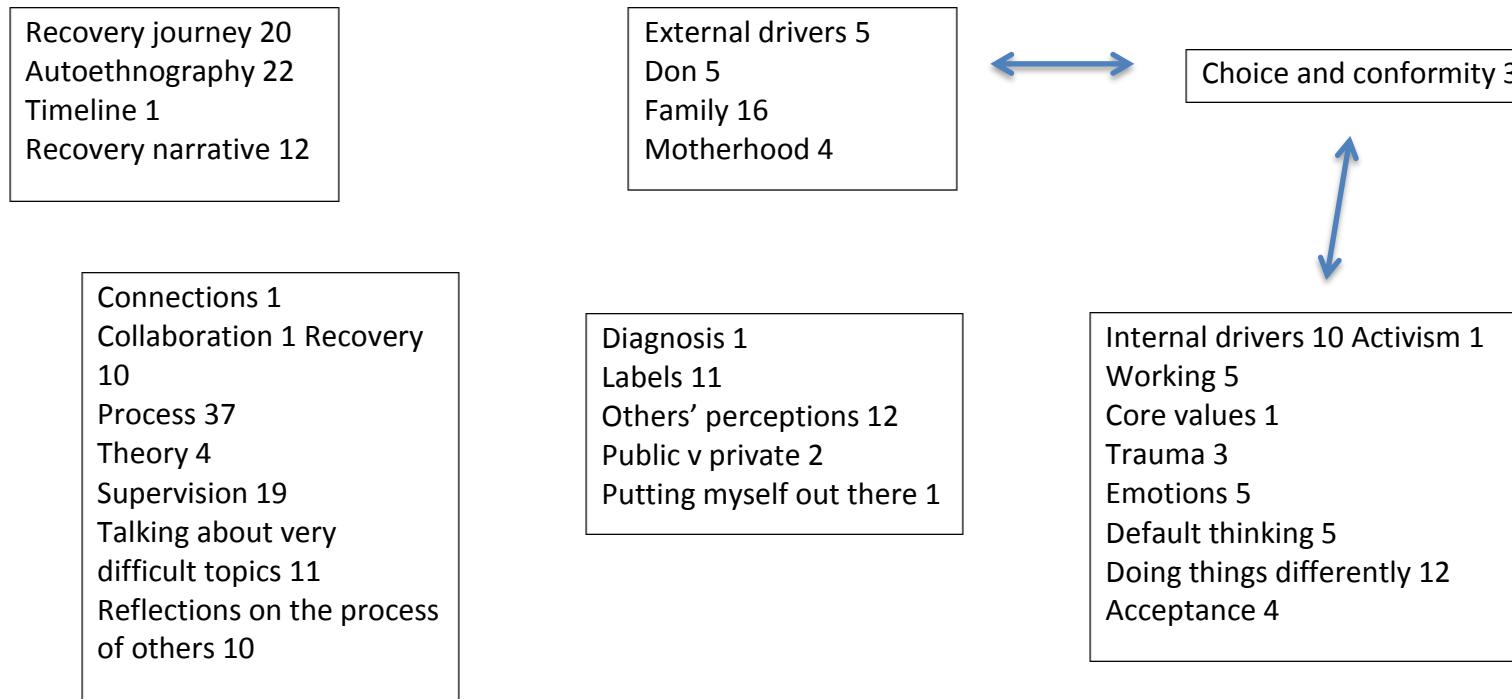
What am I going to  
ask other's to do? 7  
Omissions 4  
Timespan 6  
Breaking things into  
parts 5  
What goes in 1

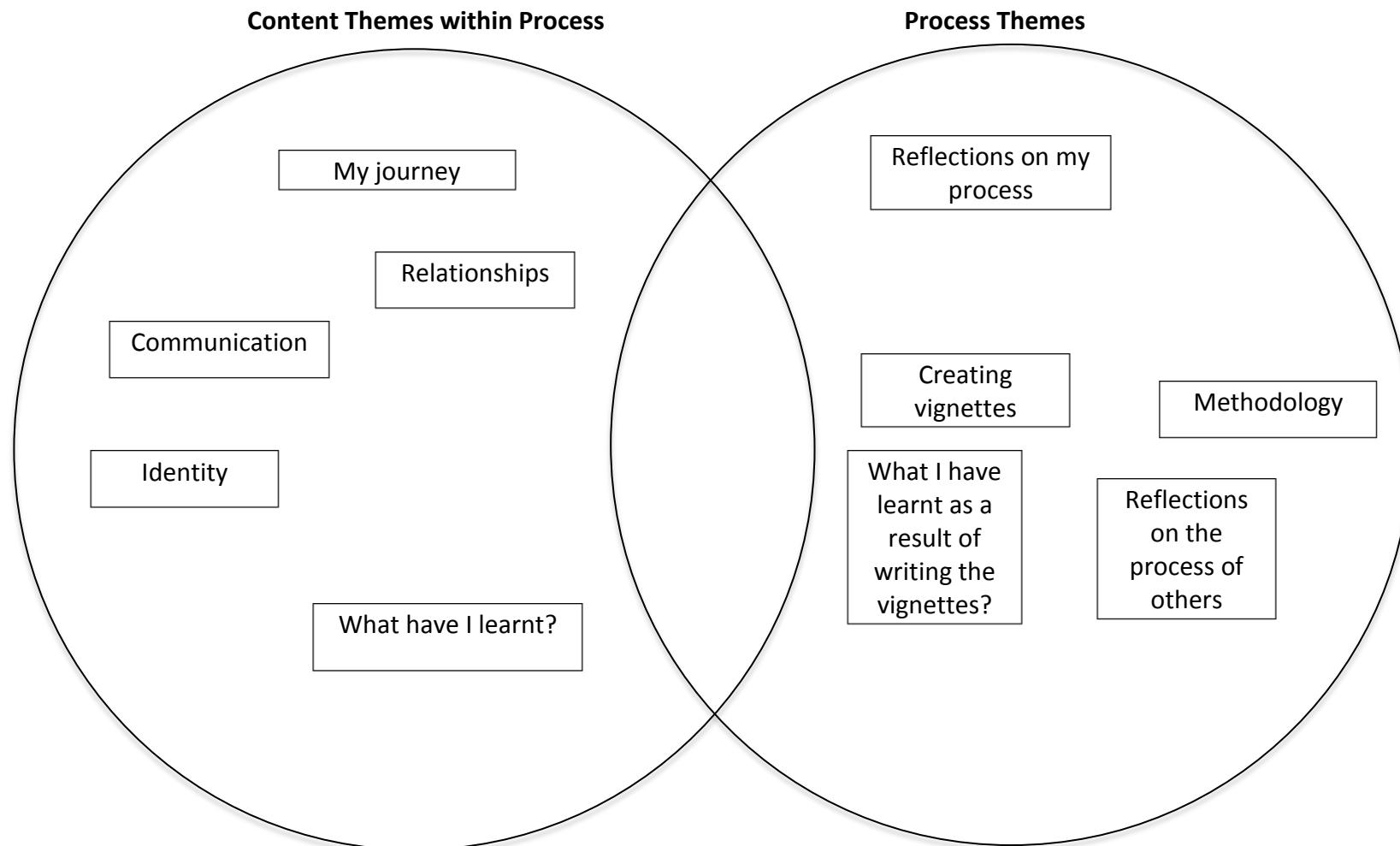
Thematic analysis  
methodology 6

Mother and family 11  
Don 5  
John Doe 1

Suicide 1  
Internal drivers 13  
Reliving trauma 3  
What I have learnt 3

External 4  
Label 1  
Collaborative working 1  
Public v private 1  
Stigma 3  
Diagnosis 3  
Medication 1  
Choice and conformity 2





## Content Themes within Process

Meta Theme	My Journey	Relationships	Identity	Communication	What I have learnt?
	Recovery Journey 10 20	Alex 1	Stigma 3	Recovery Narrative 13	Doing things differently 12
	Journey 1	Don 5 5	Label 1 10 11	Narrative 7	Growth 12
		The Role of Don 8	Diagnosis 3 1	Voicing my Narrative 12	Medication 1
	Time – Context 17	Mother and Family 11			All or nothing 2
	Time Span 6	Family 16			Working 5
	Internal 2	Other's Perceptions of me 12			Work 5
	Internal Drivers 10 13	Public Vocalisations 12			Suicide 1
		External Drivers 15 5			Public v Private 1 2
		External 4			Acceptance 4 8
		Collaborative working 1			Activism 1
		Motherhood 4			Core Values 1
					Mindfulness 13
					Emotions 2 5
					Default Thinking 5
					Realisations 19
					Choice 3 5
					Conformity/Compliance 4 2

## Code:

Red – DR and SR

Blue – Supervision

Green - Process

## Process Themes

Meta Theme	Creating Vignettes	Methodology	Reflections on my Process	Reflections on the Process of Others	What I have learnt as a result of writing the vignettes?
	Breaking things down into parts 31 5	AE 9 22	Reflections on my Process 37	Reflections on the Process of Others 10	What I have learnt? 3
	Finding where things fit 7	Recovery 10	Supervision 19	What am I going to be asking other's to do? 7	Talking about very difficult topics 11
	Adding things together 5	Theory 4			Trauma 3
	What goes in 1	Thematic Analysis Methodology 6			Reliving Trauma 3
	Omissions 4 9				Reframing 2
	Connections 1				The Impact of writing stuff 7
	Collaboration 18				Putting myself out there 1
	Memories (differing) 31				
	Timeline 1				

### Code:

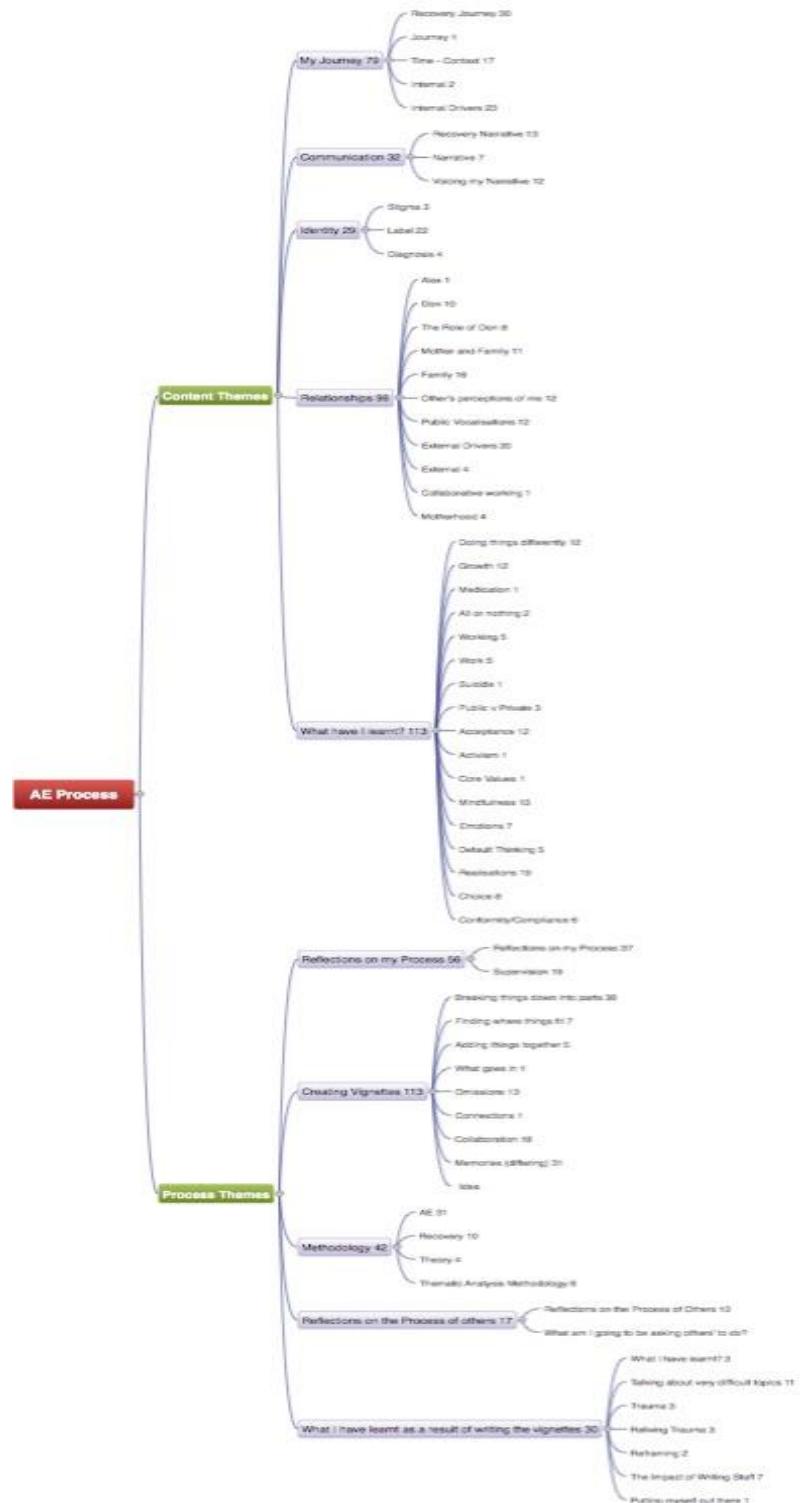
Red – DR and SR

Blue – Supervision

Green - Process

## Appendix 4.13

### Autoethnography Process: Meta-themes Mind-map



## Final AE themes and sub-themes

## Appendix 4.14

The AE sub-themes (Table 4.3) were further refined. After completing the analysis and on further reflection, it was felt that the content of some sub-themes were duplicated. Table 4.4 shows how the sub-themes were consolidated.

**Table 4.4 Final AE themes and sub-themes**

	Themes	Sub-themes
1	<b>Context</b>	<b>Background</b> <b>Places</b> – places and home <b>Time</b> – dates and time; time-context <b>My narrative</b> – personal narrative, recovery narrative, meta-narrative, internal and external drivers, juxtapositions and achievements
2	<b>My Journey</b>	<b>Recovery journey</b> – journey, memories and regrets
3	<b>Impact of my illness</b>	<b>Impact of mental illness</b> – symptoms, treatment, diagnosis, medication and physical <b>Internal and external world</b>
4	<b>Identity</b>	<b>Sense of self</b> - work <b>Stigma</b> – labels and stereotypes <b>Roles we play</b> – public and private persona
5	<b>Relationships</b>	<b>John Doe</b> - motherhood <b>Don</b> – the role of Don <b>Relationships</b> – friends, collaboration, collusions and collaborative working <b>Family</b> – dad, mother, mother and family; and family <b>External drivers</b> – didn't want others' to know, others' view of me, others' perception of me, external drivers and public vocalisations
6	<b>Emotions and behaviours</b>	<b>Emotional response</b> – positive emotions, negative emotions, abandonment, escape, endings, punishing myself, aloneness, safe, trauma, comfort, bad behaviour and good behaviour <b>Suicide</b>
7	<b>Power and control</b>	<b>Power and control</b> – power, control, agency, conformity, waiting, choice and play the game <b>Expectations</b> – empowered, disappointment and activism
8	<b>Communication and voicing my narrative</b>	<b>Communication</b> – personal narrative <b>Voice</b> – voicing my narrative, cannot voice and no language for <b>Sharing my narrative</b> – personal narrative, narrative, recovery narrative, what does recovery mean to others?
9	<b>Lessons learnt</b>	<b>Positive changes in me</b> – core values, doing things differently, hope, epiphanies, understanding and knowledge <b>On-going tensions</b> – mindfulness, medication, work at recovery, choice, conformity and compliance, public v private, default position, default thinking, ambivalence, all or nothing, acceptance, good enough, working, work, suicide and emotions <b>Reflections</b> – realisations, no regrets and activism
10	<b>Reflections on my process of writing</b>	<b>Revisiting trauma</b> – reflections on process and reliving difficult times

	<b>autoethnography</b>	<b>Creating distance</b> <b>My writing process</b>
<b>11</b>	<b>Creating vignettes</b>	<b>Writing the vignettes</b> – reframing, what goes in? and ideas <b>Collaborations</b> – memories, differing memories and omissions <b>Making connections</b> – finding where things fit, breaking things down into parts and adding things together
<b>12</b>	<b>Methodology</b>	<b>Autoethnography as method</b> – AE, recovery theory, thematic analysis of methodology and supervision
<b>13</b>	<b>Reflections on the process of Others</b>	<b>Reflections on the possible process of others'</b> – what am I asking others' to do?
<b>14</b>	<b>What I have learnt as a result of writing my vignettes</b>	<b>What have I learnt?</b> – talking about vey difficult topics, trauma, reliving trauma, reframing, the impact of writing stuff and putting myself out there

Recruitment poster. V2. 14/01/2015 Ethics ID: 12626

Health Sciences

UNIVERSITY OF Southampton

**Have you developed a Personal Narrative (Recovery Story)?**

It may have been some time ago. You may have written your narrative and/or used art, photographs or poems etc to describe your mental health experiences. You may have done it as part of a group or on your own.



If your answer is YES, you may like to take part in my study.....

**Background:**  
This study aims to explore the role of developing a personal narrative (also called a recovery story) and its potential contribution to an individual's mental health recovery.

**Who am I?**  
My name is **Sam Robertson**. I am a doctoral student (PhD) at the University of Southampton. I am also a mental health service user with a background in service user involvement, training and service delivery. I am an experienced teacher and group facilitator.  


**✓ Your Involvement:**  
Participate in a one-off focus group to discuss your experience of developing a personal narrative and any subsequent effects of the process.

**✓ Who else will be involved?**  
Other service users who have already developed a personal narrative.

**✓ The Nitty Gritty:**  
The focus group will last about 2 hours. There will be up to 8 participants, plus 2 facilitators. It will be held at the University of Southampton or in central Portsmouth. Date and time to be agreed with participants. Refreshments will be provided. Travel expenses will be paid.

**Further Details:**  
If you would like a Participant Information Pack or have any questions, please contact me:  
**07875 144632 or email [sjr1c13@soton.ac.uk](mailto:sjr1c13@soton.ac.uk)**

Faculty of Health Sciences, University of Southampton, Building 45, Highfield Campus, Southampton SO17 1BJ United Kingdom  
Tel: +44 (0)23 8059 7979 Fax: +44 (0)23 8059 7900 [www.southampton.ac.uk/healthsciences](http://www.southampton.ac.uk/healthsciences)

**Focus Group A: Themes – Codes: Extract (Page 1 only)**

**Appendix 5.2**

Audiences	Media	Reflections	Labelling	Co-Production	Identity	Sharing Story with others	Definitions or name	Content story	Agreeing Confirming Clarification
RC 40	Film 38	Film reflection 41	Labelling 37	Working with others to tell a story (Masters Students) 36	Use of name 128	Outside perspective 196	RS/RN/PN – literature not clear on distinction 136-7	About life 143	Yeah 145, 170 177 193 199
Abroad 40	Poem 38	Acknowledging pain of the past 216	I am not my diagnosis 222	I worked with a group of masters students 256-7	As long as it is not shared 129	Its really good, what you've shared and what you've said 283-4	Give a name to.. 136-8	PN – life story 151	Agreement with use of term journey 167
Who the audience is 317	Write RS 153	Recovery...wrong word... it doesn't fit but having a life that I want to live, that I'm choosing and making most of 203-7	This label 261	Dialogue 292	A student who plays on OCD 551	Really important that story was heard 289-90	PN/RN same thing 142	Different story if life story 170-1	I think that a lot of people use that 166
Who you are talking to 318	Writing about illness 171	Film would reflect my diagnosis, myself or my experience 265	I had been given a diagnosis 257	Collaboration 292	Living a lie, this mask... perfect life and inner turmoil 542-545	I started telling my story 326	About life 143	Life view 173	Doesn't it 200
	Interactive theatre 550					Not shared but it is less personal now 623			

## Focus Group B: Themes – Codes: Extract (Page 1 only)

## Appendix 5.3

Anti-Recovery	Social, Political, Cultural	Historical context of madness	External drivers	Background why shared Recovery story	Individualise mental illness	Personal journey	Causes of mental illness and distress	Recovery doesn't exist	Medical model	Value of recovery as a concept
Background d 953-66	Mad people seen as a challenge to natural order... that is, always has to take place in a social, political, cultural context 142-4	Recovery, whatever you think that is, always has to take place in a social, political, cultural context 142-4	it's in schools, it's in families, ...local policy 385-6... lack of responsibility further back 388 ... you're challenging somebody else's place in a hierarchy, their status... challenging status quo...mental health services maintain the status quo.	Enabled groups of people ... common understanding about what had happened to them 183-4	'you're the problem, there's something wrong with you, you need to work on yourself ..that's all you need to do 147-9	Question about recovery being the personal journey 139 Recovery has been completely depoliticised and turned in to something that is about a personal journey 140-2	Why people are distressed in the first place 146-7	Some people don't relate to recovery at all 200 I reject the entire notion of recovery... its used... 355-6		It's had its uses for people... it still has its uses for.. way of beginning a conversation... using a different sort of non-medicalised language... I understand how important it is to people 356-

**Focus Group A: Theme Development: Extract (Page 1 only)**

**Appendix 5.4**

Audiences	Creating a narrative to fit an audience	Others using your story for their own purposes	Concerns for audience	Effects on family	Story heard	Reaction of audience
RC 40	Trying to use the story in different ways 691	Film – presentation to their peers 267	Waffle 294	My kids have deliberately went down the path of learning psychology, doing psychology at school 1171-2	Really important that story was heard 289-90	I don't believe you 423
Abroad 40	Break it down into its constituent parts... this fits what i am delivering on that day 691-3	RC 268	'that not going to help anyone.... That's going to make them really depressed 392-3	Other family members have MH issues 1177	My experiences ... To help others 374	delivering it and then students saying thank you 477-79
Who the audience is 317	For us to give our story to a professional...story is very different to the real one... very different story to what actually on their notes 858-60	Film used in different places 268	I didn't need to give them a cliff hanger 660	They're comfortable sharing with some people.. they pick who.. using it to help them drive forward 1178-9	Others need to hear stories.. they are hopeless... they don't see people who are recovered – they need <i>role models</i> 416-8	Shocked look 482
Who you are talking to 318	Her story to them was the PTSD but her real story is about her life 869-70	Trying to tick boxes 276	Told off several times to tone down story ... maybe they are right 727	Daughter is a MH nurse 1181... she wouldn't want me sharing with her boyfriend 1182-3	Offer hope 421	Psychologist crying (Val) you are so brave 504
Where they are 319	Done before and they then relate to it 694-5	They got out of it what they needed too 313-4	Potential harm of sharing suicide story on an acute ward 737-8	Mum don't tell embarrassing stories 1185-6	Sort of positive aspects of recovery 421	Feedback - oh wow 483-4

## Focus Group A Meta-themes: Extract (Page 1 only)

## Appendix 5.5

### Theme: Continual Development of Narrative

Editing narrative	Having our own voice in our own narrative	Becoming lost in our own narratives	Constraints on developing/sharing story	Piecemeal or one off	Narrative	Creating a narrative to fit an audience	Others using your story for their own purposes	Language of Recovery
	Seeking permission i don't even know if I am allowed to do this 179-280	Social work terms-it's not me, it doesn't make sense 274-5		Harri	Changes over time 226	Trying to use the story in different ways 691	Film – presentation to their peers 267	Word recovery is quite new 158
Wouldn't got into all necessarily in narrative 225-6	'Their project, it's my voice 281	How can this represent me and my life 275-6	Time is a big constraint to what can be shared 328	Written poems since little 377	Changes with growing understanding 227	Break it down into its constituent parts... this fits what i am delivering on that day 691-3	RC 268	People talked about things in different ways 159
RS would involve some of that 181	Students making decisions about narrative poem 'I'll write a poem about your life' 272	Told off several times to tone down story ... maybe they are right 727	Fear of sharing it in public 343-4	Kept all poems since puberty 377-80	As you grow and move on and life 227	For us to give our story to a professional...story is very different to the real one... very different story to what actually on their notes 858-60	Film used in different places 268	Never talked about it as my recovery 160
RS I wouldn't go into detail 182	Other people's voices 271	Not allowed to use suicide or alcohol... my last suicide attempt... it's a huge part of my story 734	Unable to hold emotions in check	Tina – never made a story out of it (poems) but wanted to 390	It would be very different to what I had done with the students 228	Her story to them was the PTSD but her real story is about her life 869-70	Trying to tick boxes 276	Just feeling better 161

Focus Group B themes not required for meta-themes as they are added within others:

**Theme: Recovery - Political, Social and Cultural Context**

- Anti-Recovery
- Medical model
- Anti-psychiatry background
- Mental Health system
- Change system Implementation of recovery
- Personalised problems
- Personal v societal
- Micro v macro
- Conversations about wider issues of causes of distress
- Don't have a recovery story
- Don't share recovery story
- Societal causes

**Theme: Narrative**

- Personal story
- Wellness continuum

**Theme: Developing Narrative**

- Starting narrative
- Content
- Piece-meal v one-off
- Recovery is action
- Getting Started

**Theme: Impact of Sharing Narrative**

- Support
- Talking to ourselves through narrative
- Not being heard
- Messages want to give others through narrative sharing
- What people want to hear
- Impact of your story on others
- The listener
- No voice
- Voicing dissent
- Audience listening
- Hearing others stories
- Making a difference to others
- Honesty
- Sharing for the first time
- Individual v global

- Choosing parts of narrative to share rather than whole
- Relevancy
- Using story to train professionals
- How do you use your Recovery Narrative

**Theme: Other voices in narratives**

- How professionals treat service users
- Working with others
- External influences

**Theme: Focus Group and Peer Working**

- Members of FG being supportive
- Process of writing AE
- Making sense of another's point

**Theme: Making Sense of...**

- Social connections
- Knowledge
- Insight
- Personal perspectives
- Wellness Tools
- Understanding your recovery
- Realisation
- Through narrative gaining insight
- Acceptance
- Managing

**Theme: Form**

- Description of media use
- Editing
- Taking account of audience
- Content
- Time lag before getting help
- Timing
- Context of narrative

**Theme: Sense of Self**

- Identity
- It/me
- Change identity
- Regaining sense of own identity

**Table 5.6: Focus Groups (A and B) Themes and Sub-themes (basis for analysis)**

	<b>Focus Group Themes</b>	<b>Sub-themes</b>
1	Recovery – Political, Social and Cultural Context	Social, political and cultural context and value of recovery as a concept.
2	Narrative Content	Personal narrative v recovery narrative; language of recovery and narrative content.
3	Narrative Form	Media and value of storyboard.
4	Timing	Time as context; recovery cycle and continuum of wellness.
5	Developing Narrative	Process of developing a narrative; value of developing a narrative; value to self; constraints on developing narrative; reframing and editing narrative.
6	Process of Sharing Narrative	Sharing narrative with others; peer narratives and telling our narratives is a political act.
7	Impact of Sharing Narrative	Value of sharing narrative; being believed and contribution to recovery.
8	Working with Others	Commonality of experience; group dialogue and co-production.
9	Sense of Self	Sense of self.
10	Making Sense of...	Growing understanding.
11	Other Voices in Narratives	Family and peer group.
12	Phase 3 Workshops	Where to locate workshops?

**Phase 3 Email to potential Co-researchers**

**14.7.16**

Hello

I can't believe that it is a year since you took part in a phase 2 focus group of my research! I have been very busy writing it up and presenting at conferences. There is a lot of interest in my work and it has been very well received. Thank you, your contribution was so important.

I am now ready to begin work on phase 3 Developing the Personal Narrative Workshop Programme (so that people who haven't developed a personal narrative will be able to do so in a supportive peer environment). Would you be interested in working with me again to develop the programme? It will involve meeting in a research discussion group (up to three times) over a number of months, probably at Southampton University unless the majority are Portsmouth based. The times and dates will be organised to suit everyone. Hopefully, the first meeting will be at the end of August/September 2016.

If you are unable to commit to attending each meeting, you can still take part (read the transcription of the meeting and then offer your comments).

I have attached the phase 3 study pack. If you would like to take part please let me know.

I have recently been examined on phase 2 - our focus groups. The examiners suggested that I add a pen portrait of each of you. Basically add a couple of sentences about you to describe you. This can include age range, sex and a bit about you. I can do this, but I wondered whether you would prefer to do your own, which I can then include?

I look forward to hearing from you.

With very best wishes

Sam

Sam Robertson

[sam.recovery@virginmedia.com](mailto:sam.recovery@virginmedia.com)

[sjr1c13@soton.ac.uk](mailto:sjr1c13@soton.ac.uk)

07875 144632

**Phase 3: Co-Researcher Information Sheet (v.2)**

**Study Title:** What does the process of developing a personal narrative involve and how does it contribute to mental health recovery?

**Researcher:** Samantha Robertson

**Ethics number:** 22294 (Linked to Study Number 12626)

I would like to invite you to take part in my doctoral research study. Before you decide, I would like to explain why this research is being done and what it will involve for you. Please take time to read this information sheet. I am available to answer any questions that you may have. My contact details at the end of this information sheet.

**What is the research about?**

This research aims to explore the role of developing a personal narrative (also called a recovery story) and its potential contribution to an individual's mental health recovery.

This research will be conducted in three phases – you are being asked to take part in Phase three:

Phase one (development and exploration): involved writing about my own mental health recovery experience. Themes emerged from this work, which informed the topics for discussion in Phase two.

Phase two (development and exploration): This involved the focus groups that you took part in, where we explored key aspects of developing your personal narrative and any subsequent effects on your mental health recovery.

Phase three (development of workshop programme): The understanding which has emerged from phases one and two has formed the basis of how this research will progress. The expectation is to develop a workshop programme that will support service users to develop their personal narrative. The intended outcome is to produce a personal narrative workshop programme scheme of work with underpinning session plans.

It is expected that this focus group (approximately 4-6 co-researchers - you) will meet three times over a period of months to discuss the workshop programme development. If you are unable to attend a focus group meeting but would still like to take part in the study, I will send you the transcription of the missed meeting. You will be able to read it and make any comments that can be added.

**Who is organising and funding this research?**

As a doctoral student, I will be undertaking this research myself, supported by two supervisors. This research is within the Faculty of Health Sciences at the University of Southampton and is self-funded. I am a mental health service user with a background in service user involvement, training and service delivery (statutory and third sector). I am also an experienced teacher, in particular supporting service users to develop and use their personal narratives.

**Why have I been invited to participate in a focus group?**

As a service user who has previously developed a personal narrative, your experience of the process and subsequent effects on your recovery were of value. You kindly took part as a co-researcher in a Phase 2 focus group and have therefore contributed to the understanding that will be used to develop the personal narrative workshop programme.

#### **Do I have to take part?**

It is up to you whether you choose to take part in this study. You can use this Co-Researcher Information Sheet and ask any further questions that you may have (via the telephone, email or post), to make your decision about participating.

I will ask you to sign a consent form at the start of each focus group meeting. Please note, that you will be free to withdraw at anytime and you do not have to give a reason if you choose to do so. If you choose to withdraw, your contribution will be removed from the transcription of the focus group.

#### **What will happen to me if I take part?**

I will arrange the focus group meetings (at a mutually convenient time for all co-researchers) to be held at the University of Southampton. During your focus group meetings, I will audio record the group discussion and use flip chart paper to record key points.

After your focus group, I will use a transcription service (recommended by Student Finance England and the University of Southampton Enabling Service) to transcribe in its non-edited anonymised form. This may take up to 4 weeks. I will then send this transcription to you. If you wish to, you can review the transcription and make any comments. You will have up to 4 weeks to do this. There is no compulsion for you to do so – it is your participation in the Focus Group that is important.

#### **The format of the focus groups**

Each focus group will last about 2 hours (with break for refreshments). Each meeting will involve discussing different aspects of developing the personal narrative workshop programme. Each meeting will build on the work of the previous meetings.

#### **General format for each focus group meeting**

- Time will be available before the focus group is due to start (30 minutes). This will allow co-researchers (You) to arrive, meet the facilitators (Me, Di Carpenter and/or Maggie Donovan-Hall) and have a tea/coffee. This will give you the opportunity to discuss any feelings that you might have about taking in the focus group.

#### **The Focus Group in session:**

- Explanation of the study, aim of focus group and consent.
- Introductions and a brief check-in. This is an opportunity to tell the rest of the group how you are feeling.
- Warm-up activity.
- Group agreement/reminder of.
- Focus Group discussion.
- Focus group de-brief and check-out (to make sure that you are ok).
- End of the focus group.
- The facilitators will be available after the end of the focus group (30 minutes) to have a coffee and a chat to anyone who would like to stay.

### **Should I bring anything to the focus group?**

Yes, if you have a copy of your personal narrative and or any artefacts that you have used to develop your narrative (e.g. art work and photographs). If not, please just bring yourself – it is your experience of the process that is the valuable source!

### **Are there any benefits in my taking part?**

There is no financial benefit to taking part (I will cover any out of pocket expenses and refreshments). However you will be contributing to developing a workshop programme for supporting others to develop their personal narratives.

### **Are there any risks involved in my taking part?**

It is hoped that by contributing to developing a workshop programme for supporting others to develop their personal narratives will be an interesting and valuable experience for you. I am aware that many personal narratives can contain difficult and painful material; therefore if you are currently experiencing a mental health crisis, you should not take part in this study.

Working within a group can pose challenges such as negative comments from others and being heard. If during the focus group, you feel distressed, you are free to request that the focus group be stopped for a short time. You are free to withdraw at any time (there will be a co-facilitator available if you need further support). As part of my role as facilitator, there will be time to do a check-in at the start and end of your group. Your group will also develop its own group agreement. I will be available before and after your focus group for you to talk to me.

You are asked to identify a supportive relative, friend or other, whom could provide support if you need it after the focus group.

### **Will my participation be confidential?**

All information relating to this research will comply with the Data Protection Act (1998) and the University of Southampton's policy relating to the storage of confidential information. My supervisors and I will know your contact details. Your details, the audio recording and the transcription will be kept in a file (only accessed by me and is password protected) on a secure desktop at the University of Southampton. Any paper copies will be stored within a locked filing cabinet, only accessible by me.

Your part in your focus group will be anonymised (by choosing a pseudonym) on the transcription although it is difficult to remain anonymous within a focus group itself. You will be known to each other due to working in the focus group together. You may also know some of the other co-researchers from outside the focus group.

### **Who owns the material generated within your focus group?**

As we are co-researchers in the focus group we all do.

The material will be written up within my PhD, and may be used at some later stage as part of published material and used for teaching and presenting purposes.

If all the co-researchers in the focus group agree, you are free to use the transcribed material from the focus group as well. If there is not a general agreement to use the transcribed material, you are free to use your contribution to the focus group.

**What happens if I change my mind?**

You have the right to withdraw from the research at any time prior to, during and after your focus group. Your contribution to the focus group will be removed from the transcription.

**What happens if something goes wrong?**

In the unlikely case of concern or complaint, you can contact: Research Governance Office at the University of Southampton ([Rgoinfo@soton.ac.uk](mailto:Rgoinfo@soton.ac.uk)) or 02380 595058

**Where can I get more information?**

If you have any more questions relating to this research study, please do not hesitate to contact me on 07875 144632 or [sjr1c13@soton.ac.uk](mailto:sjr1c13@soton.ac.uk)

**Co-researcher invitation letter v1. 9.06.16**

Dear

**Study Title: What does the process of developing a personal narrative (Recovery Story) involve and how does it contribute to mental health recovery?**

I am writing to you in my capacity as a doctoral student at the University of Southampton who is undertaking some research as part of my MPhil/PhD. In this research, I aim to explore the role of developing a personal narrative (also called a Recovery Story) and its potential contribution to an individual's mental health recovery.

Last year, you very kindly took part in a Phase 2 focus group where we discussed your views and experiences of the process of developing your personal narrative and whether you thought that it was helpful in your mental health recovery. The themes that emerged from the focus groups will be used in Phase 3 to develop a personal narrative workshop programme. This programme will eventually support mental health service users to develop their own narratives.

I would like to invite you to take part in Phase 3 as a Co-researcher – to work with me in developing a personal narrative workshop programme. Your involvement would involve taking part in a focus group that will meet a maximum of 3 times over a number of months.

Please find enclosed a copy of the Co-researcher Information Sheet. This gives you further details about what taking part in this research might involve. If, after reading this further information, you would like to know more or would like to participate in this research, please contact me (details below). This will not commit you to participate.

Yours sincerely

Sam Robertson  
Doctoral Student  
Mobile: 07875 144632  
[sjr1c13@soton.ac.uk](mailto:sjr1c13@soton.ac.uk)

Faculty of Health Sciences, University of Southampton, Building 45, Highfield Campus, Southampton SO17 1BJ United Kingdom  
Tel: +44 (0)23 8059 7979 Fax: +44 (0)23 8059 7900  
[www.southampton.ac.uk/healthsciences](http://www.southampton.ac.uk/healthsciences)

**CONSENT FORM: Participation in Phase 3 focus group v.2**

Study title: What does the process of developing a personal narrative involve and how does it contribute to mental health recovery?

Researcher name: Samantha Robertson

Ethics reference: 23553 (Linked to Study 12626)

*Please initial the box(es) if you agree with the statement(s):*

I have read and understood the Co-Researcher information Sheet (version 1 10/06/2016) and have had the opportunity to ask questions about the study.

I agree to take part in the focus group as part of this research project and agree for my data to be used for the purpose of this study.

I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected.

I am happy for the Focus Group to be audio recorded and transcribed. The transcription will be done in its non-edited anonymised form by Transcription City (recommended by Student Finance England and the University of Southampton Enabling Service).

*Data Protection*

*I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.*

Name of participant (print name).....

Signature of participant.....

Date.....

**Take part in the Phase 3 focus group – what will it involve?**

PhD Study: What does the process of developing a personal narrative involve and how does it contribute to mental health recovery?

Are you interested in taking part in the Phase 3 focus group in this study?	Would you like more information?  You can: <ul style="list-style-type: none"><li>• Email: <a href="mailto:sjr1c13@soton.ac.uk">sjr1c13@soton.ac.uk</a></li><li>• Call <u>07875 144632</u> (please leave a message with your contact details if there is no answer. I will get back to you).</li><li>• Send me your contact details in the envelope provided.</li></ul>
I (the researcher) will contact you	I will email or send you the Co-Researcher Information Pack. This will give you detailed information about the study.  If you have any questions you can contact me (as above).  You will be asked some questions to see if you meet the requirements of the study. For example: <ul style="list-style-type: none"><li>• Are you currently experiencing a mental health crisis? If you are, you should not take part in the focus group.</li></ul>
If you want to take part in the focus group	Location: University of Southampton.  Dates and times will be arranged to suit co-researchers. Directions will be given to you.
What will happen in the focus group?	I will facilitate your focus group. There will be two co-facilitators too.  You can arrive early (up to 30 mins) for a coffee and a chat before the start. Refreshments will be available.  At the start, you will be asked to give your consent (at the start of each meeting).  There will be about 4-6 people in the focus group.  It will last for about 2 hours. This will involve discussing different aspects of developing the personal narrative workshop programme. Each meeting will build on the work of the previous meetings.  I will audio record the discussion and use flip chart paper to write any

	<p>points.</p> <p>After the focus group, I will be around for a chat (about 30 minutes).</p>
After each focus group meeting	<p>A transcription service will transcribe the audio recording.</p> <p>I will transcribe the flip chart notes.</p> <p>I will send you these transcriptions so you can add any comments.</p> <p>I will make any changes.</p> <p>I will send you the final transcription.</p>
If you are unable to take part in a focus group meeting	<p>If you are unable to attend a focus group meeting but would still like to take part in the study, I will send you the transcription of the missed meeting. You will be able to read it and make any comments that can be added.</p>

**Phase 3: Focus group (Cycle 1) Friday 7th Oct 2016 10-12****Co-researcher information**

Thank you for agreeing to take part in Phase 3 of my research. This is some background information for you.

The expectation of Phase 3 is to develop a workshop programme aimed at supporting service users to develop their own personal narrative. The intended outcome is to produce a scheme of work with underpinning session plans for the workshop programme. A scheme of work is the overview of the workshop – what is the purpose, what's included and how it will be delivered?

In our first focus group, we will discuss the points for discussion (Table 1).

These points emerged from the themes generated in phases one (my autoethnography) and two (your narrative development process). Our discussion will hopefully lead to some ideas for a scheme of work (including the rationale and some aims and objectives).

After the focus group:

- I will send you the transcription of the group for your comments
- I will put all our ideas together into a scheme of work. I will send this to you for your comments
- I will make any changes and send you the Scheme of Work that we will use to develop the session plans in focus group 2.

**Table 6.2: Narrative Development Workshop: Points for Discussion**

	<b>Points for Discussion</b>
Timing	- Allow adequate time to develop narrative. - Time to share and be heard within the group
Workshop Participants	- Narrative development may not be appropriate at a particular time – why do it?
Narrative development	- Inclusion of work around the process of narrative development - Some individuals may not understand the concept of recovery - Supporting peers to develop a coherent/ structured narrative out of what they might have already produced
Using narrative	- Work on editing narrative for different purposes - Using narrative in different settings
Relational ethics	- Explore how peers could include the narratives/voices of intimate others within their narratives
Media	- Working with peers to choose a suitable media – art/photography – (perhaps less explanation and more interpretative?)
On-going peer support in workshops	- Supporting people to get started

**Table 6.3: Phase 1 Autoethnography Themes and Sub-themes**

	<b>Themes</b>	<b>Sub-themes</b>
1	Context	Background, places, time and my narrative
2	My Journey	Recovery journey

3	Impact of my illness	Impact of mental illness; internal and external world
4	Identity	Sense of self, stigma and roles we play
5	Relationships	John Doe, Don, relationships, family and external drivers
6	Emotions and behaviours	Emotional response and suicide
7	Power and control	Power and control; expectations
8	Communication and voicing my narrative	Communication, voice and sharing my narrative
9	Lessons learnt	Positive changes in me, on-going tensions and reflections
10	Reflections on my process of writing autoethnography	Revisiting trauma, creating distance and my writing process
11	Creating vignettes	Writing the vignettes, collaborations and making connections
12	Methodology	Autoethnography as method
13	Reflections on the process of Others	Reflections on the possible process of other's
14	What I have learnt as a result of writing my vignettes	What have I learnt?

**Table 6.4: Phase 2 Focus Groups Themes and Sub-themes**

<b>Focus Group Themes</b>	<b>Sub-themes</b>
1 Recovery – Political, Social and Cultural Context	Social, political and cultural context and value of recovery as a concept.
2 Narrative Content	Personal narrative v recovery narrative; language of recovery and narrative content.
3 Narrative Form	Media and value of storyboard.
4 Timing	Time as context; recovery cycle and continuum of wellness.
5 Developing Narrative	Process of developing a narrative; value of developing a narrative; value to self; constraints on developing narrative; reframing and editing narrative.
6 Process of Sharing Narrative	Sharing narrative with others; peer narratives and telling our narratives is a political act.
7 Impact of Sharing Narrative	Value of sharing narrative; being believed and contribution to recovery.
8 Working with Others	Commonality of experience; group dialogue and co-production.
9 Sense of Self	Sense of self.
10 Making Sense of...	Growing understanding.
11 Other Voices in Narratives	Family and peer group.
12 Phase 3 Workshops	Where to locate workshops?

**Appendix 6.7**

**Phase 3: Possible Session Plan Proforma for Narrative Development Workshop v.1**

<b>Title</b>	Session x:		
<b>Aims</b>			
<b>Objectives</b>			
<b>Time</b>	<b>Content</b>	<b>Method</b>	<b>Resources</b>

## Phase 3: Session Plan: Cycle 1 Focus Group – Developing a SOW

Time	Content	Method	Resources
10.00 15 mins	<b>Welcome:</b> <ul style="list-style-type: none"><li>- Introductions</li><li>- Check-in</li><li>- Plan of focus group</li><li>- Consent Form</li><li>- Consensus on what a SOW is</li></ul>		Pens, flipchart paper, paper, post-its, marker pens Digital recorder Consent Forms SOW Proforma Parking Board
10.15 15 mins	<b>Rational:</b> <ul style="list-style-type: none"><li>- What is the workshop programme trying to achieve?</li></ul>	Brainstorm discussion Write down key points	
10.30 20 mins	<b>Review of Table 1 (as a whole):</b> <ul style="list-style-type: none"><li>- Is the list of topics complete/any missing?</li></ul>	Brainstorm discussion Write down key points	Table 1- Discussion Points
10.50	BREAK		
11.00 50 mins	<b>Individual Discussion Points:</b> <ul style="list-style-type: none"><li>- What would we want to see in the SOW that will address the point? (Breaking each topic down further)</li><li>- Develop some aims and objectives</li></ul>	Brainstorm discussion Write down key points	Laminated Topics
11.50 10 mins	<b>Wrap-up:</b> <ul style="list-style-type: none"><li>- Pen Portraits</li><li>- Set a date for next meeting</li><li>- Check-out</li></ul>		Post-its

- The Parking board is a way of keeping track of important points that may not be relevant to the task in hand but are important to the overall aims – so can be picked up later.

**Timing**

- Allow adequate time to develop narrative.
- Time to share and be heard within the group

**Workshop Participants**

Narrative development may not be appropriate at a particular time – why do it?

**Narrative development**

- Inclusion of work around the process of narrative development
- Some individuals may not understand the concept of recovery
- Supporting peers to develop a coherent/ structured narrative out of what they might have already produced

**Using narrative**

- Work on editing narrative for different purposes
- Using narrative in different settings

**Relational ethics**

- Explore how peers could include the narratives/voices of intimate others within their narratives

**Media**

- Working with peers to choose a suitable media – art/photography
- perhaps less explanation and more interpretative?

**On-going peer support in workshops**

- Supporting people to get started

## Your Narrative, Your Voice, Your Way: Extract (Page 1 only)

Process and purpose	Framework and model	Structure of w/s	W/S education and content	Context	Timing	Therap. Input	Participants	PAR Process/FG	W/S Facilitation
67 gain people's trust	254 we wont hit everyone the first time	57-62 view of CR –structure 6 sessions 2.5 hrs each	123-7 introductory info – content, expectations and issues	484 – 524 something wrong with individual?	87-8 coping better to deal with stuff, if done more than one time	154 170 confidentiality issues	82-88 potentially attending more than one round	10 engaging fg	67 gain people's trust
68 get people to open up	264-5 framework (F/W) and ethos needs to be clear	64 2.5 hrs 212-3 allows time for a break	132-3 language used on info critical, frames the whole thing	484 -524 context of individuals with life difficulties	82-88 potentially attending more than one round	166-7 not treatment or therapy	96 commitment to the process	10 introducing tasks	68 get people to open up
68 to communicate	268-9 franchise allows flexibility with delivery	64-80 discussion no of sessions	224-8 people with narratives sharing with group	511 mh is not a static concept	118-9 readiness to do more than one w/s cycle	169 we are working to help them	98-112 expectations on / and of participants	21-28 feedback to CR from c1	68 to communicate
75 on-going process	277 structure that is flexible	72-74 8 sessions 1 and 8 are spares. 6 work sessions	389 what is meant by recovery?	507-8 recapping and putting experience into a wider context	322 – 5 attend intro session and decide if they are ready... may come back later	171 it is within the group	109 different states of readiness	31-40 explanation of my process in prepping materials for c2	120 pressure on facilitators

**Discussion comments:**

- Sense that CR wanted everything incorporated and to hit all possible people at start rather than thinking that this is the first point on the development process of this framework.
- Some comments cross other into different themes – individual process also links to workshop facilitation
- Some ideas are arbitrary and are up for discussion with CR
- Practical issues layered with process issues layered with expectations of participants and co-facilitators.
- Getting to grips with being part of the group and tackling their narrative development – layers
- Timing – practical time ie length of session and timing re peoples process and state of readiness.
- 440-6 importance of context – if you benefit from w/s is there an assumption that there is something wrong with you?
- Therapy v therapeutic
- To what extent should the focus be on it all being positive (difference between PN and RN)
- What behaviours and responses do we want? Is it our place to do so? Not treating as adults
- Importance of modelling good practice
- Education good practice – therapeutic good practice – developing intervention model
- Non-participation – can still be learning and reflecting
- What makes a good group member? Facilitation motivation v individual motivation
- Encouraging agency, adulthood and choice.
- How do we ensure people commit to w/s and process?
- Content, facilitation, individual process and PAR Process
- Cycle 2 discussion was what I was expecting in C3 once session plans had been populated – but needed process of thinking, reflecting and putting ideas out there first,

<b>Key Points/Discussion</b>	<b>Thoughts</b>
Purpose	YOUR NARRATIVE, YOUR VOICE, YOUR WAY
No criteria for entry or readiness	
Acceptance of individual wish to develop narrative	
Not therapy or treatment	Could impact on participation and entry criteria. When in treatment, services are not keen for indv to do other things.
MH system infantilizes	

Space to allow participants to talk in their own time	
Why are we asking people to develop their narrative?	
Us and them	Professionals – clinical encounter different from co-production and co-attending in w/s in terms of power and ownership.
Model	Peer-led... co-production/co-delivery and co-attended within or apart from NHS. If we go down the co- route, professionals should have lived experience.
Individual choice and Opportunity	We cannot determine what an individual should get out of it, when or what they take away from it
Personal agency	In contrast to clinical encounters
Content	PN when people are at start of journey/acute – difficulty recognising aspects of narrative that are recovery based. Potentially anger
Language	Importance of language used PN rather than RN
Audience	Is audience secondary to narrative development itself – initially it is for yourself
	Do people need a starting point?
Education	Don't over educate – ultimately their story
	<p>Process:</p> <ol style="list-style-type: none"> <li>1. develop narrative</li> <li>2. what to share? <ul style="list-style-type: none"> <li>- agency</li> <li>- therapeutic benefit</li> </ul> </li> </ol>
	w/s developed in an academic environment gives it weight

**Scheme of Work Proforma for Narrative Development Workshop**

**Background Information:**

- Participant Criteria
  - There should be no entry criteria screening for workshop participants other than a willingness to take part. It is acknowledged that it is difficult to determine when the timing is right for an individual to start the process of developing their personal narrative. There should be no assumptions made about an individual's level of wellness or fitness to participate (although both the individual and workshop facilitators could review this during the course of the programme). In the spirit of mental health recovery, it is important to allow the individual choice and agency in determining participation and to be supported in their decision.
  - There will be a maximum of 6 participants (minimum of 4) per workshop programme.
- Timing
  - It is likely that workshop participants will have different states of readiness, needs, motivations and expectations (beyond their mental health) and will be at different stages of their recovery. As a result it is important that whilst the programme is structured (to achieve its aims and objectives), it is also flexible enough to support individuals. Personal narrative development is not a one-off activity but an on-going piece-meal process. This may mean that an individual who is unable to complete the programme may need time and then come back and carry on the process on a later workshop. The workshop programme should not be a 'one time only' opportunity.
  - It is important to acknowledge that some participants will already have developed aspects of their personal narrative prior to joining the workshop programme.

- There will be a time constraint in as much as each workshop programme will last for 6 weeks.
- Therapeutic input
  - There is no expectation that individual's will have had professional therapeutic input or treatment prior to the workshop programme. The workshop programme is neither therapy nor treatment – it is a training programme to support individuals' to develop a personal narrative. Although it is assumed that participation in the programme will likely be therapeutic in itself in terms of factors such as improved understanding, self-knowledge, confidence and a more positive self-image.

#### Scheme of Work Proforma for Narrative Development Workshop

<b>Title</b>	<b>Your Narrative, Your Voice, Your Way</b>
Rationale	A practical 6 week [peer led] workshop programme that will offer the opportunity and support to [service users] to develop their personal narrative.
Aims	<ul style="list-style-type: none"> <li>● Run a pilot [peer-led] personal narrative workshop programme. The workshop programme will run for 6 sessions over 6 weeks. Each session will last for 2.5 hours (including breaks).</li> <li>● Explore participants' reasons for wanting to develop their personal narrative.</li> <li>● Explore important issues relevant to personal narrative development:           <ul style="list-style-type: none"> <li>○ What is mental health recovery?</li> <li>○ What is hope?</li> <li>○ What are personal narratives and recovery narratives?</li> <li>○ Benefits of developing a personal narrative and it's possible contribution to mental health recovery</li> <li>○ The workshops are not therapy or treatment</li> </ul> </li> </ul>

- Understand challenges in developing their personal narrative:
  - Keeping safe
  - The role of boundaries and trust (Group Agreement)
  - The voices of others within participants' personal narratives
  - What is included within the personal narrative and what is left out
- Consider the use of media (e.g. photography, art, the written word or performance) in personal narrative development:
  - Advantages and disadvantages of different media (e.g. availability and cost of equipment, language and learning ability, wellness and confidence)
  - Individual choice
  - Building on existing interest and expertise of participants
- Explore different possible personal narrative development frameworks (e.g. Tree of Life, storyboards and timelines).
- Support participants to develop their personal narrative within a [peer-led] workshop programme:
  - Offer a safe environment and tools to get started
  - Opportunity to work on their personal narrative within the workshop
  - Consider the evolving and on-going process of developing their personal narrative
  - Signposting for additional support (outside workshop) if necessary
- Offer the opportunity to share their personal narrative with others:
  - To decide how much to share with others
  - To be listened to by other participants
  - To listen to the personal narratives of others (including individuals who have developed and shared their narratives)
  - To consider sharing with different audiences
  - To learn from others and to reflect on own personal narrative

	<ul style="list-style-type: none"> <li>Offer the opportunity to discuss their process in developing and sharing their personal narrative (e.g. developing own voice, acceptance, gaining a better understanding of themselves, improving confidence, identifying with others, reduced isolation and de-stigmatization).</li> <li>Consider where do participants go from here?</li> </ul>
Objectives	<ul style="list-style-type: none"> <li>Set up a pilot [peer-led] personal narrative workshop programme. The workshop programme will run for 6 sessions over 6 weeks. Each session will last for 2.5 hours (including breaks).</li> <li>[Two peers] who have developed their own personal narrative will facilitate workshop programme. The researcher will co-facilitate the pilot.</li> <li>Discussion will be used to explore participants' reasons for wanting to develop a personal narrative.</li> <li>Facilitator input, discussion and practical activities (detailed in individual session plans) will be used: <ul style="list-style-type: none"> <li>To gain an awareness of important issues relevant to personal narrative development:</li> <li>What is mental health recovery?</li> <li>What is hope?</li> <li>What are personal narratives and recovery narratives?</li> <li>Benefits of developing a personal narrative and its possible contribution to mental health recovery</li> </ul> </li> <li>Facilitator input, discussion and practical activities (detailed in individual session plans) will be used: <ul style="list-style-type: none"> <li>To understand challenges in developing their personal narrative:</li> <li>Keeping safe</li> <li>The role of boundaries and trust (develop a Group Agreement)</li> <li>The voices of others within participants' personal narratives</li> <li>What is included within the personal narrative and what is left out</li> </ul> </li> </ul>

- Facilitator input, discussion and practical activities (detailed in individual session plans) will be used:
  - To consider the use of media (e.g. photography, art, the written word or performance) in personal narrative development:
  - Advantages and disadvantages of different media (e.g. availability and cost of equipment, language and learning ability, wellness and confidence)
  - Individual choice
  - Building on existing interest and expertise of participants
- Discuss different possible personal narrative development frameworks (e.g. Tree of Life, storyboards and timelines).
- Offer time, safe space and support to participants to develop their personal narrative within a [peer-led] workshop programme. Facilitator input, discussion and practical activities (detailed in individual session plans) will be used to:
  - Explore tools to get started
  - Consider the evolving and on-going process of developing their personal narrative
  - Signpost for additional support (outside workshop programme) if necessary
- Discuss and offer the opportunity to share their personal narrative with other workshop participants. Facilitator input, discussion and practical activities (detailed in individual session plans) will be used to:
  - Decide how much to share with others
  - Be listened to by other participants
  - Listen to the personal narratives of others (individuals who have developed and shared their narratives with a variety of audiences for different purposes)
  - Consider sharing with different audiences
  - Learn from others and to reflect on own personal narrative

	<ul style="list-style-type: none"> <li>• Discuss participant process in developing and sharing their personal narrative (e.g. developing own voice, acceptance, gaining a better understanding of themselves, improving confidence, identifying with others, reduced isolation and de-stigmatization).</li> <li>• Consider and discuss where do participants go from here?</li> </ul>
Session Overview	<p>Each session will have a semi-formal structure, which will include a check-in, check out and a targeted icebreaker. For sessions 2 - 6 there will also be an opportunity for a recap of previous sessions. To support facilitators, each session will have possible time allocations for different activities.</p> <p>Within this formal structure, there will be flexibility for facilitators to go with issues that arise from the narrative development process.</p>
Session 1	
Session 2	
Session 3	
Session 4	
Session 5	
Session 6	

Items for further discussion:

What goes where Session 1-6

- Underpinning Model:
  - Reflect the recovery model (not linear, supporting agency and growth etc)
  - (Us and Them and NHS)
  - Attitude of professionals
  - Location of Workshop
- Facilitation training requirements
- Facilitator and participant support

**Phase 3: Cycle 2 Focus Group – Developing Session Plans**

**Appendix 6.12**

Time	Content	Method	Resources
10.00 15 mins	Welcome: <ul style="list-style-type: none"><li>- Introductions</li><li>- Check-in</li><li>- Consent Form</li></ul>		Pens, flipchart paper, paper, post-its, marker pens  Digital recorder  Consent Forms  Parking Board
10.15 15 mins	Session Agenda: <ul style="list-style-type: none"><li>- Recap on cycle 1</li><li>- Look through draft SOW</li><li>- Reminder of Parking Board items</li><li>- What we are going to do this session</li></ul>	Brainstorm discussion  Write down key points	SOW v.1  Parking Board items from Cycle 1
10.30 20 mins	Developing the Session Plans: <ul style="list-style-type: none"><li>- Consensus on what a session plan is</li><li>- What goes where?</li></ul>	Brainstorm discussion  Write down key points	Session Plan Proforma  Blank Session Plan Overview  Icebreaker ideas // Animals  Rating scales // Jelly bean tree
10.50	BREAK		
11.00	What goes where?	Brainstorm discussion	Blank Session Plan Overview

50 mins		Write down key points	
11.50	Wrap-up: - Set a date for next meeting - Check-out		
10 mins			

Issues	Cycle 1 Comments	Cycle 2 Comments
Underpinning Model	<ul style="list-style-type: none"> <li>• Them and Us <ul style="list-style-type: none"> <li>▪ Allow professionals in <ul style="list-style-type: none"> <li>◦ When?</li> <li>◦ Will they take control?</li> </ul> </li> </ul> </li> <li>• Partnership or Separate? <ul style="list-style-type: none"> <li>▪ Co-production, co-delivery and co-attendance?</li> </ul> </li> <li>• Reflect the recovery model (non-linear, supporting agency and growth etc)</li> </ul>	
Importance of facilitation	<ul style="list-style-type: none"> <li>• Facilitation training requirements</li> <li>• Facilitator and participant support</li> </ul>	
Size of group	<ul style="list-style-type: none"> <li>• How many?</li> <li>• Where should cut off be?</li> </ul>	
Resources	<ul style="list-style-type: none"> <li>• Practicalities of resources</li> <li>• Cost?</li> </ul>	
Location	<ul style="list-style-type: none"> <li>• Non hospital setting sounds less medical and more like a course</li> </ul>	

Gathering view of others	<ul style="list-style-type: none"> <li>• Less experienced in 'telling their story'</li> </ul>	
Participants	<ul style="list-style-type: none"> <li>• Open to different groups (others can benefit)</li> <li>• Professionals as participants</li> </ul>	
Funding	<ul style="list-style-type: none"> <li>• Who pays?</li> </ul>	

**Cycle 2: Session Plans Overview****Appendix 6.14**

	<b>Content</b>	<b>Method</b>	<b>Resources</b>
1			
2			
3			
4			
5			
6			

**Topics to be included in the session plans. v1**

**November 2016**

**Cycle 3 Introduction**

These topics have been taken from the scheme of work developed in cycle 1 of our focus group. In cycle 3 (our next meeting), we will discuss where to place these topics in the blank session plans.

I have populated session 1 (introduction) and session 8 (what comes next and showcasing) as these were discussed in cycle 2. We can of course make any changes to session 1 and 8.

Instructional/Educational Topics:

- What is recovery?
- What is hope?
- What are a personal narrative and a recovery narrative?
- Benefits of developing a personal narrative
- Different media in personal narrative development
- Advantages and disadvantages of using different media
- Individual choice, interest and expertise of participants
- Keeping safe
- Who is the audience?
- The role of boundaries

- The Importance of trust
- The voice of others within our narratives
- What is included and what is left out?
- How much to share?
- Introduction to different narrative development frameworks (e.g. Time-line. Tree of Life or Storyboard

Listening, Doing and Sharing Topics (can be done more than once):

- Listen to a peer's personal narrative
- Work on personal narrative
- Share your personal narrative

**Your Narrative, Your Voice, Your Way**  
**Narrative Development Workshop Programme**

**Phase 3: Session Plans v.1 (Sessions 1, 2 and 8 shown)**

<b>Session 1: 'Getting to Know Each Other' – Introduction to Workshop Programme</b>	
	<ul style="list-style-type: none"><li>• Welcome</li><li>• Introductions and house-keeping<ul style="list-style-type: none"><li>▪ Check-in</li><li>▪ Ice-Breaker (e.g. how did you get here today?)</li></ul></li></ul>
	<ul style="list-style-type: none"><li>• Overview of the Workshop Programme<ul style="list-style-type: none"><li>▪ Background</li><li>▪ Introduction to the content of the course and what will happen in the sessions</li><li>▪ Role of facilitators</li></ul></li></ul>
Break	
	<ul style="list-style-type: none"><li>• Ice-breaker (Building Trust)</li></ul>
	<ul style="list-style-type: none"><li>• Discussion - Initial consideration of why people have signed up for the workshop programme – why are they here today?<ul style="list-style-type: none"><li>▪ Expectations, hopes and concerns</li><li>▪ Any questions?</li></ul></li><li>• What the programme is and what it is not (not therapy or treatment)</li></ul>
	<ul style="list-style-type: none"><li>• Develop the group agreement</li></ul>
	<ul style="list-style-type: none"><li>• Check-out</li></ul>

**Session 2:**

- Welcome
- House-keeping
  - Check-in
  - Ice-Breaker
- Recap from session 1
- Introduction to Session 2

Break

- Check-out

## Session 8: On-going Narrative Development and Show-Casing Your Narrative

<ul style="list-style-type: none"><li>• Welcome</li><li>• House-keeping<ul style="list-style-type: none"><li>▪ Check-in</li><li>▪ Ice-Breaker</li></ul></li></ul>
<ul style="list-style-type: none"><li>• Recap from session 7</li><li>• Introduction to session 8</li></ul>
<ul style="list-style-type: none"><li>• Discussion of individual's process of developing and sharing their personal narrative: (this could include discussing aspects such as: developing their own voice, acceptance, gaining a better understanding of themselves, improving confidence, identifying with others, reduced isolation and de-stigmatization)<ul style="list-style-type: none"><li>▪ What was it like to begin to share your narrative?</li><li>▪ What was it like to hear the narrative of others?</li></ul></li></ul>
<ul style="list-style-type: none"><li>• What to do with the personal narrative now?<ul style="list-style-type: none"><li>▪ Different ways to use narrative (e.g. sharing for training purposes)</li><li>▪ Signposting</li></ul></li></ul>
Break
<ul style="list-style-type: none"><li>• Feedback to each other</li><li>• Programme feedback</li><li>• Show-casing</li></ul>
<ul style="list-style-type: none"><li>• Check-out and group ending</li></ul>

**Cycle 3: Topics to be included in session plans      November 2016**

- What is recovery?
- What is hope?
- What are a personal narrative and a recovery narrative?
- Benefits of developing a personal narrative
- Different media in personal narrative development
- Advantages and disadvantages of using different media
- Individual choice, interest and expertise of participants
- Keeping safe
- Who is the audience?
- Boundaries
- Trust
- The voice of others
- What is included and what is left out?
- How much to share?
- Introduction to different narrative development frameworks (e.g. Time-line. Tree of Life or Storyboard)
- Listen to a peer's personal narrative
- Work on personal narrative
- Share your personal narrative
- Listen to a peer's personal narrative
- Work on personal narrative
- Share your personal narrative
- Listen to a peer's personal narrative
- Work on personal narrative
- Share your personal narrative

**Phase 3 Scheme of Work Cycle 3 edit. V2****Introduction**

Phase 3 Workshop Programme Scheme of Work (Draft 2) is the result of the co-researcher focus group meeting for three cycles of discussion. Draft 1 was completed after cycle 1 where the scheme of work was the specific focus of discussion. The changes in draft 2 reflect the further work carried out in cycles 2 and 3. These were important changes:

- It is acknowledged that the delivery of the workshop programme should be flexible and therefore be able to reflect: co-researcher skill, local conditions, participant needs and resources.
- Number of sessions increase from 6-8 sessions.
- This impacted on the session order and content order. It allowed more time for working on, sharing and listening to personal narrative.
- Session 1 is an Introductory and Information session. There is no personal narrative development content. It gives participants the opportunity to determine if they wish to continue with the workshop programme.
- Session 8 is a Showcase, Celebration and Reflection session.
- It is essential that at least one of the co-facilitators is a peer who has mental health lived experience and has developed a personal narrative. Ideally both co-facilitators will have this experience. If the second co-facilitator is a clinician (this does not preclude them from having lived experience too), it is important that they have an interest in personal narrative development.
- Both co-facilitators should have attended a Train the Trainer course.
- The 8-session overview provides detail of the theoretical/learning content as well as giving supported space for participants to develop, share, listen to and reflect on personal narrative. The session plan overview shows the session and content order - what should be included in each

session. It does not provide details of tasks and activities (how to deliver content), suggested resources or timing breakdowns. It is important that the co-facilitators who are running each workshop programme determine this level of detail.

### Phase 3 Workshop Programme Scheme of Work. Draft.2

Title	Mental Health Developing A Personal Narrative Workshop Programme
Rationale	A practical peer-led workshop programme that will support participants (service users) to develop their personal narrative.
Aims	<ul style="list-style-type: none"><li>• Explore individuals' rationales for wishing to develop their personal narrative.</li><li>• Support participants to develop their personal narrative within a peer-led workshop programme.</li><li>• Explore important theoretical issues underpinning personal narrative development:<ul style="list-style-type: none"><li>○ The concept of recovery</li><li>○ What is a personal narrative?</li><li>○ Personal narrative and its possible contribution to mental health recovery</li></ul></li><li>• Understand important factors in developing their personal narrative:<ul style="list-style-type: none"><li>○ Keeping safe</li><li>○ The role of boundaries</li><li>○ Relational ethics</li><li>○ What is included and what is left out</li><li>○ Role of different media in personal narrative development</li></ul></li><li>• Explore different possible personal narrative development frameworks.</li><li>• Support participants to develop their personal narrative within a peer-led workshop programme.</li><li>• Offer the opportunity to share their personal narrative with others.</li><li>• Offer the opportunity to discuss their process in developing and sharing their personal narrative.</li><li>• Consider issues such as:<ul style="list-style-type: none"><li>○ The on-going process of developing their personal narrative</li></ul></li></ul>

	<ul style="list-style-type: none"> <li>○ Where do they go from here?</li> </ul>
Objectives	<ul style="list-style-type: none"> <li>● Set up a pilot peer-led personal narrative workshop programme. The workshop programme will run for 8 sessions over 8 weeks. Each session will last for at least 2.5 hours (including breaks).</li> <li>● Two peers<sup>3</sup> who have developed their own personal narrative will co-facilitate the workshop programme. The researcher will co-facilitate the pilot.</li> <li>● Discussions and practical activities (session plans) will be used: <ul style="list-style-type: none"> <li>■ To consider why participants are attending the workshop programme and their wish to develop a personal narrative</li> <li>■ To gain an awareness of important theoretical issues underpinning personal narrative development: <ul style="list-style-type: none"> <li>○ The concept of recovery</li> <li>○ What is a personal narrative?</li> <li>○ Personal narrative and its possible contribution to mental health recovery</li> </ul> </li> <li>■ To consider important factors in developing their personal narrative: <ul style="list-style-type: none"> <li>○ Keeping safe</li> <li>○ The role of boundaries</li> <li>○ Relational ethics</li> <li>○ What is included and what is left out</li> <li>○ Role of different media in personal narrative development</li> </ul> </li> </ul> </li> <li>● To listen to the personal narratives of people with lived experience that have already shared their narratives with wider audiences for a variety of purposes.</li> <li>● Discuss different possible personal narrative development frameworks such as: Tree of Life, timelines and storyboards.</li> <li>● Time, space and support to work on their personal narrative within a peer-facilitated workshop programme.</li> <li>● Share their personal narrative with others in the workshop programme.</li> <li>● Discuss their process in developing and sharing their personal narrative with others in the workshop programme.</li> <li>● Discuss their: <ul style="list-style-type: none"> <li>○ On-going process of developing their personal narrative</li> <li>○ Where do they go from here?</li> </ul> </li> </ul>

<sup>3</sup> It is essential that at least one of the co-facilitators has mental health lived experience and has some experience of developing a personal narrative. Both co-facilitators will have attended a 'Train the Trainer' course.

<p>Session Overview (Guideline)</p>	<p>It is important that the delivery of the Workshop Programme is flexible and is able to reflect: co-researcher skills, local conditions, participant needs and resources.</p> <p>The 8-session overview provides detail of the theoretical/learning content as well as giving supported space for participants to develop, share, listen to and reflect on personal narrative.</p> <p>Every session should have:</p> <ul style="list-style-type: none"> <li>▪ group check-in and check-out</li> <li>▪ ice-breaker</li> <li>▪ session introductions and recaps</li> </ul>
<p>Session 1 Introduction and Getting to Know Each Other</p>	<ul style="list-style-type: none"> <li>• Overview of the Workshop Programme<sup>4</sup> <ul style="list-style-type: none"> <li>▪ Background</li> <li>▪ Introduction to the content of the course and what will happen in the sessions</li> <li>▪ Who and role of co-facilitators</li> <li>▪ What the programme is and what it is not (not therapy or treatment)</li> </ul> </li> <li>• The Group Agreement</li> <li>▪ Discuss the importance of Trust, Keeping Safe and Boundaries</li> <li>▪ Develop the group agreement</li> <li>• Discussion - Initial consideration of why participants have signed up for the workshop programme – why are they here today?</li> </ul>
<p>Session 2</p>	<ul style="list-style-type: none"> <li>• Discuss what is hope and what is recovery?</li> <li>• What is a personal narrative and a recovery narrative?</li> <li>▪ What is the difference?</li> </ul>

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<sup>4</sup> Session 1 is an introductory and informative session. It gives participants the opportunity to decide if they want to continue with the workshop programme. There is no personal narrative development content in this session.

Why Bother Creating a Narrative?	<ul style="list-style-type: none"> <li>▪ Who is the narrative for?</li> <li>• Sharing narrative</li> <li>▪ Co-facilitator (or peer) shares their personal narrative</li> <li>• Discussion – what did it feel like to hear the personal narrative?</li> <li>• Consideration of the possible benefits and difficulties of developing a personal narrative</li> </ul>
Session 3  Mechanics of the Narrative – ‘bits and bobs’	<ul style="list-style-type: none"> <li>• Discuss different media in personal narrative development</li> <li>• Introduction to different narrative development frameworks (e.g. drawing a time-line, storyboard or Tree of Life)</li> <li>• Sharing narrative</li> <li>▪ Co-facilitator (or peer) shares their personal narrative (preferably showcasing range of media)</li> <li>• Discuss the advantages and disadvantages of using different media</li> <li>• Consider individual choice, interest and expertise of participants</li> </ul>
Session 4  ‘Plain Sailing and Stormy Seas’ – the ups and downs of creating and sharing your personal narrative	<ul style="list-style-type: none"> <li>• Exploration of the advantages and disadvantages of sharing their personal narrative with others <ul style="list-style-type: none"> <li>▪ What might it feel like?</li> <li>▪ What are their initial concerns?</li> </ul> </li> <li>• Discuss important considerations in sharing their personal narrative</li> <li>• How much to share?</li> <li>• What is included and what is left out?</li> <li>• The voice of others within their personal narratives</li> <li>• Who is the audience and why is this important?</li> <li>• Playtime – Start to have a go at developing their personal narrative</li> </ul>

Session 5  'Playtime' – doing it!	<ul style="list-style-type: none"> <li>• Listen to a peer personal narrative</li> <li>• Explore the process of the peer in developing and sharing their personal narrative</li> <li>• Work on personal narrative within a supportive environment</li> </ul>
Session 6  'Tinker Time' - Continue working on personal narrative	<ul style="list-style-type: none"> <li>• Discuss and re-evaluate their experience of developing their personal narrative and the possibility of sharing it with others: <ul style="list-style-type: none"> <li>▪ What it might feel like to share their personal narrative?</li> <li>▪ Have any of their initial concerns been realised?</li> <li>▪ How much to share?</li> <li>▪ What is included and what is left out?</li> <li>▪ The voice of others within their personal narratives</li> <li>▪ Who is the audience and why is this important?</li> </ul> </li> <li>• Work on personal narrative within a supportive environment</li> </ul>
Session 7  'Show and Tell'	<ul style="list-style-type: none"> <li>• Sharing and listening to personal narratives (or parts of)</li> </ul>
Session 8  'Reflection'	<ul style="list-style-type: none"> <li>• Discussion of individual's process of developing and sharing their personal narrative: <ul style="list-style-type: none"> <li>▪ (Could include discussing aspects such as: developing their own voice, acceptance, gaining a better understanding of themselves, improving confidence, identifying with others, reduced isolation and de-stigmatization)</li> <li>▪ What was it like to begin to share your narrative?</li> <li>▪ What was it like to hear the narrative of others?</li> </ul> </li> </ul>

and Celebrating'	<ul style="list-style-type: none"><li>• What to do with the personal narrative now?<ul style="list-style-type: none"><li>▪ Different ways to use narrative (e.g. sharing for training purposes)</li><li>▪ Signposting</li></ul></li><li>• Feedback to each other – what have I learnt from other people?</li><li>• Programme feedback</li><li>• Show-casing</li></ul>
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**Appendix 6.19****P3C3 Populated Session Plans Inc. Learning Outcomes**

<b>Session Number</b>	<b>Title</b>
1	Introduction and Getting to Know Each Other
2	Why Bother Creating a Narrative?
3	Mechanics of the Narrative 'bits and bobs'
4	'Plain Sailing and Stormy Seas' – the ups and downs of creating and sharing your personal narrative
5	'Playtime' – doing it!
6	'Tinker Time' - Continue working on personal narrative
7	'Show and Tell'
8	'Reflection and Celebrating'

<b>Title</b>	<b>Session 1 Introduction and Getting to Know Each Other</b>
Aims of session 1	<p>By the end of the session 1, participants will:</p> <ul style="list-style-type: none"> <li>• Have a clear understanding of the 'Developing a Personal Narrative Workshop Programme'</li> <li>• Be able to decide if the Workshop Programme is for them</li> <li>• Have an idea of what they would like to achieve from participation in the Workshop Programme</li> <li>• Have awareness that they can share their developing personal narrative if and when they choose.</li> </ul>
Learning Outcomes	<p>By the end of the session 1:</p> <ul style="list-style-type: none"> <li>➤ All participants will: <ul style="list-style-type: none"> <li>✓ Know the content of the 'Developing a Personal Narrative Workshop Programme'</li> <li>✓ Will be able to decide whether they wish to participate or not</li> <li>✓ Know that they can choose to share or not to share their personal narrative with others</li> </ul> </li> <li>➤ Most participants will be able to: <ul style="list-style-type: none"> <li>✓ Explain what they would like to achieve by participating</li> </ul> </li> <li>➤ Some participants may be able to: <ul style="list-style-type: none"> <li>✓ Start to consider how they might develop their personal narrative</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• Introductions and house-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker (e.g. how did you get here today?)</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>• Overview of the Workshop Programme <ul style="list-style-type: none"> <li>▪ Background</li> <li>▪ Introduction to the content of the course and what will happen in the sessions</li> <li>▪ Who and role of co-facilitators</li> </ul> </li> <li>• What the programme is and what it is not (not therapy or treatment)</li> </ul>
Break	
	<ul style="list-style-type: none"> <li>• Ice-breaker (Building Trust)</li> </ul>
	<ul style="list-style-type: none"> <li>• The Group Agreement <ul style="list-style-type: none"> <li>▪ Discuss the importance of Trust, Keeping Safe and Boundaries</li> <li>▪ Develop the group agreement</li> </ul> </li> </ul>

<ul style="list-style-type: none"> <li>• Discussion - Initial consideration of why participants have signed up for the workshop programme – why are they here today? <ul style="list-style-type: none"> <li>▪ Expectations, hopes and concerns</li> <li>▪ Any questions?</li> </ul> </li> </ul>
<ul style="list-style-type: none"> <li>• Check-out</li> </ul>
Independent Work

Comments:

- As part of reminders/recap at the start of every session, participants should be reminded that they should not discuss names of clinicians or their medications.
- It is likely that some participants may wish to reflect and work on their personal narrative between sessions. It may be useful for co-facilitators to offer guidance through optional homework or independent work tasks.

<b>Title</b>	<b>Session 2 Why Bother Creating a Narrative?</b>
Aims of session 2	<p>By the end of the session 2, participants will:</p> <ul style="list-style-type: none"> <li>• Explore 'hope' and 'recovery'</li> <li>• Explore the potential benefits and difficulties of developing a personal narrative</li> <li>• Listen to a peer personal narrative</li> </ul>
Learning Outcomes	<p>By the end of the session 2:</p> <ul style="list-style-type: none"> <li>➤ All participants will: <ul style="list-style-type: none"> <li>✓ Be aware of the concept of 'mental health recovery'</li> <li>✓ Be aware of the importance of hope in recovery</li> <li>✓ Know that there are potential benefits and difficulties when developing a personal narrative</li> <li>✓ Have had the opportunity to have listened to a personal narrative</li> </ul> </li> <li>➤ Most participants will be able to: <ul style="list-style-type: none"> <li>✓ Know the difference between 'medical recovery' and 'mental health recovery'</li> <li>✓ Consider the relevance of hope and recovery on their own mental health experiences</li> <li>✓ Think about the shared personal narrative</li> </ul> </li> <li>➤ Some participants may be able to: <ul style="list-style-type: none"> <li>✓ Consider how any potential benefits and difficulties of personal narrative development could impact on themselves</li> <li>✓ Consider the similarities and differences between the shared personal narrative and their own lived experience</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• House-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>• Recap from session 1</li> <li>• Introduction to Session 2 <ul style="list-style-type: none"> <li>▪ Discuss what is hope and what is recovery?</li> </ul> </li> <li>• What is a personal narrative and a recovery narrative? <ul style="list-style-type: none"> <li>▪ What is the difference?</li> <li>▪ Who is the narrative for?</li> </ul> </li> </ul>

Break
<ul style="list-style-type: none"> <li>• Sharing narrative</li> <li>▪ Co-facilitator (or peer) shares their personal narrative</li> </ul>
<ul style="list-style-type: none"> <li>• Discussion – what did it feel like to hear the personal narrative?</li> </ul>
<ul style="list-style-type: none"> <li>• Consideration of the possible benefits and difficulties of developing a personal narrative</li> </ul>
Check-out
Independent Work

Title	Session 3 Mechanics of the Narrative 'bits and bobs'
Aims of session 3	<p>By the end of the session 3, participants will:</p> <ul style="list-style-type: none"> <li>• Know how different media (e.g. art, photography or writing) may be used in developing a personal narrative</li> <li>• Understand that participants can choose their narrative media in line with their individual interest and/or expertise</li> <li>• Listen to a peer personal narrative</li> </ul>
Learning Outcomes	<p>By the end of the session 3:</p> <ul style="list-style-type: none"> <li>➤ All participants will: <ul style="list-style-type: none"> <li>✓ Know that a personal narrative can be developed using a range of media. A personal narrative does not have to be written and that it is a matter of choice</li> <li>✓ Be aware that there are personal narrative frameworks and techniques that can be used to support them to develop their personal narrative (e.g. a time line or a storyboard)</li> <li>✓ Understand that there are advantages and disadvantages to using different media</li> <li>✓ Have the opportunity to listen to a personal narrative using a range of media</li> </ul> </li> <li>➤ Most participants will be able to: <ul style="list-style-type: none"> <li>✓ Have a go at using one of the frameworks or techniques in their own personal narrative development</li> <li>✓ Consider their own interest and expertise in considering the media for their personal narrative</li> </ul> </li> <li>➤ Some participants may be able to: <ul style="list-style-type: none"> <li>✓ Think about how the advantages and disadvantages of using particular media in relation to their own personal narrative development</li> <li>✓ Consider any practical implications</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• House-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>• Recap from session 2</li> <li>• Introduction to Session 3</li> </ul>

<ul style="list-style-type: none"> <li>• Discuss different media in personal narrative development</li> </ul>
<ul style="list-style-type: none"> <li>• Introduction to different narrative development frameworks (e.g. drawing a timeline, storyboard or Tree of Life)</li> </ul>
Break
<ul style="list-style-type: none"> <li>• Sharing narrative</li> <li>▪ Co-facilitator (or peer) shares their personal narrative (preferably showcasing range of media)</li> </ul>
<ul style="list-style-type: none"> <li>• Discuss the advantages and disadvantages of using different media</li> <li>• Consider individual choice, interest and expertise of participants</li> </ul>
Check-out
Independent Work
<ul style="list-style-type: none"> <li>• Participants may wish to have a go at using one/ or more of the narrative development frameworks</li> </ul>

<b>Title</b>	<b>Session 4 'Plain Sailing and Stormy Seas' – the ups and downs of creating and sharing your personal narrative</b>
<b>Aims of session 4</b>	<p>By the end of the session 4, participants will:</p> <ul style="list-style-type: none"> <li>• Consider the advantages and disadvantages of sharing their personal narrative with others</li> <li>▪ The impact on others of sharing their personal narrative</li> <li>▪ How they may feel after sharing their personal narrative (there may be both positive and negative emotions)</li> <li>▪ Consider the impact on themselves when hearing the personal narratives of others</li> </ul>
<b>Learning Outcomes</b>	<p>By the end of the session 4:</p> <ul style="list-style-type: none"> <li>➤ All participants will: <ul style="list-style-type: none"> <li>✓ Know that they can choose to share or not to share their personal narrative with others</li> <li>✓ Be aware that there may be advantages and disadvantages to sharing their personal narrative with others</li> <li>✓ Be aware that, when listening to the personal narrative of others, there may be emotional effects on themselves</li> <li>✓ Know that sharing personal narratives should be experienced within a supportive environment</li> </ul> </li> <li>➤ Most participants will be able to: <ul style="list-style-type: none"> <li>✓ Consider some of the possible impact of sharing their personal narrative with others</li> <li>✓ Reflect on the potential impact of listening to the personal narrative of others</li> </ul> </li> <li>➤ Some participants may be able to: <ul style="list-style-type: none"> <li>✓ Consider factors such as: audience, voice of others and what to include when sharing their personal narrative</li> <li>✓ Think about how they may adapt their personal narrative when sharing with different audiences</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• House-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>• Recap from session 3</li> <li>• Introduction to Session 4</li> <li>• Exploration of the advantages and disadvantages of sharing their personal narrative with others <ul style="list-style-type: none"> <li>▪ What might it feel like?</li> <li>▪ What are their initial concerns?</li> </ul> </li> </ul>
<b>Break</b>	
	<ul style="list-style-type: none"> <li>• Discuss important considerations in sharing their personal narrative</li> <li>• How much to share?</li> <li>• What is included and what is left out?</li> <li>• The voice of others within their personal narratives</li> </ul>

<ul style="list-style-type: none"> <li>• Who is the audience and why is this important?</li> <li>• Playtime – Start to have a go at developing their personal narrative</li> </ul>
Check-out
Independent Work
<ul style="list-style-type: none"> <li>• Participants can choose to continue developing their personal narrative</li> </ul>

Comment:

- Playtime will be fully supported by the co-facilitators, including one-to-one support.

<b>Title</b>	<b>Session 5 ‘Playtime’ – doing it!</b>
Aims of session 5	<p>By the end of the session 5, participants will:</p> <ul style="list-style-type: none"> <li>• Listen to a shared personal narrative</li> <li>• Explore the process of the peer who has shared their personal narrative</li> <li>• Have time to work on their personal narrative within a supportive environment</li> </ul>
Learning Outcomes	<p>By the end of the session 5:</p> <ul style="list-style-type: none"> <li>➤ All participants will: <ul style="list-style-type: none"> <li>✓ Have had the opportunity to have listened to a peer personal narrative</li> <li>✓ Listen to the peer’s process in developing and sharing their personal narrative</li> <li>✓ Had the opportunity to work on their own personal narrative within a supported environment</li> </ul> </li> <li>➤ Most participants will be able to: <ul style="list-style-type: none"> <li>✓ Ask the peer questions about their process</li> <li>✓ Work on personal narrative</li> <li>✓ Discuss any concerns with the co-facilitators</li> </ul> </li> <li>➤ Some participants may be able to: <ul style="list-style-type: none"> <li>✓ Start to link the peer’s process with their own</li> <li>✓ Consider what support they may need as part of developing their personal narrative</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• House-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>• Recap from session 4</li> <li>• Introduction to Session 5</li> </ul>
	<ul style="list-style-type: none"> <li>• Listen to a peer personal narrative</li> <li>• Explore the process of the peer in developing and sharing their personal narrative</li> </ul>
Break	
	<ul style="list-style-type: none"> <li>• Work on personal narrative within a supportive environment</li> </ul>
Check-out	
Independent Work	<ul style="list-style-type: none"> <li>• Participants can choose to continue developing their personal narrative</li> </ul>

<b>Title</b>	<b>Session 6 'Tinker Time' - Continue working on personal narrative</b>
Aims of session 6	<p>By the end of the session 6, participants will:</p> <ul style="list-style-type: none"> <li>• Given that participant personal narrative development is on-going:</li> <li>▪ Explore their process in developing their personal narrative</li> <li>▪ Explore and reevaluate the possibility of sharing their personal narrative with others</li> <li>▪ Reconsider important factors when sharing their personal narrative (e.g. the audience, how much to share and the voices of others)</li> <li>• Have time to work on their personal narrative within a supportive environment</li> </ul>
Learning Outcomes	<p>By the end of the session 6:</p> <ul style="list-style-type: none"> <li>➤ All participants will: <ul style="list-style-type: none"> <li>✓ Think about their own process in developing their personal narrative</li> <li>✓ Reconsider the possibility of sharing their personal narrative with others</li> <li>✓ Revisited important factors (e.g. the audience, how much to share and the voices of others) when sharing their personal narrative with others <ul style="list-style-type: none"> <li>✓ Had the opportunity to work on their own personal narrative within a supported environment</li> </ul> </li> </ul> </li> <li>➤ Most participants will be able to: <ul style="list-style-type: none"> <li>✓ Ask questions about their process and sharing</li> <li>✓ Work on personal narrative</li> <li>✓ Discuss any concerns with the co-facilitators</li> </ul> </li> <li>➤ Some participants may be able to: <ul style="list-style-type: none"> <li>✓ Incorporate the factors relating to sharing their personal narrative, such that they feel comfortable in sharing with others</li> <li>✓ Consider what support they may need as part of developing their personal narrative</li> </ul> </li> </ul>
<ul style="list-style-type: none"> <li>• Welcome</li> <li>• House-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker</li> </ul> </li> <li>• Recap from session 5</li> <li>• Introduction to Session 6</li> </ul>	
Participants are in the process of developing their personal narratives and are possibly starting to think about sharing their personal narratives with others	

- Discuss and re-evaluate their experience of developing their personal narrative and the possibility of sharing it with others:
- What it might feel like to share their personal narrative?
- Have any of their initial concerns been realised?
- How much to share?
- What is included and what is left out?
- The voice of others within their personal narratives
- Who is the audience and why is this important?

Break

- Work on personal narrative within a supportive environment

Check-out

Independent Work

- Participants can choose to continue developing their personal narrative

<b>Title</b>	<b>Session 7 'Show and Tell'</b>
Aim of session 7	<p>By the end of the session 7, participants will:</p> <ul style="list-style-type: none"> <li>• Have time and support to share their personal narrative (or parts of) with others</li> </ul>
Learning Outcomes	<p>By the end of the session 7:</p> <ul style="list-style-type: none"> <li>➤ All participants will: <ul style="list-style-type: none"> <li>✓ Have had the opportunity to share their personal narrative (or parts of) with others</li> <li>✓ Have the opportunity to listen to the personal narrative (or parts of) of others</li> </ul> </li> <li>➤ Most participants will: <ul style="list-style-type: none"> <li>✓ Have shared their personal narrative (or parts of) with others</li> <li>✓ Have listened to the personal narrative (or parts of) of others</li> </ul> </li> <li>➤ Some participants may be able to: <ul style="list-style-type: none"> <li>✓ Reflect on their process of sharing their personal narrative (or parts of) with others</li> <li>✓ Reflect on their process of listening to the personal narrative (or parts of) of others</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• House-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>• Recap from session 6</li> <li>• Introduction to Session 7</li> </ul>
	<ul style="list-style-type: none"> <li>• Sharing and listening to personal narratives (or parts of)</li> </ul>
Break	
	<ul style="list-style-type: none"> <li>• Sharing and listening to personal narratives (or parts of)</li> </ul>
Check-out	
Independent Work	<ul style="list-style-type: none"> <li>• Participants can choose to continue developing their personal narrative</li> <li>• Reflect on their process of sharing and listening to personal narratives</li> </ul>

<b>Title</b>	<b>Session 8 'Reflection and Celebrating'</b>
Aims of session 8	<p>By the end of the session 8, participants will:</p> <ul style="list-style-type: none"> <li>• Reflect on their process of developing and sharing their personal narrative (or parts of) with others</li> <li>• Celebrate what they have and others have achieved</li> <li>• Explore and signpost ways to use their personal narrative</li> <li>• Give and receive feedback on each other and the workshop programme</li> </ul>
Learning Outcomes	<p>By the end of the session 8:</p> <ul style="list-style-type: none"> <li>➤ All participants will: <ul style="list-style-type: none"> <li>✓ Have had the opportunity to share their reflections on their process of developing and sharing their personal narrative</li> <li>✓ Have the opportunity to listen to the reflections of others</li> <li>✓ Have the opportunity to celebrate their own achievement and the achievement of others</li> <li>✓ Be aware of the further opportunities to develop and use their personal narrative</li> <li>✓ Have the opportunity to give and receive feedback from each other</li> <li>✓ Have the opportunity to give feedback on the workshop programme</li> </ul> </li> <li>➤ Most participants will: <ul style="list-style-type: none"> <li>✓ Share their reflections on their process with others</li> <li>✓ Discuss the reflections of others</li> <li>✓ Discuss how they may continue to develop, use and share their personal narrative</li> <li>✓ Give and receive feedback on each other</li> <li>✓ Give feedback on the workshop programme</li> </ul> </li> <li>➤ Some participants may be able to: <ul style="list-style-type: none"> <li>✓ Continue to reflect on their process and the process of others</li> <li>✓ Continue the on-going process of their personal narrative development</li> <li>✓ Incorporate lessons learnt from developing their personal narrative into other aspects of their life</li> <li>✓ Make a definite commitment to further develop, use and share their personal narrative</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• House-keeping <ul style="list-style-type: none"> <li>▪ Check-in</li> <li>▪ Ice-Breaker</li> </ul> </li> <li>• Recap from session 7</li> </ul>

<ul style="list-style-type: none"> <li>• Introduction to Session 8</li> <li>• Discussion of individual's process of developing and sharing their personal narrative: <ul style="list-style-type: none"> <li>▪ (Could include discussing aspects such as: developing their own voice, acceptance, gaining a better understanding of themselves, improving confidence, identifying with others, reduced isolation and de-stigmatization)</li> <li>▪ What was it like to begin to share your narrative?</li> <li>▪ What was it like to hear the narrative of others?</li> </ul> </li> </ul>
Break
<ul style="list-style-type: none"> <li>• What to do with the personal narrative now? <ul style="list-style-type: none"> <li>▪ Different ways to use narrative (e.g. sharing for training purposes)</li> <li>▪ Signposting</li> </ul> </li> <li>• Feedback to each other – what have I learnt from other people?</li> <li>• Programme feedback</li> <li>• Show-casing</li> </ul>
Check-out and group ending
<p>Independent Work</p> <ul style="list-style-type: none"> <li>• Participants can choose to continue developing their personal narrative</li> <li>• Reflect on their process of sharing and listening to personal narratives</li> </ul>