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**University of Southampton**

Faculty of Environmental and Life Sciences

**School of Health Sciences**

**Patients, Professionals and Power Dynamics: Exploring the Role of Mental Health  
Service Improvement Work within a Person's Experience of Recovery**

Volume 1 of 1

by

**Christopher James Gale, RNMH, MSc, BA (Hons)**

Thesis for the degree of **Doctor of Philosophy**

September 2020

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# **University of Southampton**

## **Abstract**

Faculty of Faculty of Environmental and Life Sciences

School of Health Sciences

Thesis for the degree of Doctor of Philosophy

## **Patients, Professionals and Power Dynamics: Exploring the Role of Mental Health Service Improvement Work within a Person's Experience of Recovery**

By

Christopher James Gale

Over the past 30-40 years health policy and literature internationally has emphasised increased user involvement in the shaping of mental health care. However, little has been written to contextualise such involvement experiences within people's own recovery from mental health crisis and their 'life story'.

This qualitative study interviewed individuals who have accessed mental health services and become involved in working with care providing organisations. Its aim was to contextualise experiences within their life 'story' and recovery, exploring identities and roles assumed by the narrators. Ten participants were recruited using a theoretical sampling strategy. The interviews were structured around an oral history/life story approach and the transcription process incorporated performance aspects, as well as spoken content.

Drawing on Braun & Clarke's approach to thematic analysis key emergent themes were clustered to identify overarching themes across all interview narratives. Storytelling devices important to life stories were also explored. The narratives recorded could be broadly split into three phases or 'acts'; 'life before mental health crisis', 'entering the mental health system' and 'enlightenment and changing the script'. The analysis and discussion identified overarching themes of 'Survival', 'Institutional Power and Dominance', and 'Asserting Power & Forging a New Identity', which traversed these acts.

The study concluded that to experience recovery from mental health crises, user involvement activity had significant value up to a point. To regain a true sense of autonomy, restoration/formation of identity and challenge services to improve their care, however, a person often needs to step outside of the mental health system. Recommendations about how this might be achieved and areas for future research are discussed.



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# Research Thesis: Declaration of Authorship

Christopher James Gale

**'Patients, Professionals and Power Dynamics: Exploring the Role of Mental Health Service Improvement Work within a Person's Experience of Recovery'**

I 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.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. 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;
5. I have acknowledged all main sources of help;
6. 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;
7. None of this work has been published before submission

Signature:

Date: September 2020



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## Definitions and Abbreviations

<b>CAMHS</b>	Child and Adolescent Mental Health Services
<b>CBT</b>	Cognitive Behaviour Therapy
<b>CTO</b>	Community Treatment Order
<b>DBT</b>	Dialectical Behaviour Therapy
<b>DH or DoH</b>	Department of Health
<b>EBP</b>	Evidence Based Practice
<b>ECT</b>	Electroconvulsive Therapy
<b>HM Govt</b>	Her Majesty's Government
<b>IAPT</b>	Improving Access to Psychological Therapies
<b>LS</b>	Life Story
<b>MCA</b>	Mental Capacity Act
<b>MHA</b>	Mental Health Act
<b>NAMH</b>	National Association for Mental Health
<b>NHS</b>	National Health Service
<b>NHWMH</b>	<i>No Health Without Mental Health</i>
<b>NRES</b>	NHS Research Ethics
<b>NSF</b>	National Schizophrenia Fellowship (now Rethink)
<b>OH</b>	Oral History
<b>ONS</b>	Office for National Statistics
<b>OT</b>	Overarching Theme
<b>REC</b>	Regional Ethics Committee
<b>SSO</b>	Survivors Speak Out
<b>VBP</b>	Values Based Practice
<b>WHO</b>	World Health Organisation



# **Chapter 1 Patients, Professionals and Power Dynamics: Exploring the Role of Mental Health Service Improvement ‘Work’ within a Person’s Experience of Recovery**

## **1.1 Introduction to the Author & Area of Interest**

My interest in the experience of those affected by significant mental distress is both a professional and personal one. Professionally, I have been a registered mental health nurse for 14 years, working predominantly within community child and adolescent mental health services (CAMHS), as well as an academic lecturer in the higher education setting, supporting the development of nursing students to registration. Personally, I have experienced periods of significant mental distress, which whilst never bringing me into the mental health system as a service user, has left me questioning why not and what makes me any different from those who have? My position as a researcher in relation to the theoretical considerations of this work is explored in 1.5.

Despite my background in working with young people, I have focused on those adults of working age. This in part has been due to the privilege I had in my early academic career in facilitating an external mental health reference group, made up of those with lived experience and those working in the voluntary sector with people experiencing mental health issues. The group members were paid for their time and input into curriculum development and teaching activity. A number not only undertook work within my faculty, but often were employed to undertake comparable activities with other organisations, such as universities and NHS mental health service providers. For a very few this was in a formal paid role; for most this ad hoc employment constituted their lives at work.

National government policy for a number of years has trumpeted the role of those with lived experience of a range of physical and mental health issues to have a say in how services are planned and delivered (discussed later in this chapter). Therefore, it comes as no surprise that opportunities to undertake service user involvement ‘work’ have become increasingly available. What piqued my interest, were the potential benefits it brought for the person with lived experience; what motivated them to travel distances in order to expose their vulnerabilities (by being identified as a ‘service user’ or even sharing intimate details of their lives) around an area of health that still carries some stigma? Certainly, the remuneration with any organisation would not

have been enough to support a comfortable lifestyle and it seemed inappropriate to glibly assume that such activity gave them a purpose; something to wake up for in the morning (although this should not be discounted as a motivator for some at certain points in their recovery). Two basic questions emerged; who are the people who undertake this service user involvement work, sometimes after they have been discharged from mental health services and what drives them?

## 1.2 The 'Service User'

Rogers et al (1993), in the wake of the NHS and Community Care Act (HM Govt, 1990) and its attempt to establish a national framework of services described three different concepts of people who accessed mental health services; the user as a patient, the user as consumer, and finally the user as survivor (defined in Table 1). There is perhaps little debate around the definition of a patient or consumer, but the term 'survivor' carries varying connotations in the literature; possibly referring to a person who has survived the trauma of severe mental distress, but equally could mean someone who has survived the experience of the mental health system (Faber, 2012). These concepts align well with the broader ideas proposed by Hirschman's (1970) ground-breaking work in relation to how individuals and organisations relate (*exit, voice and loyalty* - Table 1).

**Table 1: Concepts of the mental health service user (Rogers et al, 1993) and how individuals interact with large organisations (Hirschman, 1970)**

Rogers et al (1993)	Hirschman (1970)
User as Patient: passive recipient of care	Loyalty: individuals continue to use services, hoping to exert some influence from the margins
User as Consumer: acknowledged by governing authorities and professional groups as having a right to express their views	Voice: organisation expects to seek and respond to the views of individuals, who themselves are prepared to stand up and articulate these views.
User as Survivor: campaigning collectively as part of a new social movement	Exit: individual possesses the right to reject the organisation in favour of an alternative pathway.

Interestingly Hirschman hypothesised that hierarchical institutions (such as health care services) will always attempt to institutionalise 'voice' in order to avoid an 'exit'. This would seem sensible if 'exit' involved a serious challenge to the legitimacy of the institution's dominant position and a potential shift in the balance of power towards the individual. It is important to note, that although Hirschman's work indicates a linear process of loyalty, voice and exit, the concepts of

mental health service users, as described by Rogers et al (1993), does not. This suggests that a person's status may change after a period of being a consumer (or seeing oneself as a survivor) to the passive role of the patient, presumably as a result of significantly increased mental distress. It would be reasonable to suggest that the patient may then have the opportunity to move through the roles, as they recover from a mental health crisis; an idea that will undoubtedly be either confirmed or dismissed through the research process in this project.

Contemporary policy and practice guidance would seek to challenge Roger's et al (1993) definition of the patient as a passive recipient of care, referring to having choice and control over their lives and within the plan of care offered by service providers (Department of Health – DH, 1999, 2001b, 2011; The Mental Health Taskforce, 2016), essentially absorbing the concept of patient and consumer into one and placing an expectation on providers that they offer individuals a meaningful voice (as per Hirschman's model - 1970).

Emerging from the literature on service user involvement is a socio-political history which documents a clear transition from 'patient' to 'consumer' (loyalty to voice) in mental health, with the rhetoric of an exit type of relationship. The 'survivor' concept, however, remains very much within the language and commentaries of users themselves (Campbell & Rose, 2010; Chassot & Mendes, 2015). The historical socio-political and economic context is explored in 1.3.

## **1.3 Historical Socio-Political Context in the Late 20<sup>th</sup> & Early 21<sup>st</sup> Centuries**

### **1.3.1 Socio-Political Historians**

There has been unprecedented interest in the last 50 years in accounting for the history of treating those experiencing severe mental distress. In the United Kingdom (UK) the late Kathleen Jones and Roy Porter, both social historians, wrote prolifically around the plight of the mentally 'ill' and how society has largely failed to meet their needs (Jones, 1993; Porter, 2002). The works of Anne Rogers and David Pilgrim have added a valuable policy and social context to the UK service user experience over the 20<sup>th</sup> century (Rogers & Pilgrim, 2001; 2010). These authors have commended the vision of moving mental patients out of the asylum setting and into the community, but have expressed dismay at the way in which it occurred, and the legacy left behind. Prominent authors with their own lived experience of severe mental distress and use of services have echoed this view (Rose, 2001; Campbell & Rose, 2010).

From the early 1970s United States sociologist, Andrew Scull, has been writing about the history of psychiatry, drawing on the perspectives of the 'Antipsychiatrists' and others who have challenged the core concepts of psychiatry (Erving Goffman, Michel Foucault, Thomas Szasz,

Ronald Laing among others). Scull asserts that the treatment of those with a diagnosis of mental illness has long been a form of social control over deviant behaviour, exercised by the state and mental health professionals (Scull, 2006). Jones (1982) has been critical of Scull and others who place such a strong emphasis on social control in psychiatry, criticising their use of language; 'madness' instead of 'mental illness' and 'decarceration' instead of 'community care', which she attributed to their desire to be seen as radical. Similarly, Edward Shorter (1997), distinctly pro-medical model in his view on psychiatry, states that above all he has "tried to rescue the history of psychiatry from the sectarians who have made the subject a sandbox for their ideologies" (Preface viii); although one might suggest that this comment is ideological in itself.

What emerges from the works of these key authors, whatever their ideological position, is a slow transition over the second half of the 20<sup>th</sup> century of care for those with significant mental health difficulties from large institutions or asylums to smaller inpatient hospital units and care in the community. However, as Prior (1993) warns, clear explanations for trends within twentieth century psychiatry are not easy to identify; the complex mix of state driven law and policy, an ever-changing economic landscape, emerging and developing treatments, professional ideologies in the field and the semi-organised resistance to the label of being 'mental ill' and care services, do not necessarily present themselves in a linear fashion. As such, the brief exploration of the following key 'themes' does not indicate a hierarchy or rigid chronology of the drivers behind change for the care of this group of people.

### **1.3.2 The Dominance of the Mental Asylum in the UK (C19 and early C20)**

Prior to the mid-twentieth century the inpatient asylum-based system of mental health care had been dominant for over 100 years; large complexes accommodating hundreds of patients, often on the edges of towns or in the countryside in order to ensure fresh air and a healthy water supply (as well, as keeping them away from the main population) (Jones, 1993; Carpenter, 2010). This is not to say that community or outpatient facilities did not exist prior to the mid-twentieth century. As early as 1915 the Maudsley Hospital opened an outpatient and acute inpatient care service; its initial function to treat the victims of 'shell-shock' returning from the trenches of the First World War (Coppock & Hopton, 2000). The Mental Treatment Act of 1930 gave full legislative support to the introduction of voluntary admissions to inpatient care and the creation of outpatient services, although few were cared for in this way in the years leading up to the Second World War (Bennett, 1993). Indeed, the asylum population reached its peak in 1955, with some 150,000 residents.

### 1.3.3 Questioning of the Asylum System & 'Antipsychiatry' (1950s & 1960s)

Several key documents and events during the 1950s and early 1960s signalled a vision to dismantle the old UK asylum system and move toward an integrated system of care with units based within general hospital settings and community services. The Percy Commission Report (1958) and subsequent Mental Health Act (1959), and the Government Health minister, Enoch Powell's famous 'Water Tower Speech' of 1961 (followed by the 1962 Hospital Plan and 1963 Community Plan) all embraced this new rhetoric (Rogers & Pilgrim, 2001).

Alongside this change in direction of government policy (explored further in 1.3.6 – Page 7) was a direct challenge to the asylum-based care and indeed psychiatry itself (often coined 'antipsychiatry'), precipitated by the publication of Goffman's *Asylums* in 1961 (Goffman, 1991) and Foucault's *Madness and Civilization* in the same year (translated into English in 1967) (Foucault, 2001). The basic premise of Antipsychiatry was two-fold; firstly, that mental illness did not in fact exist, but was the creation of psychiatry and state as agents of social control to understand those experiencing problems with living (Szasz, 1960; Laing, 1990) and secondly the hospital/asylum-based system of care in fact stripped people of their humanity and possibly made their behaviour more deviant (Goffman, 1991). However, the asylum system is not without its supporters, certainly among those who promoted the safety and refuge aspect of being an inpatient (Renshaw, 1987). In a tone of pessimism, Haslam (1984) suggested: "In terms of quality of life, have we exchanged the womb-like security which the chronically disabled previously enjoyed, in what was sheltered true asylum, for the uncertainty of trying to compete in the normal and somewhat rejecting larger community" (P97). Others have pointed out that Goffman himself did not criticise the medical model explanations for psychopathology, but the unequal power relationship within the asylum system (Suibhne, 2011). Perhaps the strongest modern critic of the antipsychiatry version of history has been Shorter (1987), who insisted that the argument for mental illness being a social construct is no more convincing than if it were applied to Parkinson's disease or Multiple Sclerosis. He counters that the patient's experience of illness and society's response to them are influenced by culture and convention.

### 1.3.4 The Drug Revolution (1950s onwards)

Welshman (1999) asserts that the drug revolution of the 1950s fuelled the growing support for community care. The introduction of major tranquilisers in 1954 (Chlorpromazine being the most prominent) after very limited clinical trials on patients experiencing schizophrenia (Scull, 1984) grew exponentially. Nolan (1993) attributed this to the prestige of curing mental illness, allaying any concerns around possible side-effects. Porter (2002) agrees that the use of psychoactive

drugs enables the psychiatric system to “function better” and acknowledges that more people than ever are taking medication on a regular basis, but contests that “pacifying patients with drugs hardly seem the pinnacle of achievement” (P216).

### 1.3.5 Therapeutic Optimism & the Concept of Recovery

Bott (1976) points to the post-war mood of optimism and the subsequent creation of the National Health Service as possibly influencing the belief that all illness could eventually be cured. Nolan (1993) gives an account of army psychiatrists, such as Tom Main and Maxwell Jones, experimenting in World War II with the therapeutic community concept for returning soldiers experiencing mental health difficulties, which produced some encouraging outcomes. The therapeutic community concept would later be taken forward by the psychiatry reformers and antipsychiatrists in the 1960s (Crossley, 2006). Alongside this social model of psychiatry, there were those who placed faith in a technological solution to mental illness, with the development of insulin coma therapy, electroconvulsive therapy (ECT) and psychosurgery (Nolan, 1993).

With such therapeutic leaps (despite the criticism by some of their barbaric nature), as Busfield (1989) concludes, the next logical step was a large-scale transition to community care. However, Busfield also notes a move away from the environment as key in therapeutic activity toward a focus on the individual. Those advocating the concept of milieu therapy (Townsend, 2008) may contest this, but the rise to prominence of approaches such as Cognitive Behaviour Therapy (CBT), and more recently Dialectical Behaviour Therapy (DBT) and Improving Access to Psychological Therapies (IAPT) would bear out this argument. IAPT in particular has been the result of the UK government’s drive to widen out the support available for those experiencing mild to moderate mental health difficulties (low intensity), stepping up to a high intensity service if the problems become more moderate to severe (Thornicroft, 2018). In a study of a low intensity service Turner et al (2018) found that the telephone-based CBT work undertaken by practitioners enabled the forming of a therapeutic alliance with service users but felt like “production line therapy” (P8). The distance between long term ‘patients’ in the asylum system and the recipients of telephone-based therapy in their own home could not be clearer; which promotes the better therapeutic relationship is up for debate.

One cannot discuss the progress in therapeutic approaches to those experiencing mental distress without including the modern concept of recovery, which has been embraced by government, service providers and third sector organisations alike (Perkins & Slade, 2012). Originally a service user-led approach to working through the experience of extreme mental distress (Anthony, 1993) the recovery concept focuses very much on one’s unique ‘journey’ and the belief that as

individuals people have the capabilities to resolve their own difficulties. Although much debate and disagreement exist within recovery circles (Davidson et al, 2006), it is suggested that the definition of recovery consists of several broad concepts; firstly, the amelioration of the 'symptoms' experienced within a mental health crisis (recovery *from*) and alternatively the regaining of a fulfilling life whilst even if such symptoms persist (recovery *in*) (Davidson & Roe, 2007). This may be expressed through an active social life, return or maintenance of employments or education, or even the ability to undertake activities of daily living. Both concepts are couched within these authors' narrow understanding of mental health crisis being part of an illness or disease, from which one recovers, but nonetheless provides a more inclusive and optimistic approach, certainly within the 'recovery *in*' definition. Embedded in a more social understanding of mental health crisis, Pilgrim (2008 & 2009) offers a third concept, which suggests that the individual becomes more empowered and autonomous, at times in opposition to formal structures of the mental health system (in line with the 'survivor' concept introduced by Rogers et al (1993) - 1.2 - Page 2).

Perkins & Slade (2012) present an interesting critique of recovery within UK mental health services describing how its absorption into mainstream mental health services as a model of service provision has enabled professionals to retain a sense of power and control (a long way from its original vision) with the development of recovery 'teams' and the Support Time Recovery (STR) Worker role to implement it. They also comment that by promoting the individualism of the recovery 'journey', service providers have been able to quell any collective political or social action that may have arisen from this new approach to mental distress. This is supported by survivor academics, such as Diana Rose (2014), who criticises the mainstreaming of recovery as an alignment with "our neoliberal present" (Page 217). The more recent development of Recovery Colleges across the UK and in other parts of the world, has shown signs of reversing the individualism of recovery by fostering better relationships between participants and increasing the motivation for change (Newman-Taylor et al, 2016). Within the colleges, educational courses related to mental health are co-facilitated by clinicians and those with lived experience (Perkins et al, 2012). These are open to services users, their family and friends and staff to attend. However, the colleges are often funded by and developed under the supervision of provider organisations, and the idea that one's own approach to recovery from mental distress might be to go to bed for a month would not be deemed acceptable, as highlighted by Rose (2014). This does raise an interesting question; who holds the power to dictate what recovery looks like?

### 1.3.6 The Late 20<sup>th</sup> Century: Benevolent Government Policy or Fiscal Imperatives?

Ralph (1983) offers a lukewarm response to the theory that advances in mental health treatment, particularly the drive towards community care, was the process of a more enlightened and humane evolution of mental health services under the paternal gaze of the state.

As long ago as 1930, the UK Mental Treatment Act was seen as a radical step forward in the treatment of the mentally 'ill'. As well as being seen as the state attempting to improve the rights of those experiencing significant mental distress, some authors have suggested it served to consolidate the power of medicine (Rogers et al, 1993; Rogers & Pilgrim, 2001). The challenge has merit; as Coppock & Hopton (2000) point out the legalism of the previous 1890 Lunacy Act had been replaced by the clinical judgement of the psychiatrist. Bennett (1993) points out that compulsory detention in mental hospitals reduced in the early 1960s to a tenth of the level it had been in the 1950s (prior to the introduction of the 1959 Mental Health Act), which suggests it went some way to achieving what the 1930 act did not. However, the 1959 Act did not go all out to promote the concept of caring for those with significant mental health issues in the community, merely 'inviting' local authorities to produce community care plans, but without any promise of additional funding to implement it (Bennett, 1993). It also reinforced the importance of a medical model approach to treating people (Rogers & Pilgrim, 2001).

Health Minister Enoch Powell's famous Water Tower Speech (so called for his almost poetic description of the large and daunting water towers on every asylum site), just two years later at the annual conference of the National Association of Mental Health (now MIND), marked a clear change in direction from the old asylums to community-based units on general hospital sites. Although this was quickly followed up by 1962 Hospital Plan (Great Britain, Ministry of Health, 1962), a properly co-ordinated attempt to develop a framework for developing a national policy would not come until the mid-1970s, with the white paper *Better Services for the Mentally Ill* (DHSS, 1975). However, this was a period of deep financial crises in the UK, which possibly perpetuated the closing of the old asylums, but did little to precipitate the arrival of robust community services (Coppock & Hopton, 2000). This would align with Scull's (1984) assertion that a publicly funded welfare system in capitalist societies had come to a point where it could no longer afford expensive institution-based care. The possible bonus for governments, suggested by Scull, was that any money saving policy of transferring mental patients into the community had a "humanitarian gloss" (p139). However, Scull's argument has been challenged as being historically inaccurate; Busfield (1989) highlights that the crisis in state finances during this period was not until the 1970s, a decade after the hospital plan to close down the asylums. Enoch Powell's 1961 speech also came after the 1950s, a decade of relative prosperity.

What was required was a 'double-running' revenue stream to support the gradual closure of the large hospitals, whilst robust community services were created. This did not happen; even if it had, community care was not a 'cheap option' (Murphy, 1991). The election of a Conservative government in 1979, signalled a 'hands-off' approach to community care placing it firmly within the remit of local health and social care authorities to work together and fund the transfer of patients out of institutions (seen by some commentators as the passing of a poisoned chalice - Coppock & Hopton, 2000; Rogers & Pilgrim, 2001). The arrival of the Mental Health Act (1983) did not really help either, providing the legal framework for decision making, but not solving the day to day problems and dilemmas of community psychiatry (Murphy, 1991). Seven years later the NHS and Community Care Act (HM Govt, 1990), welcomed as the first real attempt to establish a national framework of service organisation for vulnerable groups (including those with mental health issues), did not have any significant amounts of money and resources injected into it, so it is unsurprising that a patchwork of community services sprang up and the hospital model of still dominated through most of the 1990s, even if it was smaller general hospital based units instead of the large asylums (Coppock & Hopton, 2000).

### **1.3.7 The 21st Century: A Consumer or Reinstitutionalised Mental Patient?**

Tobin et al (2002) summarises the experience of the consumer in their relationship with private companies (such as the retail and service sectors), where satisfying the customer is a priority, increasing the potential to maximise consumption and increase profits. In contrast, the relationship with a public system (such as health care in the UK), although has to account for the finite nature of resources available and the drive on the part of care providers to drive down the level of consumption through activity such as public health initiatives. Inevitably consumer choice is limited within a public system. In the drive to alter the mind-set of a population from patients to consumers, individuals are required to adopt a higher level of responsibility for their own health and well-being, actively engaging in activity that controls and minimises 'at-risk' behaviours (Walmsley, 2006).

This is very much in evidence with the approach towards a market driven healthcare system, adopted by successive governments since the 1980s; a clear departure from universalism, central to the original concept of a National Health Service (Walmsley, 2006; Newman & Vidler, 2006). Key policy during this period (DH, 1989, 2000, 2001a; HM Government, 1995) began to promote the importance of engagement between the service user and provider (such as a mental health team) in the planning of one's individual treatment or care. *The Expert patient: A New Approach to Chronic Disease Management for the 21<sup>st</sup> Century* (DH, 2001b; P9) neatly conceptualised the modern user of health service user; "The era of the patient as a passive recipient of care is

changing and being replaced by a new emphasis on the relationship between the NHS and the people whom it services – one in which health professionals and patients are genuine partners seeking together the best solutions to each patient’s problem, one in which patients are empowered with information and contribute ideas to help their treatment and care.” The NHS Plan (DH, 2000), involved the creation of national service frameworks (NSFs) for service delivery (including mental health - DH, 1999), and involved service user representatives on the working group. For community mental health this led to the creation of 50 early intervention for psychosis and 335 crisis resolution teams, as well as an increase in the number of assertive outreach teams (220) (DH, 2000). Only in the last decade has real term investment reversed, at a time where economic recession has occurred and austerity policies applied (Gilbert, 2018).

The creation of specialist community mental health services possibly represented an enlightened view of mental distress and care delivery by politicians and policymakers. However, some authors have pointed to a concurrent process of ‘reinstitutionalisation’ of service users (Fakhoury & Priebe, 2007). Graham (2006) suggested that community care at times could be akin to ‘therapeutic stalking’, where not adhering to a care plan may be “indicative of a spirit of recovery” (P89), but interpreted as disengagement and precipitate more persistent approaches to access the individual or a referral to an assertive outreach team. Indeed, the introduction of Community Treatment Orders (CTOs) as part of the most recent incarnation of the Mental Health Act (HM Govt, 2007) gave mental health professionals the power to recall an individual to hospital if they fail to comply with a prescribed treatment regime. Paradoxically, the same legislation for the first time gave people the right to access independent mental health advocacy (Newbigging et al, 2015). As Scull (2006) observes “One can readily observe a parallel extension and expansion of psychiatric forms of social control into new social settings and institutional domains” (P123). This suggests that control and supervision is still very much part of the agenda for UK mental health care.

As highlighted in 1.3.5, there are questions being increasingly raised regarding the ‘mainstreaming’ of recovery in the context of increasing coercion and control through legislation, policy and service provision. Those with lived experience of significant mental distress, whose needs are largely addressed in the community, are in danger of being as coerced or institutionalised as the patients of the asylum era of the 20<sup>th</sup> century, whilst at the same time concepts of recovery, service user involvement in policy making and co-production are being trumpeted (Perkins et al, 2012).

As a both a nurse practitioner and academic in mental health, I have become increasingly aware and uncomfortable with this dichotomy over the last 10 years. Here there is potential that

people's 'recovery' could be as much about emancipation from the deviancy of being treated as a mental patient within services, as it is about the pain of mental health crisis and ongoing distress.

### 1.3.8      **Changing Professional Ideologies?**

Murphy (1991) stated that "*Inevitably, doctors focused on providing a service for those who were most rewarding to treat, that is, those with reversible short-term illnesses which responded best to the new drugs*" (Page 10), implying that those with severe and enduring mental health problems were simply neglected. Nolan (1993) alluded to the idea that historically mental health services (community and inpatient) have always been delivered to the 'good patients', those who boost the morale of all professional staff by their progress. New drugs and shorter-term care in acute units on general hospital sites or the community promised that reward.

These motivators within psychiatry hardly appear altruistic, but perhaps understandable within the context of a field of practice which is comparatively young alongside the professions involved in physical health. It is perhaps inevitable that psychiatrists, mental health nurses, psychologists, occupational therapists, and social workers would feel the need to justify their professional position, not only within their own ranks, but also to colleagues in other branches of health care (DeSwaan, 1990). Scull (2006) is unsurprised that disciplines, such as social work and clinical psychology have risen in power and that the boundaries between the professionals have become increasingly blurred, but comments that none will overcome the psychiatrist, who has independent control over the institutions in which they work. Shorter (1997) clearly supports the centrality of the doctor-patient relationship, as best practice with mental illness, over and above the non-medical competition that has in recent decades been posed by social workers and psychologists (despite being the largest professional group in the field, interestingly nursing is not mentioned).

Parker et al (1995) presents a more diplomatic view; keen to avoid persistent attacks on psychiatrists, they invite the reader to recognise "a historical process that positions psychiatrists, clinical psychologists and other mental health professionals in relations of power over 'users' and 'consumers' of services." (Page 16). Although this perspective may present professionals as unwitting accomplices, softer than the rhetoric of hard-line critics, (Szasz, 2010, likened them to concentration camp guards!), both support view of state sponsored social control of the mentally ill with psychiatry as its tool.

Although it has its challenges, the embracing of recovery concepts by mainstream mental health service providers (see 1.3.5 – Page 6) does indicate a shift in professional perspectives on working with the mentally distressed (willingly or otherwise). The creation and proliferation of recovery

colleges in the UK and internationally (Perkins et al, 2012; Shephard et al, 2017), perhaps represent an attempt at achieving a closer working between clinicians and service users? Service users and clinicians develop and co-facilitate educational courses around well-being and social inclusion, which are open to service users, their supporters and staff. However, one is drawn back to the concerns expressed in 1.3.7 about possible coercive power enshrined within mental health law, community mental health practice and the co-opting of recovery.

### **1.3.9 The Service User/Survivor Movement and Emergence of Psychopolitics & Mad Studies**

This socio-political account so far has very much focused on the ideas and agendas of those in positions of authority; politicians and professional groups. However, it is important not to overlook the collective actions of service users themselves and the organisations set up to represent them. Crossley (2006) presents a useful narrative of social movements in mental health as far back as the 1930 and 40s, which witnessed the birth of organisations such as the National Association for Mental Health (NAMH), which would later become MIND. The early focus of this organisation was very much grounded in the mental hygiene movement; promoting positive mental health and early intervention to increase the chances of success in recovering from mental illness. NAMH and central government were seen as closely linked; indeed, government ministers would attend the organisation's annual conference as a way of consulting on mental health policy developments. Equally the NAMH was an organisation run by professionals, rather than service users; it had a medical director (usually a prominent psychiatrist) and its journal 'Mental Health' would be edited by a mental health professional (again usually a psychiatrist). It could be argued that the alignment of an organisation such as NAMH to state policy and rhetoric created a gap for more oppositional movements to gain a voice, such as the antipsychiatry movement in the UK. Again however, antipsychiatry was led by professionals; psychiatrists, such as Laing (although he consistently denied being 'antipsychiatry'), Cooper, Berke and Redler (Laing, 1990; Jones, 1993).

Crossley (2006) suggests that more radical and oppositional critique came from service users and carers themselves from the end of the 1960s, fuelled by flashpoints such as the Paddington Day Hospital Protest in 1971 (Spandler, 2006). Even the NAMH, previously seen as apologists for psychiatry took a more oppositional stance and became known as MIND by 1973 (although Crossley speculates this was due to the reduction of funding). Interestingly from a user perspective, the inception of a meaningful UK service user movement did not occur until the mid-1980s in response to concerns that no UK service users were represented at the 1985 World Mental Health Federation conference in Brighton (Campbell, 1996). In early 1986 'Survivors Speak Out' (SSO) was formed by Campbell himself and became a significant independent and service

user led voice over the following decade. SSO's influence waned by the end of the 1990s and although others have formed since (Mad Pride being the most well-known – Curtis et al, 2000) they have remained on the periphery of the mental health debate and policy.

There have been suggestions as to why this has been the case with more activist survivor organisations, when larger third sector organisations such as MIND and the National Schizophrenia Fellowship (NSF, now known as Rethink) appear to have survived the test of time and developed a more significant role in the shaping of government policy and strategy around mental health (for example see: Centre for Mental Health et al, 2012). Beresford (2019) points to survivors' historical inability to unite in developing a philosophy to counter the longstanding biomedical approach to distress as 'mental illness', and devising a language that is not tied to this model. Arguably organisations such as MIND and Rethink have been able to embrace the biomedical understanding of mental illness and challenge with a discourse that is deemed acceptable to government and policy makers. This has ensured, not only their survival, but their ability to become providers of mental health services themselves. According to the Rethink Website they provide over 200 services across the UK (<https://www.rethink.org/aboutus/what-we-do/our-services-and-groups/> - accessed 16/07/20); interestingly MIND, on its national website, does not promote this aspect of their work, but locally the Improving Access to Psychological Therapies (IAPT) service is co-provided between the local MIND and the NHS (<https://www.solentmind.org.uk/our-services/talking-therapies-italk/> - accessed 16/07/20).

The more recent emergence of Mad Studies; the merging of activism and intellectual endeavour, is posited by Beresford (2019) as the first survivor-led movement, which as attempted to create a robust theoretical and philosophical base, which can effectively challenge the dominance of the biomedical model of mental health/illness. Originating in Canada, Castrodale (2015; Page 284), describes it in greater depth as a *"field of scholarship, theory, and activism about the lived experiences, history, cultures, and politics about people who may identify as Mad, mentally ill, psychiatric survivors, consumers, service users, patients, neurodiverse, and disabled"* (the use of descriptive language is explored further in 1.6). The work of contemporary thinkers in the area of activism and academia, such as Peter Sedgewick, Diana Rose, Peter Beresford, Helen Spandler, Mark Cresswell, Mick McKeown and Rich Moth, are discussed in greater depth in Chapter 2.

Another recent phenomenon, which has the potential to influence the exposure of the mental health service user voice, is the advent of social media use across all strata of society. The most recent UK Office for National Statistics figures (ONS, 2017) suggest that the percentage of the UK population engaging in social networking was higher than all other internet-based activity in those aged 16-45 (89%). Whilst lower across the older working age adult group (45-64 years), 60% still

utilised social media. In a survey of mobile and online technology use among people diagnosed with a serious mental illness (SMI), Naslund et al (2016) found that 71% of respondents utilised social media, such as Facebook, Instagram or Twitter, with overall technology use being comparable with the general population. Naslund et al (2014) specifically looked at the use of YouTube by a small group of people considered to have a SMI by analysing the comments from and interactions with other users. Of four key themes identified, one centred on learning from shared experience of medication use and seeking mental health care. The study indicated that both positive and negative experiences were shared, suggesting that it was not merely a space created for people to criticise the mental health system. What is interesting about this is the fact that such online 'spaces' and interactions within them are the property of people with a story to tell or view to share, not the mental health care system, large third sector organisations, or national government. Like-minded activists have formed online collectives, such as Recovery in the Bin (RITB - [www.recoveryinthebin.org](http://www.recoveryinthebin.org)), to wholly reject the current system of mental health care in the UK and embrace the 'mad' label once more. Describing themselves as a 'user-led critical theorist group', they recently presented a keynote session at the 25<sup>th</sup> International Mental Health Nursing Research Conference (Burgess et al, 2019). This session entitled 'Neorecovery: A survivor led conceptualisation and critique' provided a robust challenge to the current use (or misuse) of recovery within mental health services, against the original aspirations of the recovery movement in the early 1990s. The critique by RITB will also form part of the review in Chapter 2.

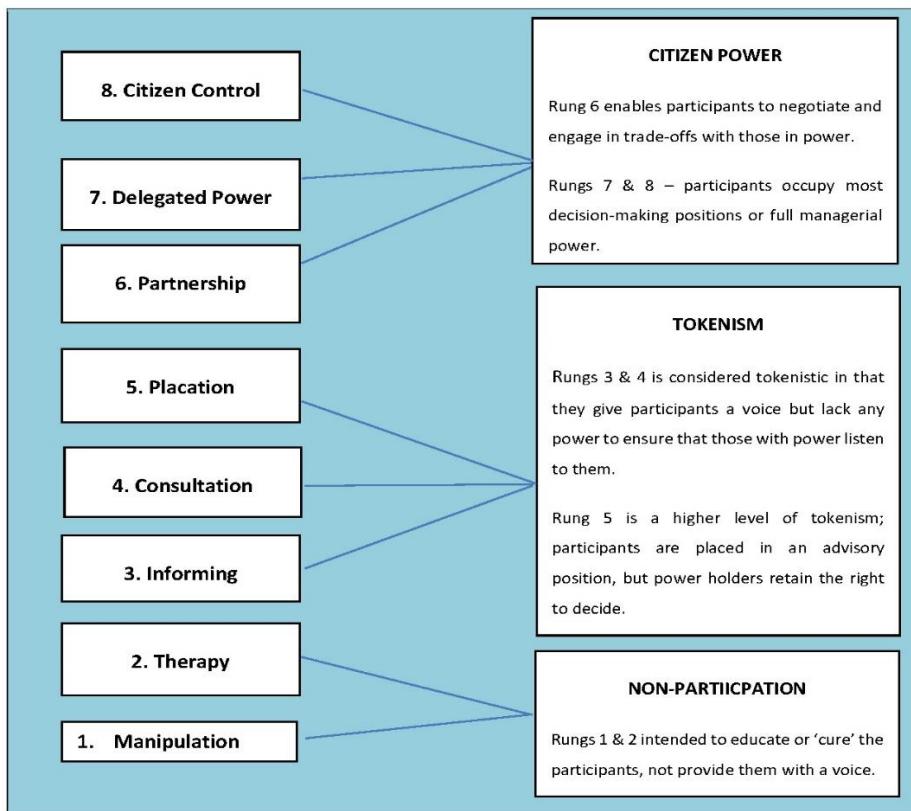
## 1.4 What is Service User Involvement?

Section 1.3 has begun to account for the mental health service user experience since the early-mid 20<sup>th</sup> century and the drive towards the user as consumer; having a greater voice in their own care. Also considered was the inclusion of those with lived experience in the planning and delivery of mental health services. This will be the focus of the literature review in Chapter 2. However, at this stage it would be helpful to give a working definition to the term 'service user involvement'. Elstad & Eide (2009) view user involvement as a single process, which may start with an individual level of involvement up to user control over services themselves. This is supported by Brosnan (2012), who explored the dynamics of service user involvement in Ireland and identified three distinctive levels of involvement; *Individual* – where the person in mental distress participates in decision making around the direct of their treatment and creation of care plans; *Operational* – the service user is consulted about operational and functional processes (how a service is delivered); finally, *Strategic*, where people are involved nationally or internationally in the future development of mental health services, legislation, staff recruitment and education, and creating peer run services.

The levels or process of involvement highlighted here, perhaps aligns with the often referenced ‘Ladder of Citizen Participation’ (Arnstein, 1969 – see Figure 1 - Page 16), which deems the earlier parts of the process (or lower rungs on the ladder) as being an expression of tokenism or even non-participation, rather than people having a meaningful influence. This stance towards individual involvement activities faces the accusation of being overly-cynical; the discussion around recovery colleges in section 1.3.5 (Page 6) does point to individual user involvement having greater meaning and the person being seen as equal to others who exist within the mental health system (families, friends and professionals). However, Brosnan (2012) and others have highlighted concerns around service providers co-opting the concept of recovery, whereby service users could be perceived as either being ‘compliant’ or ‘non-compliant’ with their recovery plan. If this is the case, then one has to speculate that the service user voice in their own care is meaningfully listened to, up to the point where it diverges from that of the professional.

As one progresses towards the top of the ladder, the value of their activity is increased, to a point where citizens have full control (in the mental health service context, the creation of peer-run services would be a helpful example).

Having briefly introduced Arnstein’s ladder here and begun to link it to service user involvement, it will be revisited within the literature review of Chapter 2. It is now important to turn to the theoretical considerations at the start of this study, which have been drawn from the discussion so far.

**Figure 1: Arnstein's (1969) Ladder of Citizen Participation**

## 1.5 Theoretical Considerations at the Start of this Work

The approach to data analysis within this work will be discussed fully in Chapter 3, but warrants brief consideration here. Dominant approaches to qualitative studies over the past 50-100 years have presented the researcher with a stark choice; employing inductive or deductive methods to their collection and data analysis. An inductive approach (favoured by Grounded Theory – Glaser & Strauss, 1967) effectively ignores the theoretical literature and factual information in relation to the topic of study, in order to generate new theory as it emerges from raw data. In contrast, a deductive approach would be rooted in a theoretical base, against which the researcher measures their data to either confirm or modify the original theory. Glaser & Strauss (1967) criticised deductive approaches for forcing the data to fit with pre-existing theory and preventing opportunities for researchers to develop higher level concepts that went beyond the qualitative material. However, Timmermans & Tavory (2012) highlight an unavoidable 'inductive dilemma' within Grounded Theory in particular, citing Glaser & Strauss' (1967) argument for "theoretical sensitivity" which consisted of the "ability to have theoretical insight into an area of research combined with an ability to make something of insights" (P46). There is a clear conflict here, which Timmermans & Tavory suggest is a revelation that induction does not generate theory.

Timmermans & Tavory (2012), drawing on the work of Charles S. Peirce in the 1930s, propose a compromise between the poles of induction and deduction. Employing the term 'abduction', they describe a process of acknowledging pre-existing theories and concepts as a starting point, but the researcher being open to surprises presented by the data. From these surprises, the research must be prepared to creatively move away from old theories in order to generate new theories. The authors are keen to stress that abduction does not amount to a quasi-deductive approach to qualitative research, as one is knowing the literature and taking up a professional position in light of this knowledge, rather than verify a uniformed, firmed up theory. The abductive approach is much more pragmatic and helpful in considering my own knowledge and professional position as both a mental health nurse and academic. As such, the following theoretical discussion emerges from my own internal wrangling regarding the current UK system of care for people with mental health challenges.

### 1.5.1 The Social Construction of Mental 'Illness'

In his book, *Creating Mental Illness*, Horwitz (2002) discusses the concept of mental illnesses as social constructions; that is a mechanism by which one is categorised as a result of behaviours that fall outside of societal norms. Charting the development of 'dynamic psychiatry' over the first two thirds of the 20<sup>th</sup> century, he discusses how what would now be deemed as pathological, were "indeterminate manifestations of unconscious mechanisms" (P208), heralded by Freud's approach to psychoanalysis and allowed to flourish as an approach to working within mainstream culture, as well as those considered 'neurotic' (Shorter, 1997). However, due to what Horwitz describes as changing "professional, economic and organizations circumstances" (2002; Page 209), he suggests that the lack of precise, scientific measurement in both classifying and treating mental distress meant that psychiatrists' legitimacy as members of a speciality in medicine was under threat. To add context, at this time there was a steep rise of other professional groups, such as psychology and social work within the mental health arena. Arguably these practitioners were as able to deliver psychodynamic informed interventions (Abbott, 1988).

In a very short period of time, there was arguably a significant shift in psychiatric thinking, exemplified by the American Psychiatric Association's creation of the *Diagnostic and Statistical Manual* (DSM – APA, 1952), which by its third edition in 1980 contained a comprehensive list of mental diseases, with defined underlying symptoms (Wilson, 1993). This has since been revised and refined several times, most recently with the publication of the DSM-5 in 2013, which introduced a more transcultural understanding and classification of mental distress (Regier et al, 2013). Horwitz (2002) and Wilson (1993) have also drawn links between this drive for scientific classification and the accommodation of third-party interests; insurance companies in healthcare

systems like the US, were more likely to pay out to clinicians for treating diseases than they would for solving problems of the human condition. As important, pharmaceutical companies also stood to benefit from distinct disease categories in order to gain market approval for their drugs (Horwitz cites the example of Paroxetine, which can be prescribed to alleviate the symptoms of social anxiety disorders but would never be used for shyness).

Horwitz (2002) suggests that 'diagnostic psychiatry' and its mental illnesses have moved beyond the realms of the mental health field and into popular culture, where issues such as depression, disordered eating, abuse of alcohol and panic attacks are viewed as diseases for which one must seek formal assessment and treatment from professionals (and are doing so in increasing numbers). This argument poses a conundrum; an advocate of diagnostic psychiatry would perhaps suggest that the classification of mental distress and the dissemination of this across the world, promotes a clearer understanding and comfort for individuals and families of their mental distress, with a set out treatment response to alleviate this. As discussed in 1.3.9, there has been a significant rise in internet and social media use over recent years, which inevitably increases the access to information of varying quality by which one may self-diagnose a mental illness. Whether the above issues are considered 'illness' or not, they are expressions of significant mental distress and it could be argued require a level of specialist knowledge and training to address. Opposing this, critics of diagnostic psychiatry may argue that such expressions of mental distress are an individual's way of coping with overwhelming situations in life that are often created by socio-economic factors, and as such should not be pathologised (Chassot & Mendes, 2015). Rather than treatment for mental distress, they would be more likely to advocate an approach that promotes acceptance and understanding of thinking and behaviours that fall outside of societal norms. The entry for a person into the mental health care system can have a significant impact on one's socio-economic status (Christian, 2009). The stigma experienced by people in significant mental distress, even if they have either been discharged from or never formally accessed services in the first instance, is well documented in research, mental health policy and even practice (Markowitz et al, 2011; The Mental Health Task Force, 2016).

The term 'Psychopolitics' was coined by Peter Sedgwick as early as the 1950s and formed the title of his ground-breaking work in 1982 (reissued in 2015). Originally written during the rise of Thatcherism, it presented a critique of the antipsychiatry movement of the 1960s and 70s (see 1.3.3, Page 5) and how the neoliberal state might use the arguments of this movement to forward their own desire to dismantle welfare provision for people diagnosed as 'mentally ill' (at this point in time with the dismantling of large hospitals and the move to care in the community). The collusion between mental health professionals (psychiatrists, nurses, social workers and others) and the neoliberal government, according to Spandler et al in their Foreword to Sedgwick (2015),

has continued into the 21<sup>st</sup> century, with the side-lining of community mental health services in favour of the new ideal of 'recovery' (discussed earlier in this chapter). The relevance of all this in a discussion focused on the social-construction of mental illness is that the alignment of neoliberalism and recovery, where individualism and individual responsibility for mental health is favoured over collectivism, serves to potentially ignore the underlying social causes of mental distress and crisis and hold the person accountable if they do not recover in a way that is socially acceptable (such as securing meaningful employment). A fuller definition and account of the influence of neoliberalism is discussed further in Chapter 2.

### 1.5.2 Identity Theory

Identity theory links an individual's social interaction with others to social roles and their internalised meanings (Stryker, 2007; Brenner et al, 2014). Individuals will have others designate a position for them, which then must be accepted and internalised. One can hold multiple identities, depending on what is deemed most salient in any given circumstance. A person will organise these identities into a hierarchy of importance, to be used across a range of situations.

Stryker (2007) further looks at how entry into positional roles are dictated by larger social structures (cultural groups, societies or institutions). This is particularly relevant to this research in terms of identifying possible continuities or contrasts of relational roles and identities across the participants' lived experience, before and during their engagement with mental health services and subsequent involvement work. In essence, does the experience of engaging with the large social institution that is the mental health system positively contribute to the development of a 'recovered' self-identity, given the person's life trajectory prior to the onset of a mental health crisis?

Crane and Ruebottom (2011) present an interesting discussion linking social identity theory and stakeholder theory, highlighting that stakeholders are often viewed in terms of the economic and contractual roles/relationships that meet the needs of the organisation engaging with them. What is less considered by these organisations is the underlying attachments that brings stakeholders together in the first place (e.g. the lived experience of accessing mental health care). A commonality of experience that can help form a collective identity, which may be of great benefit to individuals who have lost previously held individual identities through mental health crisis (e.g. spouse, child, parent, learner, professional) and are left only with the identity of mental health patient/service user. How people believe they have been perceived by professionals and organisations as both an individual stakeholder and as part of a larger group of 'experts by experience' will also feature in my research.

Stryker (2007) also considers how personality theory, with its emphasis on identity being dispositional structures of traits (as opposed to the internalised meanings of social roles) may not necessarily seen as polarised from identity theory. If one were to take a psychosocial perspective, the two fit together well; considering the impact personality traits may have on shaping social cognition and relational behaviours. When considering the current study, this places importance on the participants' recollection of their lives; for example, if they were naturally shy or introverted, how did this influence their social development, how they coped with mental health crisis and the role of 'patient', and ultimately the negotiation of their role as a service user expert?

### **1.5.3 Concepts of Power and Empowerment**

Positive rhetoric of central government towards the empowerment of users of mental health services is evident throughout all key policy since the mid-1990s (Hui & Stickley, 2007; Centre for Mental Health et al, 2012, HM Govt, 2017). However, using Foucauldian discourse analysis, Hui & Stickley (2007) have highlighted two areas for concern within policy until that point. Firstly, users of mental health services are described using a number of terms, including 'patients', 'clients' and 'users', but are rarely referred to as 'people', which may cast doubt on the genuineness of empowerment rhetoric. To the credit of the current government, *No Health Without Mental Health* (DH, 2011) and *The Government's response to the Five Year Forward View for Mental Health* (HM Govt, 2017) expresses more inclusive language and the subsequent *NHWMH Implementation Framework* (Centre for Mental Health et al, 2012) makes direct reference to 'people' with mental health problems and families/carers being "involved in all aspects of service design and delivery" (p.10). However, a further concern is the distinct lack of definition within all key documents as to what service user involvement actually might look like and what is involved in establishing it within health and social care organisations. As designated providers, it remains with the health and social care organisations to interpret the policy wording and develop strategies to empower service users to become involved in the planning and delivery of care.

Before considering the concept of empowerment further, it is important to explore some key theories of power itself; more specifically how it is generated within and distributed between different groups and individuals operating in the same environment. Hui & Stickley (2007) explore two possible concepts of power; the Constant Sum Conceptualisation and Non-Constant Sum Conceptualisation. The former, developed by Weber, proposes that usable power is finite within any given context, meaning that for a true balance of power, one group has to concede or 'lose' some of the power they possess to another (Lukes, 1974). In the context of mental health care and service delivery, the group traditionally holding the power has been the professionals or service

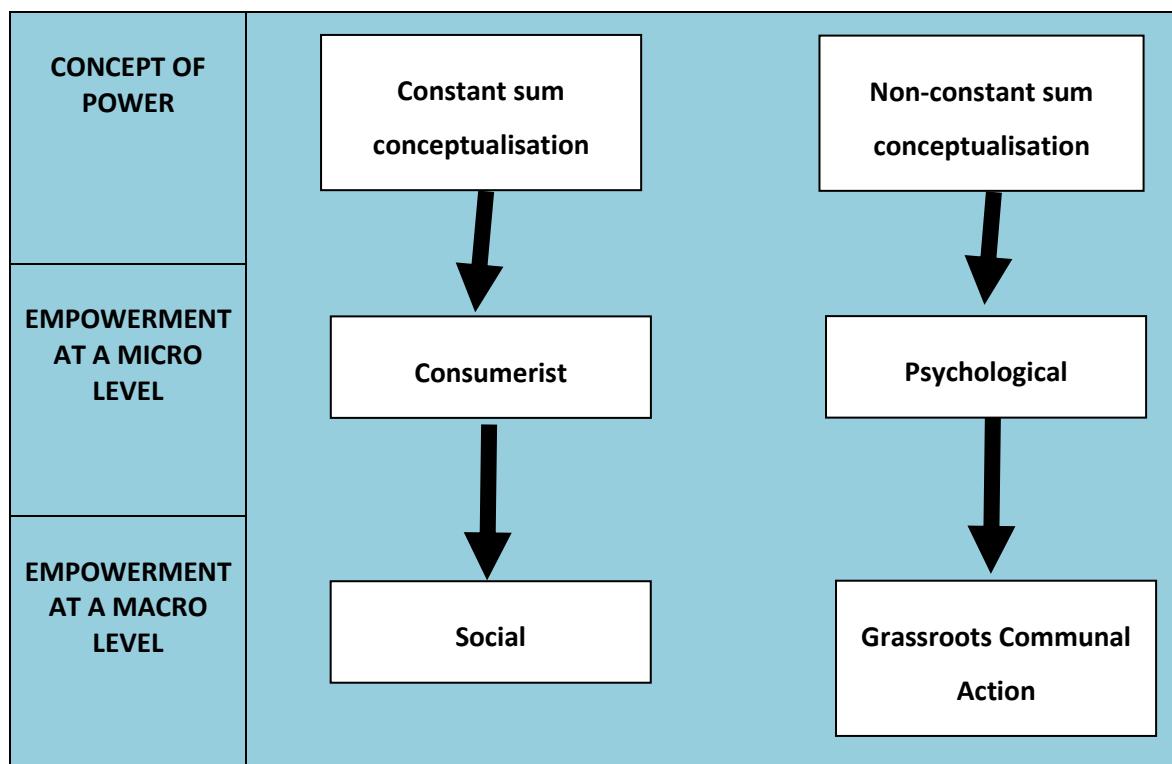
providers (Hitchin et al, 2011). Some authors have described this as a very masculine perspective on power; the battle between two sides to ultimately seize control (Ghaye, 2000). The Non-Constant Sum Conceptualisation of power holds a very different view, which has been aligned with the feminist position (Ghaye, 2000; Barnes & Bowl, 2001). Here power is infinite because it can be generated from within an individual or group through knowledge and learning (Foucault, 1980; 2001), increasing self-esteem (Watkins, 2001) and achieving goals through the sharing of power (Barnes & Bowl, 2001).

To account for the concept of empowerment more fully, Masterson and Owen (2006) describe two levels; the individual (micro) level and the social (macro) level. At the micro level two strands of empowerment exist; the psychological and the consumerist. The psychological model is based on the Rogerian concept of personal growth through relationships, which inevitably translates to a sense of increased sense self-confidence and empowerment in individuals (Rogers, 1961). This model has been criticised, because in reality no formal transfer of power needs to take place, potentially leading to the continuation of power imbalances between the service user and care provider (Ryles, 1999; Wright, 1995). However, if one subscribes to the notion that power is generated from within and is therefore limitless (non-constant sum conceptualisation), the psychological model does have merit (Masterson & Owen, 2006). The consumerist model in essence develops from the psychological, concerning itself with ideologies of self-care, responsibility, determination and personal control, very much fitting with the Thatcherite vision of engagement with health services by the populace (Ghaye, 2000). As with the constant-sum conceptualisation of power, this the consumerist model involves delegating and sharing formal power, but has been criticised for being a rhetorical device that merely reinforces the elevated position of professionals and service managers (Fryers et al, 2001; Ostler et al, 2001), whilst simultaneously off-loading responsibility onto citizens, whom may not possess the economic, social and educational resources to manage it (such as mental health service users).

The social (macro) level works on the basis that people share common agendas, which are best achieved by large-scale collective action, and like the micro level, can be divided into two strands. The first, socio-cultural change, involves creating fairness of opportunities via legislation, inclusive policy and equitable financial and/or organisational processes (Anderson, 1996; Townsend, 1998). A key example of this would be the US Civil Rights Act of 1964. The second strand would be grassroots communal action, which has been witnessed within the mental health service user movement described in section 1.3.9 (Page 12). This involves citizens coming together to take ownership of the agenda and challenge discrimination and inequality in a direct way (Campbell, 1996). There is clear alignment here with the non-constant sum conceptualisation of power and Social Democratic Theory (Fryers et al, 2001; Ostler et al, 2001).

Figure 2 summarises this discussion of power and empowerment. Whilst the mental health service user movement has strived to generate power for itself (non-sum conceptualisation), supported in later years by the guiding principles of the recovery movement, the other socio-political considerations within this chapter would lead me to suggest that participants' narratives are more likely to be underpinned by empowerment transferred over from professionals (constant-sum conceptualisation).

**Figure 2: Summary of power and empowerment concepts drawn from Hui & Stickley (2007) and Masterson & Owen (2006)**



In a key study exploring the views of a small number of prominent service user activists Ames (2009) highlights four key themes around the resistance to the formalised pressure of dominant professional groups. The identified themes were *reformism* (sticking with the values of service user involvement, however long it may take); *rationalization* (seeking to instigate change by closely collaborating with statutory bodies); *professionalism* (becoming a user professional within services); and *pride* (rejecting hierarchies and standing out as having expertise by experience). These themes will be important to consider when exploring the power relationships experienced by participants in their service user involvement activity.

#### 1.5.4 Position of the Researcher

In light of the above theoretical considerations, it is important to offer my personal perspectives in relation to each. As highlighted at the beginning of 1.5, the abductive approach allows me to acknowledge my internal wrangling as a nurse, academic and researcher, and set the tone for the remainder of the thesis, whilst also allowing surprises to emerge from the data.

The social construction of mental ‘illness’ and power held by mental health professionals have long been areas of discomfort for me, given that the academic environment in which I had developed nursing students very much aligned with the biomedical model of health and illness. The ongoing anxiety among programme staff and students that there was not enough teaching focused on specific diagnosable mental disorders (e.g. depression, schizophrenia, bipolar, or personality disorders) and developing a robust knowledge of the Mental health Act (1983, updated in 2007) seemingly contrasted with my nursing practice in young people’s mental health, where the explicit labelling and detention under the MHA was avoided where possible. The reality, of course, was that use of phrases such as ‘emerging...’ or ‘features of...’ allowed us to hold onto the professional power afforded by a biomedical understanding of mental health, whilst basking in glory of being more systemic in our practice than our counterparts in adult mental health services.

Two encounters started me to question what I thought I knew, what I had been trained to know and practise. My experience of working with the external mental health user reference group (discussed at the beginning of this chapter), however, had begun to expose me to narratives of extreme mental distress and the subsequent ‘recovery’ via the mental health system; nothing shocking there, as their experience is what we wanted the students to be exposed to. However, what came into sharp focus were the underlying traumatic experiences that may have prompted the mental health crisis, the fact that one’s rights were curtailed once the status of mental patient was awarded (formally and informally), and the power held by professionals to decide if and when someone was ‘fit’ to be discharged from their care. For example, how long were post-bereavement expressions of grief, or low mood after the birth of a child deemed acceptable before they became a diagnosis of depression, requiring intervention from a statutory mental health service? How was this decided and by whom?

At the same time, my practice was being supervised by a Psychodynamic Psychotherapist, who’s favoured client group was young adults with a diagnosis of Borderline/Emotionally Unstable Personality Disorder. Her mission was to bring the traumatic experiences to the fore in order to work through with the individual, then at the end of therapy convince the named psychiatrist to remove the person’s diagnostic label in the clinical notes. In many ways this is a positive outcome

for that person, particular in terms of removing barriers to future life opportunities. However, it also raised some uncomfortable truths; the primary 'truth' was that a person's behaviour and thinking had been judged by experts to be acceptable enough that the diagnostic label of BPD/EUPD could and should be removed, whilst there was no neurobiological evidence that anything had changed (no MRI or CT scan had been performed). Also, given that the socioeconomic and stigmatising impact of a mental health diagnosis (BPD/EUPD in particular – Stalker et al, 2005) is profound (as discussed earlier in this chapter), the power of an expert's opinion is equally significant. One may argue that as a person is an expert in their experience of mental distress, so is the psychiatrist/nurse/therapist through their professional training and experience of working with multitudes of distressed individuals. However, both sets of expertise are influenced at a macro level by societal views on mental health, which themselves are guided by politics, legislation, policy and of course the media. The professionals have the added obligation of a 'duty of care' to adhere to within their respective codes of conduct (e.g. NMC, 2018).

Whilst the presence of neurobiological differences in some called 'deviant' behaviours is undeniable (Alzheimer's Disease being a prominent example), I cannot escape that concept mental ill health is largely a social construction, with professionals like myself placed in the position of applying this construction to people's lives.

The discussion of power and identity does not end with my professional background as a mental health nurse; as an academic researching mental health survivors, a similarly uncomfortable experience awaits. The work of Cresswell and Spandler (2012) focused on the engagement between academic individuals and the psychiatric survivor movement, drawing on the Psychopolitics of Sedgwick (1982), and Gramscis' (1971) theory of the intellectual, later modified by Barker and Cox (2002). This is of significance to my research with mental health 'experts by experience'. Cresswell and Spandler (2012) suggested that the relationship between Psychopolitics and academia manifested itself in three ways:

- Credentialing by the state, via the cultural capital of academia, of 'psy-experts' (psychiatrists, nurses and others) tasked with administering the mentally 'ill'
- Penetrations of the psyche by biotechnologies of natural and social sciences, where mental distress is managed by pharmacological and psychological treatments, justified by a positivist evidence base.
- Academic gaze of the social sciences, which takes the Psychopolitical field and social movement organisations as the 'object' of their research.

The ways highlighted here would be the property of what Barker and Cox (2002) described as the ‘academic intellectual of social movements’, whose theoretical endeavour was restricted to the formulation of abstract generic propositions, which marginalise the social movement activist and curries favour with other academics through publications, impact factors and citations. In contrast, they described the ‘movement intellectual’, who was an activist located within the social movement itself. Their focus would be on producing knowledge within the movement and for its advancement, as opposed to of it and about it. Barker and Cox (2002) posit two key questions to the intellectual about their theoretical work; *whose side are you on and what is to be done?*

As a new researcher undertaking a doctoral degree, there is potential for a crisis of personal ethics. Within academia there is a pressure to publish empirical work in robust peer reviewed journals in order to garner the very accolades (impact factor, citations, and so on). Barker and Cox (2002) suggests this puts the researcher firmly on the side of academia (and by default failing to advance the social movement). How could I be authentic with the people I would interview, knowing that I was potentially exploiting them for academic gain (a doctoral degree, with possible post-doctoral research in the future), whilst contributing little or nothing to the social movement of service users/survivors? As a personal value, integrity in what I do is core.

Mercifully, both Barker and Cox (2002) and Cresswell and Spandler (2012) recognise the complexities of academic work, themselves existing in that sphere. They conclude that intellectuals who study social movements exemplify ‘lived contradictions’ (Barker & Cox, 2002; P25). Cresswell and Spandler (2012; P146) distil this down into three;

- 1) *Agent or Object?* – How does the academic balance viewing social movement organisations (SMOs) as critical agents of change and ‘gazing’ upon them as objects of research?
- 2) *Solidarity or Recuperation?* – How does the academic live the contradiction between engaged solidarity with SMOs and the lure of ‘recuperation’ (researcher’s politico-ethical stance constrained by economics and prestige in academia)?
- 3) *Experience or Theory?* – how does one live with the contradiction between engaging with the SMOs own theory and the ‘amnesia’ of ‘theoretical imperialism’ (the belief that all theory must be generated in a scholastic way by trained intellectuals)

To complete this positional discussion, I will answer the three questions as fully as possible in the context of being an early career doctoral researcher. My response to the first question may well be borne out of naivety as a researcher, but my aim is to create narrative accounts of people’s

lived experience *with* them. To achieve this a careful choice of methodology is required that minimises potential power imbalances between myself as the researcher and the participants; discussed fully in Chapter 3. The use of language, considered in 1.6, plays an important role in this. It is also important to note that identity as a survivor activist or agent of social change is not a prerequisite for inclusion in the research (although this may be revealed as part of their narratives). This possibly allows me to hold the perspective that SMOs are the critical agents of change, with any theoretical work I contribute hopefully supporting that change.

In response to the second question, having made clear my stance that mental distress as an illness is primarily a social construction and begun to appreciate the ‘Psychopolitics’ in the UK over many decades, I would stand in solidarity with grassroots collectives who seek an alternative understanding of and approach to supporting those experiencing mental distress. This would involve an opposing stance to the influence of neoliberalism on mental health care and its agents (discussed further in Chapter 2), as well as the individualistic focus of mainstream recovery practices. In terms of constraints on this stance in the face of academic progression, I am able to hold a short and longer term view. In the shorter term ‘living contradictions’ inevitably feature, as the internal and external research governance processes dictate my ability to undertake the interviews and complete my doctoral degree. However, in the longer term, the advent of Mad studies (discussed earlier) would allow an academic space for me to contribute knowledge that is authentic to who I am and what my research participants tell me.

To the final question; adopting the abductive approach, described at the beginning of 1.5, allows me to start with the theoretical considerations discussed and politicoethical stance taken, but be open to surprises from the data and the potential for new theory to be generated. Any theory generated would aim to add to the theory and debate existing within SMOs, hopefully in a way that promotes positive, meaningful change to the current system of support for the mentally distressed. At this point, reputational gain in academia comes behind the above and my passion for developing dynamic and free-thinking student nurses as an educator.

## **1.6 Operational Definitions and Terminology**

### **1.6.1 ‘Mental Illness’ or ‘Mental Distress/Crisis’?**

The term ‘mental illness’ very much is the property of the biomedical approach, which as previously discussed in this chapter, rose to prominence in the mid to late 20<sup>th</sup> century. One exhibits a set of behaviours (symptoms) which indicate dysfunction in cognition, emotion and behaviour, as interpreted and judged by a mental health professional, possibly with the aid

of a diagnostic manual (APA, 2013; WHO, 1992). In many countries, the notion of disability (a major limitation to personal activities) has also been included within a definition (Manderscheid et al, 2010). Although there has been a concerted shift towards the separation of 'mental health' (which all people experience) and 'mental illness' (which a proportion of the population experience), an integration of physical and mental illness and health, as well as recovery being a goal rather than cure (see 1.3.5, Page 6 for a fuller discussion of recovery) (Manderscheid et al, 2010), the term 'illness' and the concept that there is something fundamentally wrong with a person remains (Chassot & Mendes, 2015).

Chassot and Mendes (2015) describe 'mental distress' as much broader than experiencing a defined symptomology, describing a complex set of phenomena, which may include:

- A person's cognitive, sensory and emotional experience
- How their social experience is impacted by this experience
- Changes in social behaviour and the responses of others to them.
- Their experience in mental health services
- Their identity and self-perception around mental distress
- The meanings created and adopted to make sense of these experiences

This latter understanding explicitly incorporates the contribution of social factors and identity/self-perception to the lived experience, highlighting the influences of third parties (those in a person's social world and mental health services themselves) on a person's mental wellness or distress. Given that the topic of interest within this project is the role of mental health service user involvement activity in the context of a person's recovery and life narrative, the interface between the individual and their social world is of central importance.

In light of the above and my stance on the social construction of 'mental illness', the term will not be used within this project, unless highlighting the biomedical perspective or directly quoting the literature or study participants. Instead, the term 'mental distress' is utilised and I would not ask any informant if they had a mental illness diagnosis, or what it was if they had already volunteered this information. It would only be relevant if they raised it as part of their narrative and/or exposed it as a perceived influence on the behaviour of others towards them.

### **1.6.2 'Patient', 'Consumer', 'Service User', 'Survivor', 'Expert by Experience'?**

The multiple terms used to describe people who have accessed mental health services for support around their mental distress each carry a connotation around how the person is viewed by another or a person views themselves. The term 'patient' very much aligns with the biomedical

view of mental distress, as well as the historical experience of asylum-based care, discussed earlier in this chapter.

The terms 'consumer' and 'service user' are perhaps the most common descriptors of this group of people used within research, policy and guidance over the past 30 years, in an attempt to move away from the passivity of the patient role. However, Dolly Sen, in her alternative take on the Diagnostic Statistical Manual makes an interesting point: "Why am I called a 'service user' when I have no choice over services? If I went to Argos for a kettle and somebody pumped me full of drugs I didn't want, pushed me on the floor because I complained my kettle was faulty, or electrocuted by said kettle, you know, I wouldn't want to go back" (Sen, 2016; P25). Both terms imply choice, when that isn't available to many experiencing mental health issues (for example, if they are detained under a section of the Mental Health Act, 2007 or Deprivation of Liberty under the Mental Capacity Act, 2005). 'Survivor' has become an increasingly used term within groups who adopt a more oppositional stance to the traditional models of understanding, treating mental distress, or indeed their interface with the mental health system overall (Curtis et al, 2000; Farber, 2012). Whilst many will feel this represents an accurate summation of their experiences, there will be others who may view the professional response and treatment of their distress and any subsequent service user involvement work as key positives in their recovery.

This would leave two very similar terms; 'expert by experience' and 'those with lived experience', both of which are clunky expressions, but perhaps more neutral in tone than the others. They allow for expertise to be drawn from both positive and negative experiences of mental well-being, as well as the experience of accessing services (similar to 'survivor'), or even working within services. These terms will be utilised interchangeably throughout the chapters. The adoption of these terms, for me, represent the best of an unappealing set of options; it can misleadingly suggest that one's lived experience of mental distress and accessing services is the only expertise that one can offer. In reality, of course, a person could be a professional in education, business, law or even health care, but also experience a mental health crisis. Presently, it is sufficient to state that I am cognisant of the flawed nature of these terms, but also interested in how the participants manage this within their own narrative.

### **1.6.3      'Informant', 'Participant', 'Interviewee' or 'Narrator'?**

This has perhaps been the most challenging of decisions related to operational definitions and terminology. The first three terms would very much fit with the activity of qualitative research (recruiting people, interviewing them, analysing the data and drawing conclusions); in the early stages when the potential interviewees may not be known to me as a researcher and their

application in the latter stages would ensure anonymity and confidentiality. However, as discussed fully in Chapter 3, the research methodology utilised for this project very much focuses on the storytelling devices used by participants, as well as the content of their interviews. Therefore, for Chapters 1-3, the term ‘participant’ will be used, but ‘narrator’, thereafter (Chapters 4-6)

## 1.7 Research Aims, Objectives & Questions

As indicated at the beginning of this chapter, the aim is to explore the experiences of adults who have accessed mental health services and then gone on to engage in service user involvement work. Leading on from this, the key objectives are:

- Present the experiences of people who have accessed mental health services and then gone on to service user involvement activity.
- Explore how the power relationships between the informants and professionals may have evolved in light of this changing role.
- Examine how the experience of service user involvement work fits within the informants’ overall life ‘story’ and recovery from significant mental distress.

Through achieving these objectives, the primary research question and subsidiary research questions below will be addressed:

What is the informants’ experience of power and empowerment when involved in the planning and delivery of mental health services and the role such experiences have had in their overall recovery?

- i) What barriers have service users faced to effectively participate in the planning, delivery and recruitment activities within mental health provider organisations?
- ii) To what degree do the concepts of power and empowerment concern mental health service users who have contributed to planning and recruitment activities?
- iii) To what extent do service users view themselves as part of a broader social movement, alongside other groups that have been historically marginalised or oppressed?
- iv) To what extent have service users been able to successfully overcome any barriers and if so, what approaches have they taken?
- v) How has the experience of user involvement work impacted on the recovery of service users?

vi) How do the narratives of service users participating in this project inform the future policy and practice of involving of experts by experience in the planning, delivery of and recruitment to mental health service providers in the UK?

## 1.8 Organisation of the Thesis

### 1.8.1 Chapter 1 Precis

The reader is provided with an overview of the historical socio-political context of the UK mental health service user since the early-mid 20<sup>th</sup> century and how the role of 'consumer' has been developed in an increasingly market driven health service over the past 30-40 years. The broad concept of involving service users in the shaping and delivery of mental health services is explored and theories of power and empowerment potentially related to this are introduced.

### 1.8.2 Chapter 2 Precis – Review of the Literature

This chapter presents a critical review and synthesis of key themes emerging from the literature in relation to the experiences of people engaged in mental health service involvement activity. The emerging themes will enable comparisons to be made with my own research findings later in the thesis.

### 1.8.3 Chapter 3 Precis – Study Design

This describes the broad methodological approach and method employed, as well as considering the ethics of undertaking sensitive research with potentially vulnerable participants. The specific methodology, the Life Story approach, is described and justified, as well as how it will inform the data analysis in Chapter 4. Importantly, the study participants will be formally introduced.

### 1.8.4 Chapter 4 Precis – Analysis and Emerging Findings

This chapter provides a summary of the comprehensive analysis of the ten interviews, exploring the contextual influences on the interview itself. Following this, the broad structuring of the narratives, overarching themes and sub- themes are discussed.

### **1.8.5      Chapter 5 Precis – Discussion**

This chapter addresses each of the subsidiary research questions in turn, synthesising the literature with the analysis and findings in Chapter 4, in order to answer the primary research questions.

### **1.8.6      Chapter 6 Precis – Conclusions and Recommendations**

This chapter provides conclusions to the research in this thesis, discuss the strengths and limitations of my work, outline the contribution to knowledge it makes and offer recommendations for future research.

## Chapter 2 Critical Interpretive Review of the Literature

### 2.1 Introduction and Purpose of the Review

Wright & Bartlett (2008) suggest that the results of a literature search can be best captured by identifying themes and utilising a narrative approach to illustrate potentially diverse perspectives, which may emerge over a longer historical period. This process has already been instigated within Chapter 1 (1.3 – Pages 3-14), introducing the contextual factors that have prompted my interest in the experience of mental health involvement activity and helped to formulate the research questions. The discussion within this chapter should be considered as ‘Part B’; a more in-depth exploration of the key issues.

#### 2.1.1 Evidence Based Practice and a Critical Interpretive Review

The concept evidence-based practice (EBP) is framed by Hamer (2003) as a process of “finding, appraising and applying scientific evidence to the treatment and management of healthcare” (P6). Sackett et al (1996) suggests it is the integration of individual clinical expertise and the best available external clinical evidence (note the absence of lived experience within this remark). This approach to the design and delivery of effective health care has only been a global concept since the 1970s and applied with real meaning in the UK National Health Service since the early 1990s (DH, 1991). Polit & Beck (2006) comment that quantitative research studies reflect the goals of EBP (as defined above), seeking to impose controls on research situations to minimise bias, systematically measure data collected, use statistical analysis and identify any generalisations. These types of studies are often considered to be more scientific and therefore informative about future directions in practice than qualitative studies.

The research questions set out in Chapter 1 very much emphasise people as being ‘experts’ in their own lived experience of mental distress, accessing services and subsequent involvement activity. This suggests that the literature drawn on for this focus on the subjective meanings and values of the participants to explain a phenomenon (qualitative research). This more direct interaction with participants aids the identification of patterns or themes which can then be explored further for the generation of theoretical concepts. This clearly presents a challenge to the traditional, efficacy focused hierarchy of evidence and what Dixon-Woods et al (2006) refer to an “aggregative synthesis” of data.

A critical interpretive approach focuses less on summarising data in a systematic way and more on integrating the concepts emerging from different sources of literature (Dixon-Woods et al, 2006). This widens the scope for inclusion to single case studies, expert accounts and others which would traditionally be rejected within a systematic review. What this enables, is the contribution of potentially marginalised perspectives, which are deemed too radical or unreproducible in the wider literature. As highlighted by Dixon-Woods et al (2006), this approach is justifiable on the basis that it remains grounded in the available evidence (which has been widened), and therefore provides context for my research.

This is not to say that there is no judgement made as to the quality of papers that purport to be empirical studies. Adapting the National Health Service (NHS) National Electronic Library for Health criteria for assessing the quality of qualitative papers, Dixon-Woods et al (2006) pose the following appraisal questions:

- Are the aims and objectives of the research clearly stated?
- Is the research design clearly specified and appropriate for the aims and objectives of the research?
- Do the researchers provide a clear account of the process by which their findings were produced?
- Do the researchers display enough data to support their interpretations and conclusions?
- Is the method of analysis appropriate and adequately explicated?

## 2.2 Search Strategy

Within a Critical Interpretive review, the requirement to provide an auditable search strategy does not carry the same weight as in a traditional systematic literature review. It is sufficient to state at this point that the following activities were undertaken:

- Search of electronic databases for English language publications that focused on mental health service user involvement activities (using truncated keywords; ‘user’ AND ‘involv\*’ OR ‘participat\*’ AND ‘mental’)
- Electronic database and internet search for literature related to the areas of Psychopolitics, mental health survivor activism and Mad studies (introduced in 1.3.9)
- Manual search (15 years) of three key journals, which appeared consistently in the search through electronic databases (the *Journal of Mental Health*, *Health Expectations*, and *Disability & Society*).

- Cross-referencing the reference lists of the relevant publications identified to find any other texts or articles that were relevant inclusion in the CIR.

The studies included in Appendix A (Pages 196-206) have been appraised by me as sufficiently addressing the above questions, but importantly sit alongside other forms of literature that inform the debate about mental health service experts by experience. As such, this table will present only the relevant themes or concepts that emerge to inform the Critical Interpretive Review.

### 2.3 Concepts Emerging from the Research Literature

The research questions articulated within Chapter 1 focus on three key areas; exploring the actual experience of service user involvement activity, the dynamics of power within relationships when undertaking involvement activity and where the experience of such activity fits within a person's recovery from mental distress and navigating the mental health system. However, these are all set within a historical socio-political context (1.3). By discussing the findings and drawing out relevant theory and concepts, an overarching narrative of Psychopolitics and involvement activity is presented in 2.4.

Within the literature there was a narrative that such work bought significant benefits to the individual, other service users they broadly represented and professionals or policy makers. Interestingly, discussion of the benefits to the individual in terms of 'recovery' is underrepresented in the research, when compared to the benefits for organisations and service improvement. This is highlighted by Chassot and Mendes (2015), whose study into the experience of mental distress and recovery of 12 members of the service user/survivor movement is perhaps the most closely aligned with my own project. The notion of recovery the authors chose to frame their work carries weight within this project; recovery being a process of overcoming multiple invalidations, whether this is through their experience of mental distress, the social isolation and discrimination experienced because of this, or even the invalidation of professional intervention, which the authors suggest should be open to critical questioning. Interestingly Chassot & Mendes (2015) found that the social experience of service user involvement was a key theme across their interviews, both in a positive and surprisingly negative way. For a number there was a sense of community and belonging by being actively involved and part of what they considered to be a user/survivor movement (supported by Treichler et al, 2015). However, some had their legitimacy as a service user representative questioned by peers, if their diagnostic label was not serious enough (an echo of the discrimination experienced in other studies at the hands of professionals). The relative importance of community or collegiality within service user involvement activity will be ascertained through the recruitment of participants and analysis of the interview data. A further study which potentially shed light on this area is the work of Restall (2013), who undertook semi structured interviews with different stakeholders from lived experience, advocacy and professional and political backgrounds around the outcomes of service users becoming involved in policy development. Helpfully this study considered the relative benefits and costs at all levels, from the personal level of the involved service user (micro) to through to the overarching impact on the lives of all people accessing services for their mental distress (macro and meso). At a personal level, some service user contributors reported experiences of

disempowerment. However, this was balanced out by others who had reported increased feelings of confidence, self-esteem and satisfaction, with one pointing to the reciprocity of such work (giving back to the service that had helped them). A key discussion point made by Restall (2013) from her findings was that the micro-level outcomes could be pursued simultaneously with the meso-level ones (transparency in decision making around policy development to change people's experience of care for the better), which potentially would minimise the risk of user involvement being merely symbolic and supporting a predetermined position.

A second key theme within Chassot and Mendes (2015) was that of 'Identity and Identity Reconstruction', where the authors encountered discourses which challenged the established concepts of mental illness and facilitated a questioning of previously held identities of being the mental patient. The result for some respondents was an opportunity to fight perceived injustices within the mental health system and recover something of their 'spoiled' identities. This focus on identity ties in with the Chapter 1 discussion related to Stryker's Identity Theory (1.5.2 – Page 19) and self-identity may be another theme that emerges from the analysis of my interview data in Chapter 4.

Conspicuous by its absence within this theme of the literature review are studies related to the personal impact of Recovery Colleges on service user co-facilitators (see 1.3.5 – Page 6). Although preliminary findings are emerging from a small number of studies into this initiative (such as Newman-Taylor et al, 2016), these focus on outcomes for attendees (service-users and staff), rather than experiences of co-facilitators in terms of their own recovery.

Finally, the experience of recovery, where the impact of involvement activity is focused on the individual or group with lived experience, rather than what they can bring to benefit professionals, service providers and policy makers. Here the literature is less prevalent, but some key ideas do emerge. Significantly, those engaged in this activity value the esteem-building, social experience and sense of community, particularly if they identify as being part of a service user group or wider social movement. This can act as an antidote to the sense of isolation one can experience when in a mental health crisis. However, at times the attitudes of professionals, managers and even other service users can undermine these positives and potentially serve to reinforce some of the negative beliefs held as part of experiencing mental distress. Whatever the effect, the literature suggests that such activity can influence one's sense of self-identity, which will be explored further with the participants in this project.

In terms of the benefits for the broader group of mental health services users, Simpson & House (2002) found that when directly working with employed peers, service users felt more able to

share their experience of care and showed greater satisfaction with their individual circumstances (although almost the opposite view is drawn from Crawford et al, 2002). For those experts by experience operating in a more strategic level (through service and policy planning and evaluation), there emerged a sense that they embraced opportunities to challenge professional hierarchies, by highlighting the use of inaccessible professional language within meeting settings (Crawford et al, 2003; Hitchen et al, 2011) and ensuring that the lived experience was incorporated with scientific research in shaping policy and practice (Harding et al, 2010; MacDonald et al, 2014). Interestingly, two studies highlighted the service provider view of a lack of representativeness in service user consultants (Crawford et al, 2003; MacDonald et al, 2014); however, the findings by Rose et al (2010) suggested that although service user activists possessed greater knowledge about forms of involvement activity than non-activists, the perceptions of what improvements were required within services were similar. This is supported by Crawford & Rutter (2004), who found that four issues rated as the highest and two of the lowest priorities for service change were the same for service user groups and a random sample of individuals accessing services.

As suggested earlier in this section, some studies articulated the benefits to professional staff of involvement work, particularly in the form of education and training. Simpson & House (2002) reported a more positive attitude by staff towards service users generally after training facilitated by a service user, a point supported by mental health service managers in an Australian state (Bennetts et al, 2011). Here participants recognised that 'consumer consultants' had a significant value as the driving force behind participation to achieve improved outcomes for all accessing support, despite the sometimes-negative attitudes of key professional disciplines, such as doctors and nurses (this is supported by the findings of Crawford et al, 2003). This leads to a further narrative of commitment by active service users to overcoming barriers in order to achieve meaningful change. Alongside the resistant attitudes of professional staff, barriers identified were around the under-resourcing of service user participants (Bennetts et al, 2011), and the potential emotional impact on the individual in relation to their activity (Hitchen et al, 2011). This final barrier is important when considering the potential power dynamics in the service user-professional relationship. Respondents in the Elstad & Eide (2009) study highlighted the importance for service user respondents that professionals recognised and supported them if they identified a deterioration in mental well-being whilst undertaking involvement activity. This too has resonance with Doherty et al (2004), who highlighted that whilst professional staff perceived the benefits of service users becoming paid healthcare assistants, at least half expressed concern about the additional support requirements of these individuals. This does create an interesting debate regarding the relationship dynamics between professionals and the

experts who have previously, or indeed continue to access mental health services. This will be explored further within this project, and leads to the next key area identified in the literature; the experiences of power and empowerment.

The experience of power in service user involvement activity appears to centre on a key question; who governs the agenda? Horrocks et al (2010) found that the concept of user and carer involvement was a high priority for the service provider, but the time in settings where service users may affect change around the philosophy and strategic direction of care were dominated by processes and actions (echoed by Hodge, 2005). Even at the level of the governing board, service user governors experienced frustration in exerting direct influence in meetings, alternatively viewing such activity as opportunities to network with powerful individuals with a professional background (MacDonald et al, 2014). Other studies found that service user members were often isolated as the only person present because of the experiential knowledge (Robert et al, 2003; McDaid, 2009) and that any outward expression of emotion was not tolerated (McDaid, 2009) or minimised in subsequent meeting minutes (McDonald et al, 2014). Rutter et al (2004) found in two London mental health Trusts that the professionals and managers had an expectation that service users would address their organisational agendas and conform to Trust management practices; similar to Hodge (2005), who posited an objectification of the lived experience by such behaviours. Rose et al (2016) found that one of five user-lead organisations engaged with two NHS providers ceased to operate; the authors attributing this to that group's refusal to adopt the rules and norms of the managerial discourse.

Robert et al (2003) suggested that user feedback on services may be influenced by an ambivalent relationship with staff, and that meeting all the requests made by service user members "would be incompatible with safe and appropriate care" (Page 70). This suggestion of ambivalence has some merit; as one Director of Mental Health in the study pointed out, a service user team member could be in a position where they are detained under a section of the Mental Health Act, presenting significant challenges for ongoing relationships with those who represent the detaining authority. However, the comment regarding the ability to meet all the service user requests is revealing; it places the power firmly with the service provider and its staff, who will make the ultimate judgement as to whether contributed ideas are both 'safe' and 'appropriate'. This would align with the Lukes' (1974) three-dimensional (or 'faces') concept of power discussed in Chapter 1 (1.5.3 – Page 16), particularly face two, where power is regulated by controlling the agenda and face three, where service users are manipulated to accept the decisions that are made by the professionals holding the power.

MacDonald et al (2014) link their findings around the role of service user governors to Lowndes & Roberts' (2013) 'third wave' institutionalism; the idea that all institutionalism is based upon common conceptualisations of rules, practice and overarching narratives, which act as a constraining force for anyone within them. If one subscribes to this happening with service user involvement activity, such environments potentially set up negative comparisons between the approach taken by service user contributors and professional others, undermining the confidence of the former (Harding et al, 2010; Restall, 2013).

Linked to the issue of comparative roles and status, three of the selected studies focused on the impact of the emerging peer support workforce within provider organisations (Byrne et al, 2016; Collins et al, 2016; Rebeiro-Gruhl et al, 2016). As found by Doherty et al (2004), there was broad agreement that the Peer Support Worker (PSW) role brought an additional dimension to the care provided for service users, as well as being potentially beneficial to the PSW themselves. However, in Rebeiro-Gruhl et al (2016) the PSWs themselves felt that their role was stifled by the delegation of generic healthcare assistant duties, preventing them from engaging with what they viewed as the PSW role (working alongside the mentally distressed as a support mentor). Of additional concern, Byrne et al (2016) found that the medical model of care dominated the culture of services, which imposed significant limitations on PSW work. PSW respondents felt they remained within a disempowered and discriminated group in society by virtue of their status as mental health service users.

The picture so far suggests service users being placed in a position of powerlessness, whether or not they are engaged as external contributors of paid staff members. This highlights inconsistency where arguably there should not be any; involvement for those with lived experience is trumpeted as a way of increasing a sense of personal agency, as well as making services more responsive to people's needs when a mental health crisis happens. Instead, the opposite appears to be widely experienced; a sense of disempowerment and/or co-opting by professionals and managers.

However, it is important to consider examples in the literature that seek to explore ways in which disempowerment is challenged. Significant is Armes' (2009) study, which conducted eight semi-structured interviews with members of the British Service Use/Survivor Movement (BSUSM) and further discussion groups with 13 activists. The focus was on how participants coped with the pressure from purchasing authorities to formalise their work. Four discursive tactics were identified; *Reformism* (working jointly with non-user/survivor allies to achieve their agenda), *Rationalization* (reluctantly engaging in dominant ways of working in order to ensure continued service user involvement and advocacy), *Professionalization* (becoming formally employed within

provider organisations to gain professional status and achieve the service user agenda) and *Pride* (complete rejection of the professional hierarchies, celebrating mutual support amongst service users/survivors and challenging the stigma they experience. These discursive tactics will be important to revisit when analysing the findings within this project to see if there is a common or perhaps alternative way in which the participants manage their interface with provider organisations and professionals through their activity.

In summary, those accessing services for mental distress, becoming involved as experts by experience and professionals/provider organisations all agree that such activity can offer significant benefits to all stakeholders. Acting as role models of what is deemed an 'appropriate' recovery experience, they can directly get alongside those in distress in a way that a professional may not be able to, therefore complementing the care already provided. They are also in a good position to influence the attitudes of front-line professionals through involvement in education and training around the lived experience. However, on a more strategic level, contributing to meetings or forums which inform policy, planning and service delivery, the expert by experience faces a number of barriers to overcome in order to achieve meaningful change, not least the sense of isolation in such settings and the accusation from both professionals and other service users that they are not truly representative (despite evidence here to suggest they are).

The experience of power relationships within service user involvement activity arguably centres around the 'third wave institutionalism' posited by Lowndes & Roberts (2013), where as an individual expert by experience or a group, one must adopt the rules, language and behaviours of the more powerful partner (professionals and service providers) in order to be listened to and respected. Those who cannot change and adapt potentially could be frustrated and have their confidence undermined as an individual or cease to be involved altogether as a group. However, as highlighted by Armes (2009) there are some who will resist these formal pressures in different ways to achieve the service user agenda.

This review so far has focused on the 'what' of mental health user involvement; what happens when someone moves into this type of work in terms of their individual recovery from crisis, the response they receive from professionals and the impact their work has on the lives of others who are going through their own crisis and accessing services. The picture is not entirely positive, which prompts a discussion of what the literature says about the 'why'; why is the individual impact of involvement work on people's recovery considered so lightly, when personal recovery is the capstone of modern mental health care? Why does one have to accept third wave institutionalism to avoid being ignored (at best) or (discredited (at worst) by professionals,

managers, and policy makers? Why can a type of work that should increase a sense of power and agency serve to have the opposite effect? To answer these questions the review must return to the historical context, Psychopolitics and influence of neoliberalism briefly introduced in Chapter 1.

## 2.4 Neoliberalism, Psychopolitics and Mad Studies

It is argued that in the UK from the late 1970s until the present day, a neoliberalist ideology has dominated the political landscape (Ramon, 2008). Drawing on the definitions of Deakin (1994) and Pratt (2006), the major tenets of neoliberalism can be described as:

- The superiority of market as an institution for optimal resource allocation (this would include healthcare), thereby minimising the bureaucracy and inefficiency of the state
- Resisting the perceived burden to the government and the public purse of a welfare economy
- The superiority of individualism over collectivism
- Individual self-reliance and moral responsibility over interdependency

Recovery in the Bin (2016), introduced in 1.3.9 (Page 12), are more critical in their definition of a “...political and economic belief system that enforces privatisation, deregulation and cuts to spending, in which governments dismantle trade barriers, abandon public ownership, reduce taxes, eliminate the minimum wage, cut health and welfare spending, and privatisate education.” The impact of this ideology on the NHS as the UK’s major provider of mental health care is the creation of a hybrid “liberal collectivist regime” (Ramon, 2008), whereby the universalism of a national health service is married with the market economy principles. In mental health, as discussed in 1.3.6 (Page 8), this has been an influence in the move from large long-term inpatient care to more cost-efficient care in the community setting. Along with most other sectors of health, statutory (NHS) care providers have been organised into Trusts as distinct business units operating semi-independently from central government (HM Government, 1990). The meaning of all this for the person experiencing a mental health crisis is complex and warrants exploration.

As highlighted by Foucault (1977), “the judges of normality are everywhere” (Page 304). This is apparent in the case of people experiencing mental distress (1.5.1, Page 17 discusses the social construction of mental illness). In the context of a neoliberal state with a liberal collectivist healthcare system, people in crisis cease to become a contributor to the market economy, but a welfare burden, costing the taxpayer thousands of pounds in care provision, welfare benefits and lost productivity. Those who are unable to undertake paid work as a result of their mental distress

continue to be a burden in the longer-term. In 1.3.5 (Page 6) I discussed the emergence of IAPT services to address mild to moderate depression and anxiety and avoid longer term engagement in secondary mental health services. A key outcome measure of the success of IAPT with the individual is a return to employment (NCCMH, 2018), and by default economic productivity. The concept of recovery within secondary mental health services (obviously countered by the aptly titled 'Recovery in the Bin') focuses on being occupationally active in either paid or unpaid roles (Kelly et al, 2010). As suggested in 1.3.5 (Page 7), to stay in one's bed as an approach to recovery is unlikely to be deemed acceptable; the market designates what behaviours are acceptable and will lead to its definition of happiness and fulfilment (Eposito & Perez, 2014).

The judgement between what is considered productive and non-productive from the perspective of the neoliberal state and health professionals will inevitably impact on the behaviour of others toward those with lived experience of mental health crises and the designated identity that is then accepted and internalised (as discussed in 1.5.2, Pages 19-20). If one is considered deviant or the 'other' from mental health professionals or managers through their status as a 'non-productive' entity, there is a real risk that their involvement work is considered solely as a therapeutic step towards becoming a productive member of society (the lower rungs of Arnstein's 1969 ladder – Figure 1, Page 16), rather than offering any real contribution to change. The findings emerging from the research literature in 2.3 point to this potentially being the case, with exclusion from the important strategic agenda items, accusations of non-representativeness and disempowerment, concealed behind an engendered sense of personal recovery from deviancy.

The emergence of Mad studies, briefly introduced in 1.3.9 (Pages 12-14) draws on Sedgwick's vision (1982) of a new politics that sees an integration of demands held by psychiatric survivors, mental health workers and the wider population (Moth & McKeown, 2016). McKeown, et al (2014) suggests that the "recognition of shared interests and contradictory positions between services users and workers opens up possibilities of a more nuanced negotiation of identity issues and the appreciation of experience of mental health and service use or care work from each other's perspectives" (Page 282). Ultimately, the agenda is to challenge the influence of neoliberalism on the law, policy and service provision and usher in a radical rethinking of the support offered to those in mental distress. Spandler et al (2016) propose five key areas of debate in relation to modern psychopolitics:

- The tension for activist between pacing energies in prefigurative mental health politics (developing alternatives to the present system of care) and defending welfare services (arguably a necessary precursor to transforming the field of mental health).

- Asserting the human rights dimension in mental health activism (e.g. challenging compulsory detention under the Mental Health Act), which may prioritise individual liberty over the state's obligation to support those in distress and their families.
- The role of families/carers in activism, as a group who are often criticised for colluding in coercion of their loved ones and the restriction of their freedoms.
- Developing a refined socio-historical materialist theory of mental distress
- Exploring how socioeconomic class intersects with other forms of oppression (such as psychiatric coercion)

In relation to this work, the debates within Mad studies ask important questions about how participants view the work they do and the identity they accept and internalise in their relationships with other actors in the system. Do they see it as activism? What is their agenda; a radical transformation of the way in which we care for the mentally distressed, or to share their personal story as an encouragement to service users and workers alike? Do they feel exploited as part of a neoliberalist agenda to maintain the status quo (through the medium of the biomedical model of mental illness)? Ultimately, do they possess a sense of power and agency, which so often is taken from people when in a mental health crisis?

It is acknowledged that the questions posed here focus on the individual experience, and that Mad studies are keen to focus on the collective nature of mental health activism (to challenge neoliberalism). The sense the participants feel about being part of something bigger, a social movement of service users/psychiatric survivors, within their involvement work will be a key consideration going forward.

## 2.5 Summary of Literature Review and Gaps Addressed by this Study

This review has briefly highlighted some key narratives of service user involvement emerging from the literature, some of which challenge some beliefs held by professionals or provider organisations. It has also discussed some of the key impacts of neoliberalism on mental health care in the UK through the lens of psychopolitics and the emerging field of Mad studies.

In 1.4 (Page 15) of Chapter 1, I briefly introduced Arnstein's Ladder of Citizen Participation (Arnstein, 1969), which started with 'manipulation' on the bottom rung, through to 'citizen control' at the top. When applied to the literature related to mental health service user involvement activity, it would suggest that there is a long way to go to attain universal 'citizen control' of services. The ethos of Recovery Colleges, promoting partnership working between professional and those with lived experience, potentially climbs up the lower rungs of 'citizen power' (partnership working), but arguably does little to counter the concept of mental distress

being deviant, as dictated by the ideology of neoliberalism. One must recover. It would also appear that most other forms of user involvement activity, from participating in meetings or forums, through to being employed in a Peer Support Worker role, achieve 'placation' at best; the highest level of tokenism, where participants are placed in a visible position, but power holders (professionals and managers) retain the right to decide.

It is important now to establish where my research fits within the literature, most importantly the gaps it intends to address. The research questions set out in Chapter 1 were:

**Primary research question:**

What is the participants' experience of power and empowerment when involved in the planning and delivery of mental health services and the role such experiences have had in their overall recovery?

**Subsidiary research questions:**

- i) What barriers have service users faced to effectively participate in the planning, delivery and recruitment activities within mental health provider organisations?
- ii) To what degree do the concepts of power and empowerment concern mental health service users who have contributed to planning and recruitment activities?
- iii) To what extent do service users view themselves as part of a broader social movement, alongside other groups that have been historically marginalised or oppressed?
- iv) To what extent have service users been able to successfully overcome any barriers and if so, what approaches have they taken?
- v) How has the experience of user involvement work impacted on the recovery of service users?
- vi) How do the narratives of service users participating in this project inform the future policy and practice of involving of experts by experience in the planning, delivery of and recruitment to mental health service providers in the UK?

Perhaps the most closely aligned to the focus of my research is Chassot and Mendes (2015), whose aim was to examine the subjective experience of those who are or have previously been actively involved in the service user/survivor movement. This study provides some potentially helpful themes from their qualitative interviews; the making sense and reframing of mental distress, the social experience of involvement and identity & identity reconstruction; all linked to the global experience of recovery. Where our respective studies diverge is that Chassot and Mendes (2015) focus specifically on participants who self-identify as members of the British service user/survivor movement (locally or nationally); the rationale being the authors' particular

interest in political activism within the service user/survivor movement. Whether or not my participants formally identify themselves as part of a wider socio-political movement or even a user/survivor organisation, will be a question within my interviews, but a definitive 'yes' will not be one of the inclusion criteria (as is the case with Chassot and Mendes, 2015). My aim is to be broader than the role of political activist and allow as many expressed identities to emerge from the data across the span of the participants' lives. It is hoped this will ascertain whether or not their experience of mental health services (as user and consultant) facilitates the creation of new roles or identities, restores some former ones, or both. Importantly, though implicit throughout their work, the exploration of power dynamics within user-professional relationships is not stated as an explicit aim of the Chassot and Mendes (2015) study; it is core to my research (see 1.5.3 - Page 20 & 2.3).

Linked to identity formation, my research will contextualise the lived experience of involvement work within their life 'story' (discussed further in Chapter 3), which goes beyond just a chronology of events. Chassot and Mendes (2015) go further than most by placing the activities of the user/survivor movements within the context of people's recovery but they do not look back to who these people were prior to their entry into the mental health system and how much the precipitants of their experience of significant distress are either challenged or reinforced by becoming a member of that system, whether as a recipient of support or active in involvement work. This risk of a narrower (and admittedly straightforward) approach to user/survivor engagement with the mental health system is that the discussion becomes service-centric, rather than person centric. That said, by aspiring to be person-centric I must exercise caution against an equally narrow individualistic approach, i.e. disregarding the historical socio-political context in which the person's account is told.

It is now important to look forward to Chapter 3, which discusses the methodological approach and method employed within my research. Methodology refers to the strategy or plan of action laying behind the choice of a particular method, and linking this to the desired outcome of the research. Method refers to techniques or procedures employed to gather and analyse research data.



# Chapter 3 Methodology

## 3.1 Research Paradigm

As summarised at the end of Chapter 1, the aims of this research study are to:

- Present the experiences of people who have accessed mental health services and then gone on to service user involvement activity.
- Explore how the power relationships between the informants and professionals may have evolved in light of this changing role.
- Examine how the experience of service user involvement work fits within the informants' overall life 'story' and recovery from significant mental distress.

### 3.1.1 Qualitative Research Methodology

Mason (2002; P1) crafts a useful summary of qualitative research, explaining it as a medium through which "we can explore a wide array of dimensions in the social world, including the texture and weave of everyday life, the understandings, experiences and imaginings of our research participants, the ways that social processes, institutions, discourses or relationships work, and the significance of meanings they generate". Holloway & Galvin (2017; Page 3) breaks this down to a set of core characteristics which run through the range of methodological approaches and will be met throughout this chapter and Chapter 4:

- The data has priority and the theoretical framework derives directly from this, rather than being predetermined
- Qualitative research is context bound and researchers must be sensitive to the context.
- Researchers immerse themselves in the natural setting of the people whose situations, behaviour and thoughts they wish to explore.
- Researchers also focus on the 'inside view' of the participants (perceptions meanings and interpretations).
- Researchers use 'thick description'; they describe, analyse, and interpret, going beyond the reports, descriptions and constructions of the participants.
- The relationship between researcher and participant is close and based on a position of immersion in the field and equality as human beings.
- Reflexivity in the research makes explicit the stance of the researcher, who is the primary research tool.

### 3.1.2 Refining the Qualitative Method: Oral History and the Life Story

As discussed in Chapters 1 and 2, any lived experience of significant mental distress, accessing services and then possibly going on to undertake involvement work will inevitably be set within the wider historical social, economic, and political influences surrounding those accessing modern mental health services. As such, the specific methodological approach to this research should be cognisant of historical context.

Oral history would be a potentially appropriate methodological approach to this research; agreed by authors in the field as both a research methodology (the process of undertaking and recording interviews with individuals or groups in order to draw out information about the past) and also a product which in itself becomes a historical record (Abrams, 2010). Proponents of oral history are keen to distinguish the approach from other forms of personal testimony, as it records information directly from the narrator within their lifetime (unlike oral tradition, which is passed down through generations) and the shifting balance of power between interviewer and narrator. This also differs from biography or autobiography, where the 'story' may be influenced by the socio-political agenda of the interviewer or author (Abrams, 2010).

As a historical source, Portelli (1991) identifies six elements that make oral histories different to other oral testimonies; orality, narrative, performance, subjectivity, memory and mutability (defined in Table 2 – Page 49). However, as a sociological source, there is considerable overlap between oral history the life story approach (Plummer, 2001), which concerns itself with seeking an individual's perspective on their life at the moment of giving their narrative and considers itself firmly rooted in history as well (Plummer, 2001). Indeed, Plummer (2001) comments that when at its most effective, life story research "brings a focus on historical change, moving between the changing biographical history of the person and the social history of his or her lifespan" (Page 39). Elements such as story, plot, characters, poetics, themes and genres are considered central within data analysis (Plummer, 2001) and perhaps are comparable to some of the elements set out by Portelli (Table 2 – Page 49).

**Table 2: Comparative summary of Oral History & Life Story methodological approaches**

Oral History – Portelli (1991)	Life Story (History) – Plummer (2001)
<p><b>Orality:</b> The form of the narrator's account, rather than the content itself. The tone, volume and rhythm carry meaning which is embedded in the individual's culture and experience. The interview recording is the real historical document, not the transcript that is created for publication.</p> <p><b>Mutability:</b> The narrator's natural resistance to being pinned down - no story will be repeated exactly the same. Oral history researchers should have awareness that by transcribing the recording, this natural mutability then becomes fixed.</p> <p><b>Subjectivity:</b> Oral history seeks to identify the emotional and political responses of the individual or group and their representativeness, contrasting with the traditionally generalised accounts of events produced by those in power.</p> <p><b>Memory:</b> Oral history accepts the fallibility of memory, asking the core questions around why people remember things in a certain way and forget some elements of their story.</p>	<p><b>Speech acts &amp; the conversational unit:</b> the narrator's account is viewed as a linguistic unit, governed by language rules, which like Oral History, will be imbedded in the culture and experience of the individual (as with orality). This can be open to revision, as the speaker discards old meanings and introduces new ones (Linde, 1993). This is comparable to the mutability posited in OH, in that no story will be repeated the same and fully acknowledges the cementing of this with transcription.</p> <p><b>'Truth' in Life Storytelling:</b> Like OH the LS approach recognises the fallibility of memory and the organisation of narratives about our past experience through the elements listed here ('narrative truth' as opposed to 'historical truth' – Spence, 1982)</p>
<p><b>Narrative:</b> The individual or group story will be dramatised in narrative form, therefore any analysis must utilise elements of narrative theory in literature and folklore.</p> <p><b>Performance:</b> The narrator's performance should be explored alongside the content of the interview; have they crafted the information provided in order to give the interviewer what they think is wanted or to present themselves in a particular light?</p>	<p><b>Story:</b> LS addresses narrative and performance, like OH, but perhaps more explicitly couches this within the conventions of storytelling; <i>"Our life is essentially a set of stories we tell about our past, present and future"</i> (Kenyon &amp; Randall, 1997; P2). The four elements of how this is told are below.</p> <p><b>Plot:</b> Often has a dynamic tension which gives momentum, some coherence and makes it interesting to listen to. Kenyon &amp; Randall (1997; P67): <i>"Plot carries us from initial calm through ensuing conflict to eventual climax, conclusion and (once more) calm"</i></p> <p><b>Characters:</b> 'Story types', rather than 'stereotypes' (e.g. 'hero', 'villain', 'fool') – usually there is a protagonist, antagonist and a witness.</p> <p><b>Genres &amp; Structures:</b> clustering of plots into images &amp; thematic lines can lead to fall into formal patterns, types &amp; structures, often performing definite functions (e.g. comic, tragic, romantic or satirical)</p> <p><b>Tropes:</b> The use of imagery &amp; metaphor to contextualise within a particular 'frame' of the individual life story and an overarching problem (Loftland, 1974)</p>

It has been argued that that attempts to delineate the two can amount to false boundary construction (Bornatt, 1989). However, differences perhaps enter between the two, when exploring the agenda of the researcher for undertaking the interviews. The oral historian seeks insight into a historical event or period within by creating a historical record between the interviewer and people who were present (the archived recording of the interview) and if they wish would leave the material for others to analyse and interpret. For life histories/stories, the coproduction of a physical historical record around a specific aspect of a person's life is less important than understanding their overarching story, which may or may not join with other stories to form a metanarrative regarding a particular social or psychological phenomenon (Atkinson, 1998). As stated in Chapter 1, for me as a researcher, it is the individual life stories, the motivations behind engaging in service user work and its place in their recovery that are of particular interest. Therefore, it would seem more appropriate to adopt a life story methodological approach, whilst acknowledging the significant overlap with oral history. This subtly divided methodological allegiance does carry some advantages in that the work of prominent oral historians, such as Portelli or Thompson (2000) remains as relevant to the discussion as the writings of Plummer or Atkinson.

### **3.1.3 The Life Story Methodological Approach**

It is important to return to my brief definitions of 'methodology' and 'method' at the end of Chapter 2, given that when describing oral history and life stories so far, I have referred to them as a 'methodological approach'. This is with good reason, as arguably neither's methodology could be considered with the precision of other qualitative methodologies, such as Phenomenology or Grounded Theory. Within both there are many nuanced decisions one may make at almost all stages of the research (for the life story approach these are articulated in 3.1.3). If one were to summarise the life story approach as a methodology, it could be as succinct as the process of undertaking and recording interviews to draw out information about the past and the subjective meanings attached by the person/people. The term 'methodological approach' is more appropriate.

Having established the life-story methodological approach as potentially being the most appropriate for my research, a fuller account of the 'doing' of life story research is warranted, aided by Plummer's (2001) core text. Plummer sets out seven stages of undertaking life story research, which will be discussed in the context of my research. However, he also cautions against these being used as set of chronological instructions, highlighting the need to "blur and blend" (Page 122) what he refers to as 'phases' in order to manage the messiness of real-world research with people.

The first phase is termed 'Getting Problems'; identifying broadly what issue is for the researcher, then refining it into a more focused problem to address. This is important, as Plummer asserts that questions should shape the method and not the reverse; life story research is not always appropriate. In the context of my study, the primary and subsidiary research questions were established in Chapter 1, focusing on the lived experience of people through mental health crisis, accessing services, and the becoming an expert by experience, but in the context of their lives. Plummer (2001) helpfully assists by articulating specific sub-sets of life story approaches; a sociological approach is interested in the cultural aspects of life (race, gender, class, education and others), whereas a psychological approach will focus on a person's developmental experiences. This study blends the two into a psychosocial approach to the interviews and analysis. Whilst important to explore the participants' experience of the culture within mental health services as both a service user and expert by experience, it was equally pertinent to understand its relation to their unique life story and how the narrative 'truth' of that story has been assembled (effectively incorporating a narrative and psychological 'truth' articulated by BenEzer, 2002).

The second phase, 'Planning', is really what it says; deciding the who, how, where, when and what of the study. This is largely addressed in 3.3 ('Undertaking the Study'), but briefly considered here. Plummer considers two broad paths the researcher may take to address the recruitment of participants and how the interviews are set up; either through luck and chance and being pragmatic, or through "selective sampling" (Plummer, 2001; Page 133). Neither purports to be seeking a sample whereby generalisations can be drawn from the findings; they are looking for participants who are information rich. The latter approach involves the use of a clear set of criteria and aligns with the earlier stages of my study; all participants met a set of criteria to ensure that they embodied the experiences sought through the research questions. I initially targeted those whom I had worked with. However, the network of relationships formed among these experts (see 3.3.2) prompted recommendations being made to me by those completing their interviews of others that similarly would have a narrative to contribute (luck and chance).

The third phase involves the actual 'doing' of the research, most commonly via a recorded interview. Plummer identifies two ends of an interview continuum in life story research, a positivist pole and interpretive pole. It may come as a surprise to the reader that any life story research could be considered positivist, with an emphasis on standardised questionnaires to ensure objectivity, and the interviewee being more passive in shaping the narrative. Plummer suggests that this approach suits longitudinal research, which may seek to establish a more objective view of history. Scott and Alwin (1998) discuss how some people may be interviewed and reinterviewed at different points across time, in order to develop measures which can be

employed to capture the unfolding of people's lives in the future. In this approach an intricate level of detail is gained about almost all aspects of the narrator's life, and may include the additional material provided by diaries, letters, photographs or even accounts given by family or friends. However, this does not align with my aim to capture people's narratives at a single point in time. Described by Plummer (2001) as the short life story, a single interview is usually one of a series of narrator accounts, lasting between 30 minutes and 3 hours and tending to be more focused. The short life story favours the interpretive end of the interview spectrum (given greater attention in Plummer's work). In practical terms, this approach will be flexible, utilising interview checklists rather than questionnaires and foresees a more active role for both interviewee and interviewer in shaping the data that emerges. This aligns closely with my research aims and objectives, discussed in Chapter 1. 'Undertaking the Study' (3.3) explores the 'doing' of my research in greater depth.

Phase four focuses on the management and organisation of the data collected via the interviews, in my case this will be through an audio recording, which is then transcribed by me. Plummer (2001) suggests there are three forms of documentation relating to the interview transcript;

- Core files – contains all the interview data in its purest unedited form.
- Analytic files – where newly transcribed data is read to draw out themes/concepts, which are then recorded in an appropriate file.
- Personal log – designed to capture the researcher's changing personal impressions of the interview, participant, and own involvement in the process (reflexivity)

The account of all three and how they are employed within this research can be found in 3.4 ('The Process of Data Analysis').

The fifth phase in many ways overlaps with the fourth, centring on the analysis and interpretation of the data. It is here that the traditional issues of representativeness, validity and reliability are acknowledged, but challenged. Section 3.1.1 discusses in some depth the trustworthiness of life story data and how it has been considered in my work. It is here that the relationships between life stories and theory becomes most important. Plummer (2001) suggest that life stories can be used in three broadly different ways; to challenge some overly general theory, illustrate or illuminate some wider theory, or take a story as a way of building a wider sense of theory. My work sits between the first two; by adopting the abductive approach (see 1.5, Page 17), pre-existing theoretical positions are acknowledged, but allow for the research to generate surprises (I went on to discuss the social construction of mental 'illness', Identity and Personality Theory, and concepts of power and empowerment). In 3.4 ('The Process of Data Analysis'), the use of Braun &

Clarke's (2006) Thematic Analysis is discussed, with its application to my interview data accounted for within Chapter 4 ('Analysis and Emerging Findings').

Phase 6, 'Presenting', refers to the writing up of the data analysis and discussing if and how the findings challenge, illuminate or generate theory. Within this work, Chapter 5 takes the findings of Chapter 4 and discusses them in light of the research questions posed. As the conclusion to a doctoral thesis, my Chapter 6 outlines the contribution to knowledge my research makes and offers recommendations for future research.

Finally, Plummer's (2001) seventh phase refers to the archiving; bringing together life stories to leave for posterity. Here, there is a significant overlap with oral history, however, as discussed in 3.1.2, the importance of this differs between the two (OH placing the greater emphasis). As discussed in 3.2 and 3.3, the archiving of interview recordings and transcripts was something that I would ask participants to consider and consent to (if they chose), but it would not be a criterion of their inclusion in the research itself.

### **3.1.4 Rigour in Qualitative Research and Trustworthiness of the Life Story Data**

Throughout the oral and life history literature the importance of the relationship between the narrator and interview on the quality of the data gathered is emphasised (Thompson, 2000; Plummer, 2001; Yow, 2005; Abrams, 2010). A good interviewer-narrator relationship will encourage a coherent narrative flow, containing a meaningful balance of information and reflection. A poor relationship is likely to result in short, factual answers, which will ultimately produce a poor or incoherent narrative (Abrams, 2010).

Having asserted that the relationship between interviewer and respondent is a central tenet in creating a useful, flowing narrative, the broader debate around rigour in qualitative research, should also be considered in relation to this project. Arguably the defining literature in the area of qualitative rigour are the works of Lincoln and Guba (1985) who take the rigour criteria of the traditional positivist paradigm and translate it into terms that fit more appropriately with naturalistic. They highlight the paradox between internal and external validity within the positivist paradigm and attempt to address this in their trustworthiness. Instead of internal validity, they seek a truth value or credibility; assuming that multiple constructed realities exist, and therefore the researcher seeks adequate representation of those constructions. Instead of external validity, there is a shift to applicability or transferability; the researcher provides enough contextual information/descriptive data as possible, in order for a different researcher to create sufficiently similar conditions for making similarity judgements between the outcomes of the two.

When revisiting the issue of rigour set out in an earlier article (published at a similar time to Lincoln and Guba's), Sandelowski (1993) challenged some of the underpinnings of their work; of note, their assumption that validity (credibility) cannot be demonstrated without reliability (dependability), which in her view, is almost counterintuitive to the 'art' of qualitative research, where narrative data is essentially revisionist; "remembrances about the past in a fleeting present moment soon to be past" (Page 4), which will change with each time of telling. Portelli (1991) denies that the discrepancies between 'fact' and memory are failings, but enhance its value in ascertaining how crucial events have been made sense of by those that lived through them. As such, one is not necessarily interested in random fragments of an experience, but capturing whole stories that are created from memory. BenEzer (2002) refers to 'narrative truth' as a distinct entity from 'historical truth' (objective reality of an occurrence) and 'psychological truth' (the interviewee's beliefs about what occurred), which will dictate what is expressed or consciously/unconsciously withheld, how the content is organised the role of the accompanying non-verbal text.

The above carries significant resonance with my research, where narrators will invariably have told their 'story' on many occasions as part of the service user involvement role. In such instances, it is helpful to identify inconsistencies within and between narratives and explore whether or not this reveals a function of storytelling or performance. Alongside this, there is the potential for a consistent narrative that wishes to push forward a particular agenda; whether this is to provide me with the answers they think I am wanting to hear or seizing the opportunity to criticise and challenge a perceived power imbalance between themselves and professionals or services, of which I am a member.

The acknowledgement of potential bias does not absolve me as a researcher from the responsibility to minimise it where it is possible. This is why reflexivity is so important in acknowledging our investments rather than trying to delete them (see 3.2.2). A comparison between the interview schedule provided to the participants and the one developed for me as the interviewer (Appendix E – Pages 227-232) highlights the low-key approach used with the narrators; highlighting that the main focus is their experience in user involvement work, but that the context of that experience (early life, experience of mental distress and accessing services) is also important to the narrative. Additionally, although I was open about my professional background, I introduced myself, first and foremost, as a doctoral researcher.

## 3.2 Ethics

Although the intent of this research study was not to replicate the professional-patient relationships experienced by narrators when they accessed mental health services, inevitable comparisons can be drawn (as previously stated, to unknown participants I introduced myself as a doctoral researcher, but was also open about my professional background). Confidentiality would be assured, should the narrator desire this for themselves, and reference to family, friends, professionals and services would require anonymising within transcripts, as they obviously would not have given informed consent to be included. As with a professional-client interaction, confidentiality could potentially be broken if any current risk or safeguarding concerns emerged around the narrator themselves or another person (NHS England, 2015), however, they would be informed of this prior to any action being taken. Thankfully, this did not emerge as an issue within any of the interviews.

Another important ethical consideration was the potential distress to narrators as a result of discussing potentially difficult or sensitive life experiences. There were no formal gatekeepers employed within the recruitment of participants (such as a member of a care team), partly because the theoretical sampling approach employed (3.3.1 – Page 68) and also due to the fact that not all were currently accessing services. The more informal approach to recruitment carried a potentially greater risk of harm to individuals (although it was hoped would be more empowering), so clear procedures would be required to minimise this risk. The procedural and relational ethics within this project are discussed across 3.2.1 (below) and 3.2.2 (Page 66).

### 3.2.1 Procedural Ethics

Procedural ethics, as defined by Guillemin & Gillam (2004) is the process of seeking approval from a formal ethics committee to carry out research involving people. For this project there were three formal stages of ethical approval; faculty peer review, university research ethics committee and NHS research ethics committee. In addition to this, all documentation was reviewed by a trusted service user/expert by experience colleague and suggested changes made prior to submission to the university ethics committee.

#### 3.2.1.1 Peer Review

Two doctoral level academic colleagues reviewed a larger ‘milestone’ document; a research proposal which incorporated a background to the study, literature review, research aims/questions, methodology and finally ethical considerations. Whilst the reviewers suggested a few minor amendments to the proposal, only one related to the ethics process. The *Pre-Interview*

*Consent Form (Version 1)* had originally utilised a British Library Oral History template, which contained 'old English' and were not as reader-friendly as they could have been. This was amended to reflect more modern language (*Version 2* – Appendix E – Pages 227-232). Permission to proceed to submission for university ethical approval was granted in January 2014.

### **3.2.1.2      Expert by Experience Review**

The feedback given by the service user colleague centred mainly on the refinement of the interview schedule for narrators (which became the final version – Appendix E – Pages 227-232). However, one or two additional amendments were suggested around the language of the consent form, which led to the third version being submitted at the next stage.

### **3.2.1.3      University Research Ethics**

The formal research proposal was submitted to the University of Southampton's ERGO system (No: 9374), which included the following:

- Research Protocol (Appendix B – Pages 207-214)
- Participant Information Sheet (V1) (final version (2) in Appendix C – Pages 215-219)
- Participant Consent Form (V2) and Recording Release Consent Form (V2) (final versions in Appendix E – Pages 227-232)

The project was given favourable opinion without any further amendments required in May 2014.

### **3.2.1.4      NHS Research Ethics (NRES)**

Once university research ethics permission had been granted, the research proposal required submission to a NHS Research Ethics (NRES) Committee; although I did not plan to recruit the narrators through any NHS channels, such as putting up posters in ward areas or community service waiting rooms, all were likely to have been current or former service users of NHS mental health services (two were also currently employees). For the REC application to NRES Committee South Central - Oxford C, a more extensive application form was completed (Ref: 14/SC/1063) The information and consent forms used for ERGO were submitted again here, with an additional Participant Invitation Letter (Appendix C - Pages 215-219) to accompany the PIS, and a short CV for myself and the primary supervisor at the time. My primary supervisor at the time and I attended the Oxford-C REC in July 2014.

Given that one of the primary functions of an ethics committee (and indeed me as the researcher) is to protect potentially vulnerable participants, the measures below were outlined in the NRES application to ensure that this was comprehensively addressed:

- No participant would be interviewed if they are currently an inpatient within mental health services, either informal or detained under a section of the Mental Health Act (2007), or subject to a Community Treatment Order (CTO).
- Prior to the interview participants would be asked to identify a significant other (relative, friend or professional) with whom they can speak if the interview process does cause emotionally charged thoughts and feelings.
- Participants would be reminded that they are able to stop the interview at any point if it becomes too emotionally distressing for them.
- If I as a researcher with a background in mental health care believed that the interview was beginning to trigger a severe emotional stress or trauma response, then I would suggest ending the interview and discuss with the narrator about meeting again to complete it at another time.

At the REC committee meeting, it was felt that as an addition, a contact list of professional organisations whom the narrator could contact if experiencing mental distress after the interview should be included. This was challenged by me at the time, as I believed that the narrators would likely have previously developed written crisis plans, detailing helpful sources of support should they experience significant distress. To provide a list of telephone helplines could be perceived as paternalistic or patronising in a study where I was trying to minimise the sense of power imbalance. In addition to this the ethics committee stipulated that the identity of all participants was to be anonymised. Whilst this was done to protect the vulnerability of the narrators, it did not leave them with a choice around how they wished to own their 'story' (i.e. being able to publically share their personal lived experience and receive acknowledgement for doing so). However, in order to receive full ethical approval, I was required to create a list within the Pre-interview consent form (Appendix E – Pages 227-232). Full NRES committee approval was received in August 2014 (Appendix D – Pages 220-226).

### 3.2.2 Relational Ethics & Reflexivity

Slattery & Rapp (2003) define relational ethics as the act of doing what is important to be "true to one's character and responsible for one's actions and their consequences on others" (P55). Carolyn Ellis, a leading voice in this area, highlights the requirement on researchers to act "from our hearts and minds, to acknowledge our interpersonal bonds to others, and initiate and maintain conversations" (Ellis, 2007; P4); essentially that the researcher-narrator relationship may change as a result of the interview event. Whilst not auto-ethnographic in nature (as with Ellis' research), my study demands the sharing of intimate information; narrators are being asked to

share some of the most personal aspects of their lives growing up, how their path into the mental health system unfolded and the process of recovery since. Explored in greater depth within Chapter 4, several narrators disclosed experiences of significant abuse by family members, bullying and rejection by institutions, and degradation by healthcare professional groups of which I am a registered member. The objectivity of a positivist research approach would require a respectful 'distance' from the narrator and their stories. The reality, as outlined by Ellis (2007) and Guillemin & Gillam (2004) is very different in qualitative research; how do we demonstrate a humane response to emotional or traumatic discourse, whilst being non-exploitative and mindful of our role as researchers (rather than friends or in my case, a mental health professional)?

One of the narrators, 'Maggie', whom I had not met in person until the day of the interview, emailed and asked to meet for a cup of tea several weeks afterwards, with no explicit agenda given. Having recently spoken with Beth, as my first interviewee and with whom I had longstanding professional relationship, she recounted the emotionally draining impact of the interview experience and that it had taken her several days to recover. Therefore, with Maggie it felt appropriate to accept her invitation to a tea house, in case she had experienced similar to Beth. To an extent this was the case; Maggie had felt emotionally exhausted afterwards, but also anxious that she had not provided the information I had hoped for within the interview. By meeting with her I was able to provide reassurance that the time she had given up for the interview had been very helpful from a research perspective, but also as a human being her story had impacted me on an emotional level. Ellis (2007) rightly points out that there are no definitive rules or universal principles to guide every type of relationship or encounter one has with a research participant, other than to 'do no harm' (in biomedical ethics referred to as 'non-maleficence' - Beauchamp & Childress, 2013). This arranged meeting felt appropriate; I had not offered any therapeutic intervention, but had been able to validate the significance of her lived experience and its relevance to my research. We have remained in occasional email contact since. Reflective comments on my relationship with each of the 10 participants is part of my formal introduction of them in 3.3.2.

The post-interview contacts with both Beth and Maggie did raise ethical question marks regarding the implications of asking people to listen back to their recorded interviews alone, even with the recommended sources of support provided beforehand. However, it was of central importance that they had ownership of their story and that they had access to the same audio and written information that would inform my data analysis. This marks an important difference from their experience of assessment within mental health services, where the raw data (a person's live responses to the interviewer's questions) does not exist, unless it is recorded. Instead what the person may see is the professional's interpretation of their responses within case notes or a

formal report. The connotations for the power relationships are clear and it was something I wished to minimise within my relationship with the participants.

### **3.3 Undertaking the Study**

#### **3.3.1 Recruitment of Narrators, Gaining Consent and Arranging the Interview**

Glaser & Strauss (1967) refer to 'saturation', the point at which repeated stories and perspectives are being shared by different narrators, as guiding the decision on sample size. It is noteworthy, however, that when interviewing people with lived experience one can never establish true representativeness (Moss, 1974) and this project has not attempted this. Greater value is in the depth and quality of information discovered through the interview process against its future purposes, and this has been my primary consideration when recruiting narrators (Sandelowski, 1995; Portelli, 1991; Ritchie, 2003).

A theoretical sampling strategy was employed (Warren, 2001) whereby respondents are sought out who epitomise the focus of the project questions; those with lived experience of mental distress and utilising services, who were actively involved in service improvement activity within a county in the South of England. Using what Warren (2001) refers to as the "snowballing process" (Page 87), I approached two established service user contacts, with whom I had developed a positive working relationship over several years in academic practice. This, of course, carried a risk that knowing me in a professional capacity (as a nurse academic colleague) would skew their individual interview narrative to provide the data they believe I might want. Through their support and recommendation, further potential participants who met the inclusion criteria were identified, and they in turn did the same (hence the 'snowballing'). Whilst providing a useful insight into the networking activity that may take place among experts by experience, this did involve an initial reliance on them verbally conveying of the purpose of the research and appraisal of me as a potential research interviewer.

The issues highlighted above were addressed in two important ways. Firstly, in relation to their own interview narrative, the impact of my relationship with all participants on the narrative truth expressed is an important source of analysis (as discussed above). Secondly, the initial service user 'recruiters' were asked only to seek permission for me to contact other potential participants (and pass on contact details if they agreed), from which I could then post or email the formal *Participant Information Sheet* (Appendix C – Pages 215-219) and *Pre-interview Consent Form* (Appendix E – Pages 227-232). This enabled them to make an independent and informed decision about whether or not they wished to proceed with arranging an interview.

Given that within qualitative research there is not an imperative to have large numbers of participants (Holloway & Galvin, 2017), 10 participants were recruited, with the caveat that should those interviews not be of sufficient depth or quality to produce identifiable themes within the analysis, further interviews would then need to be undertaken. The inclusion/exclusion criteria employed is detailed in Table 3 (below).

**Table 3: Inclusion/exclusion criteria for recruitment of study participants**

Inclusion/Exclusion Criteria	Rationale
Historical and/or current user of adult mental health services (Age 18-65)	Statutory mental health services in England are usually divided into three age-related categories; Child & Adolescent Mental Health Services (CAMHS, 0-18 years), working age adults (18-65 years) and older persons (65 years+). Arguably mental service user involvement activity with working age adults is more developed than the other age groups and would generate a larger number of respondents
Currently not in an acute phase of mental ill health or distress.	To protect the narrator from being exploited at a vulnerable time.
Accessed services within a county in the South of England	Restricting the geographical area in which the SU has been active (and therefore organisations working with) will allow for useful comparative analysis of narratives.
Has been actively involved in the planning and delivery of services and/or recruitment and education of staff members within mental health organisations	It is the narrators' experiences of these activities within their story that are the focus of the project questions. There was a conscious decision not to include participants who had been involved exclusively in research activity (peer or professional led). It is acknowledged that this is a rapidly expanding area of involvement activity, arguably warranting a research study in its own right, but does not primarily focus on the SU researcher's own lived experience.

When posting the *Participant Information Letter* and *Participant Information Sheet* (Appendix C – Pages 215-219), potential narrators were given my contact details to ask any further questions prior to deciding whether or not they wished to proceed. Three of a total of 14 potential narrators did not respond once they had received the information; they were followed up with a reminder email 3 weeks later, which included the message that thanked them for their time and informed that further follow up would not be made. One narrator had consented and was keen to

participate, but unfortunately experienced deterioration in her mental health and had an extended period of absence from work. The remaining 10 interviews were arranged via email, with the *Pre-Interview Consent Form and Interview Schedule (Participant)* (Appendix E – Pages 227-232) sent to minimise any potential anxieties, whilst maintaining the ‘space’ to articulate their experiences. The completed consent form was collected at the start of the interview giving the narrators freedom to withdraw at any point, without feeling a sense of obligation. All consenting narrators were asked their preferred location for the interview.

### **3.3.2 The Narrators and their Network**

The narrators have all been given pseudonyms to maintain their anonymity and are introduced in the chronological order in which they were interviewed.

#### **3.3.2.1 Beth**

Beth is a white British woman in her early 50s, who reported a history of significant mental distress dating back to her late teens, but did not formally access mental health services until her mid-late 20s (inpatient and community). Prior to accessing services, she was pursuing a successful career in secondary education. Beth did not return to her career in education, but became increasingly involved in offering her expertise by experience in the third sector, statutory health services and the university in which I work (as part of an external reference group advising on the mental health curricula for nurses). Beth was formally employed by an NHS mental health trust for 5-6 years, with the remit to involve other service users in informing service activities and development. She left the organisation to pursue higher level academic study and now has a formal research role within a different NHS mental health trust.

I had known Beth for approximately 3 years prior to the interview in a work capacity. She was interviewed at home. I have had intermittent contact with Beth since the interview in September 2014.

#### **3.3.2.2 Orla**

Orla is a white woman in her 50s who grew up in the Republic of Ireland, but moved over to the UK in her early adulthood. Degree educated, she had a long career in the civil service, before developing significant mental health issues in her late 30s/early 40s. She experienced a number of admissions to hospital under a section of the Mental Health Act (1983, revised in 2007) and was medically retired. As part of her recovery she was invited by her psychologist to join a formal service user group within the local NHS trust, who would become involved in a range of activities from interview panels, to conference presentations, to teaching professionals as experts by

experience (group membership also included Beth, Elsa, Ruth, Jess and Geoff). This was interrupted for a period of time by readmissions to a mental health unit. At the time of interview, she was starting a formally employed role as a ward-based peer support worker.

I did not know Orla prior to our interview, which was conducted at her home. As an interviewee recruited via Beth, it is likely that Orla knew more about me than I did about her. Since the interview in October 2014 I have not had any face-to-face contact with Orla, but hear of her progress through others connected to involvement work.

### **3.3.2.3 Elsa**

Elsa is a white Australian woman in her late 50s, who experienced a strict Catholic upbringing in rural Australia, before moving to the UK in the late 1970s. Although she reported mental distress throughout her life, this did not severely impact upon her mental health and prompt a referral to services until she was in her early 40s, after experiencing bullying in the workplace. Her involvement in mental health services as a user was in the community setting and she was proactive in accessing opportunities to utilise her expertise by experience (paid for sessional commitments) within a local mental health NHS trust. She continues to be involved in service activity, sharing her lived experience of mental distress and care.

Like Orla, I did not know Elsa before the interview at her home (October 2014), and she was another participant recruited via Beth. I have seen Elsa on several occasions since our interview at formal and informal events related to mental health care, where we have spoken as warm acquaintances, rather than researcher and participant. Elsa's interview was the longest (approximately 2 hours and 40 minutes) and the most detailed regarding her early life, path into mental health crisis and experience of recovery.

### **3.3.2.4 Simon**

Simon is a white British man in his early 40s, whom I had known for approximately 2 years prior to the interview in a work capacity. He experienced mental health difficulties from his late teens, but did not access community mental health services until his late 20s. His involvement work was initially on a voluntary basis at a local day centre for people with mental health difficulties, but this led to him being invited to participate in service user work with the local mental health Trust and other sector organisations (including the university).

At the time of interview, which took place at the University (October 2014), Simon's service user work was decreasing, as he was in paid employment as a support worker in a social care setting. By early 2018 it had finished and he was in full-time paid employment.

### **3.3.2.5 Ruth**

Ruth is a white British woman in her mid-40s, who experienced two significant episodes of mental distress, which prompted her accessing of services; first as an adolescent and then again as an adult after giving birth. In between these two episodes she pursued a very successful career in nursing and in higher education as a lecturer/practitioner. Her engagement with community and inpatient mental health services has been both informal and formally under a section of the Mental Health Act (1983, revised in 2007). Her service user involvement work commenced by being 'put forward' to join the local Trust's formal service user group (with Beth, Elsa, Orla, Jess and Geoff). She has been involved in teaching, professional interviewing and strategy planning both within the NHS locally and higher education settings.

I had known Ruth for approximately 4 years prior to the interview in a work capacity (the longest of all participants). Ruth had been part of the university external mental health reference group. The interview took place in her home (October 2014) at a time where Ruth was starting to undertake less work within my organisation and more in paid employment. She has since ended her service user involvement work and we have had only occasion contact via email.

### **3.3.2.6 Mark**

Mark is a white British man in his mid-40s, who revealed very little about his lived experience of mental distress and engagement with services, although indicated that it had been for many years. He had been employed within the health service as a manager, before undertaking a paid service user engagement role (similar to the role fulfilled by Beth).

I did not know Mark prior to our interview, which took place in his office (October 2014). We did meet on two occasions shortly after the interview, with a few others, to discuss the idea of writing a book about mental health. However, this idea did not develop further and we have had no face to face contact since.

### **3.3.2.7 Mike**

Mike is a white British man in his early 50s and is husband to Beth. He has never formally accessed mental health services (despite having lived experience of mental health difficulties), describing himself as a 'service refuser'. He was however, carer for Beth throughout her experience of services; in the earlier days whilst also pursuing a professional career in

engineering. He eventually left engineering, becoming involved in the third sector and statutory mental health services as community involvement and peer worker. Like Beth, he had been part of the university external mental health reference group.

I had known Mike for approximately 3 years prior to the interview in a work capacity. He was interviewed at home. I have had intermittent contact with Mike since the interview in November 2014.

### **3.3.2.8 Jess**

Jess is the youngest narrator, as a white woman in her early 20s. She first developed significant issues around her mental health in her mid-late teens, being admitted as an inpatient to both child and adolescent and adult settings. With Beth, Elsa, Orla, Ruth and Geoff she became involved with a local Trust's formal service user group, but has also undertaken work with numerous organisations at a national level to inform policy and service delivery for young people experiencing mental distress.

I had known Jess for approximately 2 years prior to the interview, again in a work capacity as part of the external reference group. At the time of the interview in her home (February 2015) she was reducing her service user involvement work whilst increasing her paid employment in a physical healthcare setting. We have had occasional email contact since. Jess was unique among this group of participants, in that she was the only one to have experienced the transition from child & adolescent mental health services (CAMHS) adult mental health services.

### **3.3.2.9 Maggie**

Maggie is a white British woman in her 50s, who grew up and married into a strict Christian brother's community, developing significant mental health issues in her late 30s/early 40s. Her lived experience of services had been both as an inpatient (under the Mental Health Act) and in the community, but she was being discharged from care at the time of interview. Her service user involvement work has focused a great deal around sharing her experiences with student and qualified professionals in both the health service and higher education settings.

I did not know Maggie prior to our interview (September 2015), which was conducted at a friend's home (which she was house-sitting). Maggie was recruited via Beth (although her name had been mentioned too by Elsa) This did take some time to arrange; when making initial contact via email, I had referred to her by her full name ('Margaret'), as 'Maggie' felt disrespectful towards someone I had never met in person. Unfortunately, I did not receive a response for some months, after which Maggie got in contact. She explained that the delay in response was due to my use of her

full name, something which had been used by her parents and brought back unpleasant memories. She had been initially upset, but once she felt better had got in touch. In trying to be respectful, I had inadvertently caused distress, for which I apologised. This did cause me some apprehension prior to the interview, concerned that the story may be guarded and minimal. However, the opposite was true – like Elsa, Maggie has prepared to go into significant depth about her background, path into mental health crisis and recovery. As previously mentioned, we met soon after for tea and I have seen her at formal and informal service user related events since.

### **3.3.2.10 Geoff**

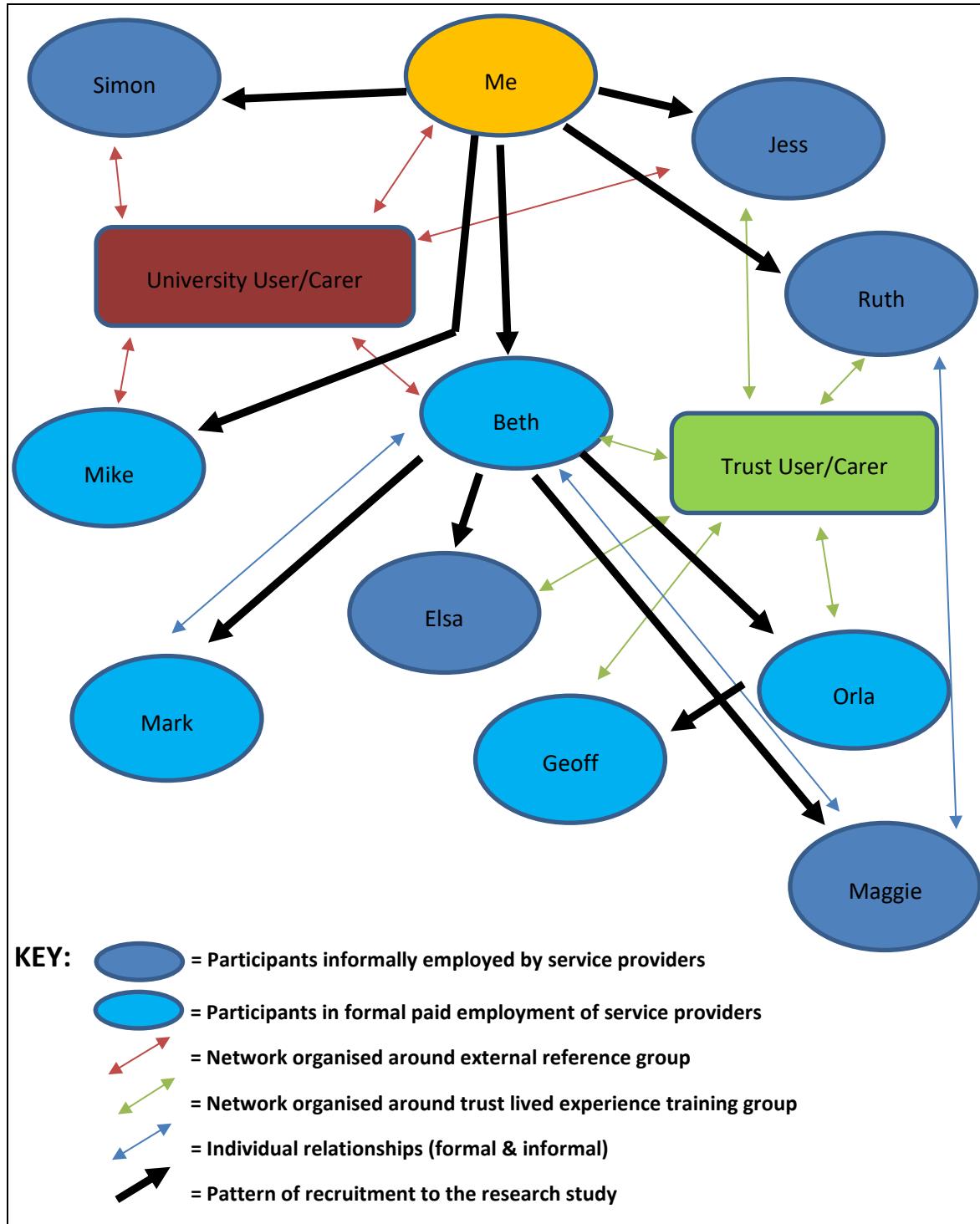
Geoff is a white British man in his late 50s. He reports having difficulties related to his mental health for much of his adult life, but accessed services for the first time in his mid-40s. He has engaged with both inpatient and community services for many years and was formally discharged a few months prior to the interview. He is employed in a substantive role as a peer educator/recovery course leader within a local mental health trust.

Geoff was a contact recommended by Orla and we had not met prior to the interview, which took place at his place of work in October 2015. We have not had face-to-face contact since the interview, but he remains working within his recovery role.

### **3.3.2.11 Making the Connections**

Figure 3 (Page 66) summarises the pre-existing networks that linked the participants, including me as the researcher. This reveals two key organisational bodies, a NHS trust user/carer training group and a university external reference group, either or both of which linked nine of us (8 participants and one researcher). Of the two who were not linked in this way, one was connected via their formal employment within the same trust and the other, whilst undertaking her service user activity within other service provider or educational organisations, had developed relationships with fellow experts by experience through wider forums. The larger arrows reveal the theoretical sampling strategy (3.3.1) in action; five approached directly by me, four via Beth and one via Orla.

Figure 3 : Network of Relationships Between Research Participants



### 3.3.2.12 Narrator Demographics

The universal descriptor 'white' and in the main 'British' when introducing the narrators is not lost here and requires addressing before the findings are discussed more fully. Another common

denominator, worthy of consideration is that fact that all narrators, with the exception of Jess, were educated to undergraduate degree level, several also having completed a master's degree. Some had embarked on professional careers; management, teaching, engineering, the Civil Service.

There are two potentially important factors in play here; the approach to recruiting narrators into this study and the way in which mental health services recruit those with lived experience into user participation work. As previously discussed in 3.3.1 (Page 68) the decision was taken to employ a theoretical sampling strategy (the 'snowballing process' – Warren, 2001), which perhaps unsurprisingly revealed a network of contacts, who are similar to each other in terms of age (with the exception of Jess), social class, ethnicity and educational attainment. Elsa, within her interview, appeared particularly aware of age and how she as a woman in her 50s could be identified with by young adults navigating a mental health crisis and engaging with mental health. The alignment of people in similar social groupings is well documented (Hosokawa et al, 2007), but it is important to highlight that the commonality with this group is their recruitment to user involvement work with a mental health service provider (none reported having first met their contacts through accessing a service at the same time). This does raise questions around potentially targeted recruitment by service providers of a certain type of person with lived experience of using mental health services.

### **3.3.3 The Broad Interview Process**

For the purpose of recording interviews, the British Library and UK Oral History Society ([www.ohs.org.uk](http://www.ohs.org.uk)) recommends the use of a good quality digital recorder, which enables the transfer of a clear recording directly onto a personal computer, as well as potential long-term storage within an appropriate online repository. In order to preserve the anonymity of the narrators, video recording did not take place. A positively reviewed, mid-range digital audio recorder (Zoom H4N) was purchased for this purpose.

As previously highlighted, the interviews took place in a location of each narrator's choice. Seven preferred their home address, two asked for the interview to be at their place of work and one came into the university, where the interview took place in a pre-booked room. The first interview with Beth took place in September 2014, with six others following across October and November of that year. Jess was interviewed in February of 2015, with Maggie and Geoff completing the process in September and October 2015. The *Interview Schedule (Participant) and Interview Schedule (Interviewer)* in Appendix E (Pages 227-232) did not undergo any iterative changes between the first and final interview to maintain a broad uniformity of approach. However, as the

interviews progressed, I began to make note of comments or conversation topics, which had not been anticipated by me when developing the interview schedules, but were important to explore with all (this is described further in 3.4.1). An area of note was capturing the participant's view of themselves as activists, which was brought to light throughout Beth's interview and became an important area of analysis and discussion (see 4.6.3 – Page 121).

The length of the interviews ranged from approximately 50 minutes (Jess – the youngest) to 160 minutes (Elsa – the eldest), which was possibly dependent on the story each wanted to tell and the age (how much 'story' there was to discuss). Although all narrators were sent the *Interview Schedule (Participant)* (Appendix E – Pages 227-232), neither party referred directly to them during the interview itself. Within Elsa, Jess' and Orla's interviews, the recording was paused and restarted several times; Elsa wished to take breaks to make us a drink, have a cigarette or just move to another room in the house, whilst Jess' interview was stopped to manage the excitable family dog! Orla paused the interview 5 minutes in to close some doors and reduce the ambient noise talk. At the end of the interview, I discovered that due to an error on my part, the first 5-minute segment did not record. I immediately confessed to my error to Orla, but we agreed that having ended her 'story' with the present day, it would have felt odd to have re-recorded the beginning. This was addressed by me adding a bullet-pointed summary of the first five minutes to the transcript for Orla to approve.

When there was an emerging sense that the narrator was coming to the end of what they wished to say, I asked if there was anything they felt was relevant to add. This gave the opportunity for them to say 'no' and effectively bring the interview to a close or focus their thoughts on the remaining key points.

### **3.3.4 Transcribing the Interviews, Consent to Release & Data Protection**

#### **3.3.4.1 Transcription**

Abrams (2010) remarks that oral history researchers are taught that one should be as faithful as possible when reproducing the narrator's account to reassure both the narrator and future reader of the authenticity of the data. This, of course, can be open interpretation; could one be considered unfaithful to the interview and participant if they omit vocal interruptions, such as 'er' or 'um', or lengthy pauses in the dialogue? Atkinson (1998) suggests it is dependent on the purposes of the research; omitting such anomalies can create a more flowing narrative and potentially save the sense of embarrassment a narrator may feel when reading it back, but if analysis of linguistics is an important element, they should remain. Both agree that some form of editing is inevitable at points in the transcription process.

For this project I took an early decision to transcribe the audio recordings myself, rather than pay for a transcription service. This in part was due to cost, but primarily because I wished to remain as close to the data as possible, which included the noting of vocal anomalies or pauses (relative length of which was indicated by the number of dots after the previously spoken word). These could later be examined as linguistic devices for their relevance to the overall storytelling process (for example, one of the narrators had a stutter, which became more pronounced when they were discussing difficult parts of their story). However, the final archived transcript at the end of the study would remove these devices, as well as anonymising people and services.

### **3.3.4.2 Interview Transcript Consent & Future Copyright**

For the reasons discussed above, two versions of the transcript were sent to the narrators (unedited and edited/anonymised), along with a copy of the original audio recording for them to keep. They were asked to listen to the recording and read the transcript to highlight any errors I had made, which could then be amended. If no such errors were found, a stamped addressed envelope was included for them to return a signed *Recording Release Consent Form* (Appendix E – Pages 227-232). Another important issue is that of copyright; as collaborators in the interviews, all the narrators and I legally own the copyright to the interview data. The *Recording Release Consent Form* requests the participants to assign sole copyright over to me. Forms were returned by most, but not all participants, which would prevent me from uploading some audio recordings to an online repository. However, the *Pre-Interview Consent Form* (Appendix E – Pages 227-232), which had to be signed before the interview could proceed, allows me to use extracts (anonymised) within the thesis and any subsequent publications.

Of those who did return the *Recording Release Consent Form*, none identified any errors or parts they wished to change. One participant (Elsa) asked for reassurance that the names included in the un-edited transcript would not be in the public domain. I responded via email to reiterate that only edited recordings and transcripts would be made available.

### **3.3.4.3 Data Protection - Storage of Recordings & Transcripts**

Whilst the project is running, all audio recordings and transcripts was stored on a protected drive within the university's IT system, which is backed up on a daily basis and accessible only by me. Once the project was completed, the edited version of the recording and transcript (to preserve anonymity of the narrators, other people and health care organisations) could be permanently stored within the university library's e-Prints system, making it available to internal and external parties with an interest in this area. All identifiable information would be permanently deleted or destroyed.

### 3.4 The Process of Data Analysis

As discussed earlier in this chapter, the life story approach considers both the content and form of the text (Table 2 – Page 49). However, it does not really detail a ‘how to’ of analysing the life story, aside from pointing to specific areas of exploration (plot, characters, genres & structures, tropes). Discussion of the plot, characters (4.3.1 – Page 79) and tropes (4.7 – Page 132) is integrated into the analysis within Chapter 4. When considering the thematic content (genres & structures), Braun & Clarke’s (2006) pragmatic discussion of thematic analysis provides a relevant and applicable approach to analysing interview transcripts. They challenge the reader to make a number of decisions in order to frame the type of TA most appropriate to their research question and group of participants. This decision-making process in relation to my research is summarised in Table 4 (Page 73), ensuring that my analysis remains faithful to the broad principle of adduction (Timmermans and Tavory, 2012) discussed in 1.5 (Page 16). Table 4 also provides brief comment on why other methods such as Conversation Analysis or Interpretive Phenomenological Analysis (IPA) (tied to or stemming from a particular theoretical or epistemological position), and Grounded Theory or Discourse Analysis (methods independent of theory/epistemology) were not chosen to frame my analysis. The steps taken within the process of my data analysis are described in the following sections.

#### 3.4.1 Step One - Listening to the Interview Recording and Initial Noting

The process of listening to the audio recordings and making initial notes actually took place prior to the full transcribing and within 48 hours of the interview. The purpose of this was to capture a summary of the interview encounter whilst it was still fresh in my mind, highlighting key words, phrases and story-telling devices (Appendix F - *Example of Initial Interview Noting & Reflexive Comments (Beth)* – Pages 233-246). These would later be drawn on to inform the formal analysis (see example in Appendix G – Pages 247-252). In addition to this, I completed a reflexive account within a day of each interview, to understand some of the dynamics I had sensed at the time, which may or may not have impacted on my questions and their narrative (example of reflexive comments after Beth’s interview can also be found in Appendix F – Pages 233-246).

These two activities were important to promote rigour within the formal analysis, as the transcribing process was very lengthy (approximately 8 hours per 1 hour of recording) and in some cases was not completed for some weeks or even a few months afterwards. This was particularly the case for the first 7 interviews, which took place over a relatively short period (9 weeks).

### 3.4.2 Step Two - Exploratory Comments on the Transcript

Once the transcription was completed, key phrases or quotations (narrative remarks) were highlighted and exploratory annotations were made, that could be drawn out to support the thematic analysis (see Appendix F – *Example Annotation of Interview Transcript (Beth)* – Pages 233-246). It was at this point that an analytical table was drawn up (see Appendix G – Pages 247-252), with the original transcript of the interview in the left-hand column and the narrative marks and exploratory comments in a central column (highlighted in **black** and **blue** respectively).

### 3.4.3 Step Three – Early Thematic Comments & Emerging Themes

Using the newly created analytical table (example in Appendix G – Pages 247-252) and drawing on the exploratory comments, emerging thematic comments and questions were included (highlighted in **red**), which were distilled further to form the emerging themes set out in the right-hand column (highlighted in **green**). It would be these emerging themes that would be taken forward for comparison with those emerging from the other interview transcripts.

### 3.4.4 Step Four - Analysis over the Participant Data Set

Whilst I did not have a written list from Beth's interview transcript analysing the next narrative, prominent emerging themes, such as abuse/rejection and the tragic turn would inevitably be in my consciousness. Rather than ignoring this, I felt it important to acknowledge any potential bias of analysis and consciously look for new themes that were not strong or even present in Beth's narrative. My decision to undertake Theoretical Thematic Analysis recognises my pre-existing theoretical and analytical interests (encapsulated within the research aims and questions set out in Chapter 1 – 1.7, Page 29). However, there is the caveat that I must be prepared to encounter new and unexpected themes to emerge from the data.

All the emerging themes were assigned a colour to represent the participant from whose interview they emerged (Beth = black, Mike = yellow and so on). Each single theme also included reference to the page of the transcript from which it was identified, in order to check back on the context from which it emerged. Initially Beth's emerging themes were printed, cut into individual pieces of paper and then reassembled into clusters of larger themes. Thematic headings were created, under which all emergent themes and corresponding thematic comments (middle column of Appendix G – Pages 247-252) were re-evaluated to check they were appropriately placed. Working sub-themes (ST) were then arranged with others. Although I was clearly cognisant of the potential themes identified, they did not form rigid headings under which I would place the emerging themes from the second transcript analysis. Having repeated the semi-

independent process of identifying clustered sub-themes for the second transcript, the two were then merged into one document, amending as appropriate to create a single set of sub-themes. This process was undertaken with every transcript analysis, each time amending current themes, introducing new ones or flagging up others that did not appear to be reflected in more than one or two of the narrator's experiences (but may re-emerge in the analysis of subsequent transcripts).

What materialised after all ten analyses were merged is represented in Appendix H (*Extract of Merged Thematic Analyses* – Pages 253-261). From Appendix H the reader will note two things; the overarching title of *Act 1: Life before Contact with Mental Health Services* and discrepancies with what would be finally established as Overarching Themes (OT), and Sub-Themes (ST), discussed in Chapter 4 and summarised in Figure 4 (Summary of Overarching and Sub-Themes - Page 133). Detailed discussion of 'acts' in the stories can be found in 4.3.1 (Page 89), but in the early stages of thematic analysis documented in this chapter, the acts had a more prominent structural role than they would eventually have. The explanation for this can be found in 4.3.1.4: *The Dilemma of Acts and Thematic Analysis* (Page 91). The discrepancies between Appendix H and Figure 4 (Page 133) represents a continuous process of revisiting sub-themes; merging them, splitting them and re-merging them again, even as I was writing up the analysis in Chapter 4 and creating Tables 10 (Page 92), 11 (Page 106) and 12 (Page 125). Prior to the analysis process a fellow doctoral colleague referred to arranging themes as being akin to 'weaving air'; I did not truly appreciate these words until I undertook it for myself.

### **3.5 Summary of Chapter 3**

This chapter as identified and justified my selection of the Life Story as my broad methodological approach, accounted for the university and NHS research ethics processes undertaken to seek study approval, detailed the approach to the recruitment of participants and process of collecting and analysing the data that would emerge from my interviews. Chapter 4 will now present the emerging findings from the data.

**Table 4: Framing of this study's approach to Thematic Analysis using Braun & Clarke (2006)**

Issues to Resolve	Options	Decision
<b>Braun &amp; Clarke identify two broad camps in qualitative analytical methods</b>	<ol style="list-style-type: none"> <li>1) Those tied to or stemming from a particular theoretical or epistemological position (e.g. Conversation Analysis or IPA)</li> <li>2) Methods independent of theory/epistemology &amp; can be applied across theoretical/epistemological approaches (e.g. Grounded Theory or Discourse Analysis)</li> </ol>	<b>Methods independent of theory/epistemology -</b> The aim of this research is to throw light on the psychological impacts of SU involvement in one's recovery experience, but also raise awareness of the identity or place this affords them within social discourses and realities (see discussion of the abductive approach in 1.5 – Page 15). Therefore, whilst my approach is not free of theory/epistemology (the authors suggest this is impossible in any case), it is independent of one specific theoretical/epistemological position.
<b>Braun &amp; Clarke break the epistemology of Thematic Analysis into three 'methods'</b>	<ol style="list-style-type: none"> <li>1) Essentialist/Realist = reports experiences, meanings and the reality of participants</li> <li>2) Constructionist = examines the ways in which events, realities, meanings, experiences, etc., are the effects of a range of discourses in society</li> <li>3) Contextualist = sits between the two above and characterised by theories, such as critical realism, which acknowledge the ways in which individuals make meaning of their experience and the ways in which the broader social context impinges on those meanings, whilst retaining a focus on the material &amp; other limits of 'reality'</li> </ol>	<b>Contextualist -</b> The TA in my work is more aligned with the Contextualist method (3), as it doesn't go as far as the interpretive position of IPA (there is a reality of policy and service evolution), but looks at how most of the participants view the world (and their identity within it), in light of this reality.
<b>Inductive versus Theoretical Thematic Analysis?</b>	<ol style="list-style-type: none"> <li>1) Inductive = Similar to GT, the themes identified are strongly linked to the data themselves, so may bear little relation to the specific questions asked in the interview and not be driven by the researcher's theoretical interest in the area or topic. Therefore, is a process of coding the data without trying to fit within a pre-existing coding frame/analytical preconceptions (they do acknowledge after this that data is not coded in an epistemological vacuum!).</li> <li>2) Theoretical = Driven by the researcher's theoretical or analytical interest in the area and tends to align with a more detailed analysis of an aspect of the data (answering a specific research Q, as discussed in the previous point)</li> <li>3)</li> </ol>	<b>Theoretical -</b> Although the authors pose these two options, they themselves acknowledge the difficult of fitting into one or another. As indicated above, there is a theoretical and analytical interest for me, summarised in project aims and research questions in Chapter 1. Therefore, my analysis would align with the theoretical (2), but with the caveat that I am prepared to encounter unexpected themes emerging from the data the abductive approach).
<b>Semantic or Latent Themes?</b>	<ol style="list-style-type: none"> <li>1) Semantic = specific level – researcher looks for explicit/surface meanings, not going beyond what has been said or written.</li> <li>2) Latent = interpretive level – a deeper level, where there is an attempt to theorise the significance of the patterns in semantic content and their broader meanings/implications (often in relation to the previous literature).</li> </ol>	<b>Latent -</b> The Life Story approach requires an examination of the way in which those stories are constructed and links them to the content of the interview, comes on the back of the literature review in Chapter 2. Therefore, my analysis will delve to the interpretative latent level (2).



## Chapter 4 Analysis and Emerging Findings

### 4.1 Introduction

This chapter provides a summary of the comprehensive analysis of the ten interviews (an extract of the detailed analysis Beth's interview can be found in Appendix G – Pages 247-252). Firstly, it explores the contextual influences on the interview itself. Following this, the broad structuring of the narratives, overarching themes and sub- themes are discussed.

### 4.2 The Story: Influences of Relationship, Gender & Setting

#### 4.2.1 Pre-existing Relationships

My discussion of relational ethics in 3.2.2 (Page 57) focuses on the relationship between researcher and participants during and after the interview encounter. The discussion presented here centres on the influence of relationships that may or may not have existed prior to the interview. As highlighted in Figure 3 (Page 66), I had directly recruited five of the ten participants through our work within the university where I was employed as a Senior Teaching Fellow in Mental Health and facilitator of the external reference group. This group had input into curriculum development and specific learning activities with pre-registration nursing students, based on their expertise by experience of accessing or representing services, rather than historical mental distress. Interestingly, this created a scenario where despite working together for up to 3 years, I was not aware of any of their mental health diagnoses or their experience of mental health treatment. This was advantageous in that I would come to the interview with minimal preconceptions regarding the content of their narratives, however it was impossible to ignore that they had known me in the capacity as both a mental health professional and academic. To that point all our interactions had been on my 'territory' (the university), which potentially could reinforce a sense of power imbalance before the interview had even started, as per the constant sum conceptualisation of power (see 1.5.3 – Page 18). As a member of university staff, I had invited them to meetings for which they would be remunerated by the institution I represented.

The relationship that troubled me most was the one with Beth, who was a key support in the recruitment of Orla, Elsa, Maggie and Mark to the study, but also was the expert by experience who reviewed my interview schedule before its use. I was conscious of how my relationship with Beth may influence both the content and flow of the interview and my subsequent data analysis, certainly as I had been privy to more contextual information when reading some auto

ethnographic 'vignettes' written as part of her own research study. The inclusion of this contextual information could be viewed as advantageous, enabling me to triangulate with the original interview data. However, this did not fit with discovering the narrative 'truth' (3.1.2 – Page 48; Spence, 1982; BenEzer, 2002) and my desire to explore why certain parts of the story' received greater focus or were addressed superficially. I made a choice not to include any information other than that provided within the interview, but would not be able to escape the implicit knowledge I held about her. However, to distinguish the interview encounter from other scenarios in which Beth and I had interacted, it took place at her home, the first time I had been there. This set me up as an external researcher being an invited guest into an environment that was hers only, and therefore promoting balance within the power relationship as much as possible. We have remained in regular face-to-face contact since as supportive peers undertaking research studies.

Given the issues highlighted here, it would be reasonable to assume that having no prior relationship with the participant would be preferable. Whilst recognising that the interview encounters were not quasi-therapy sessions, but formal research, the underpinnings of therapeutic alliance warrant further consideration. The importance of developing a therapeutic alliance is recognised as an influencer on outcomes in formal therapy (Horvath et al, 2011).

Bordin (1979), when exploring the concept of a therapeutic alliance, describes three connected dimensions; agreement between the two parties (in Bordin's work, the patient and therapist) regarding the goals of the interaction, the tasks required to achieve the agreed goals, and the emotional bond between the participants. With the provision of information prior to the interview and the obtaining of written consent, arguably for all ten participants the first two dimensions are present. However, the relational connection, albeit on an emotionally superficial level, was more likely to be present with Beth, Mike, Ruth, Simon and Jess, and definitely not with the others (recruited via a third party). Therefore, the lack of relationship with some, creates the possibility of polarised interview outcomes, either impeding the depth and richness of their narrative, or freeing participants from the any pre-existing power dynamics.

What emerged, in terms of depth of information and emotional content response, fitted with this polarised potential. Some people who I had never met before shared on a very intimate level, whilst others who I knew kept the narrative on a largely formal level. An additional factor in this study was my own mental health nurse training and experience, central to which is the ability to quickly form and maintain therapeutic relationships with service users. From my perspective, of the four interviews which provided the greatest depth of information, three were with people whom I had never met (Orla, Elsa and Maggie).

However, before one becomes wedded to the notion of my expertise as an interviewer being a crucial influencer on the depth and quality of information, the other influences of gender and interview setting require exploration.

#### 4.2.2      Gender & the Interview Environment

The gender divide among the participants was almost even, with six females and four males. What raised internal questions for me during the interviews and became more apparent when listening back, was the spectrum of emotional expression across the ten. With the exception of Mark, all disclosed traumatic life events as part of their narrative, which for some included their experience of mental health services. However, my observation was that the male narratives tended to be at the lower end of the spectrum of emotional expression, whilst the females were arguably at the mid to high end. As an example, with two participants, whom I had not met prior to the day of the interview, Geoff mentions early on in his narrative “one develops coping mechanisms in childhood that become really unhelpful in adulthood” (Page 1), then later states his first contact with mental health services came “after trying to take my own life” (Page 3). Contrast this with Elsa’s pointed comments regarding her mental distress; “...I always feel like I’m screaming with my mouth shut. I think when I’m telling people the truth, when I’m asking for help, they don’t see” (Page 25), and later; “I went to my GP and said what was happening and I said *I need to know, I want to be assessed because there’s something in me that’s causing this (...bullying at work...). I need to know how to respond to things healthily.*” (Elsa – Page 31). Arguably the events leading up to first contact with services for Geoff was more emotionally catastrophic than Elsa, but the expressiveness is reversed. Plant et al’s (2000) study which made the distinction between emotional experience and emotional expression, suggested that gender stereotypes were more aligned with the latter. It has been well documented that societal demands on males to maintain emotional control is higher than it is for females (Mahalik et al, 2003; Pollastri et al, 2018).

As a male researcher this may potentially also influence the responses of both male and female respondents, although the evidence base in the literature is scarce. Indeed, the only study I found focusing specifically on the importance of research interviewer gender was from 1993 (Williams & Heikes, 1993). Their qualitative study, observing interviews of male nurses by either a male or female researcher, found that the male respondents were more open to sharing their experiences with female researchers than males (although were likely to frame this within language that would be considered socially appropriate). These findings align with my experience with three of the four male participants in this study, with Mike being more openly expressive of emotion and less ‘matter of fact’ when recounting difficult experiences. The interview with Mark lacked any

discernible emotional expression, in no small part due to subject matter he was prepared to cover. As with the other participants, I had sent pre-interview information and at the beginning of the interview had articulated what by then was a reasonably standardised reminder. However, Mark referred to being a recipient of mental health services for approximately 25 years and gave no further information regarding his own lived experience. As a researcher this felt to me as if I was interviewing him for a news or journal piece, in which he talked in great depth about his role as a service user involvement co-ordinator and his philosophical views on mental health services. This provided a different depth and richness to the overall data, and certainly aligned with one of the significant themes that emerged later on, but did position Mark's account as the 'exception' in relation to earlier themes.

As discussed in Williams & Heikes (1993), there was a gap in the research literature pertaining to female respondents to researcher gender. Having undertaken a brief literature search, it appears that this gap remains. I am, therefore, required to draw tentative observations from my own research encounters with the female participants. Interestingly, it is here that the pre-existing relationships link back into the discussion. Although largely open about their lived experience and how this had affected them on an emotional level, emotional expression within the interview itself was not as prominent with those women whom I had worked alongside than it was with those I was meeting for the first time. On reflection, the previous relationship with some of the women was in a formal setting (the university), where we worked together from our own fields of expertise (mine by training, theirs being lived experience). Potentially this created an impetus to them be 'professional' during the course of the interview, but desiring to convey the emotional gravity of their story. With the women I had no prior relationship, arguably there was greater freedom to express emotion if I was able to create an environment that made them feel comfortable to do so.

This helpfully leads to discussion regarding the influence of interview setting on the data. The choice of interview setting was entirely dictated by the narrators, with an offer made by me to arrange a room at the university should they find this most comfortable. The choice of location also appeared to run along gender lines, with all the female narrators opting to be interviewed in their home environment. With the exception of Mike, who was interviewed at home a few weeks after Beth, the male narrators decided the interview would be taken away from home. Simon, who works as a residential support worker, was the only person to accept the offer of being interviewed at the university. Unfortunately, the interview space was a large skills room, which did not help to create an intimacy of environment that may foster the interviewer/interviewee relationship. Simon had visited the university on many occasions to attend the external reference group and did not appear unduly perturbed, however, there was a greater formality to the

exchange. Mark and Geoff, whom I had not met before, both decided to be interviewed in their places of work. For me, I felt very much like I was a guest in their professional environment, which set the tone of both interviews. As previously highlighted, Mark would not discuss any personal information; Geoff and Simon did speak of their lived experience, some of it traumatic in nature, but in a very 'matter of fact' tone.

In their home environment, all the women made us both a hot drink prior to the start of the interview (a few several times during too!). All interviews took place in their living room space, so whilst I was a guest in their environment, undertaking a formal research interview, the contrasting lack of formality was noted.

### 4.3 Constructing the Story

Within life stories, the 'story' refers to the raw content, referred to by Wengraf (2004) as "the lived life" (P232), which can be divided down by the researcher into discrete chronological phases, often divided by turning points (usually significant life events). This raw content awaits organisation by its narrator (referred to by Wengraf as "the told story" – P232).

#### 4.3.1 The Plot in 'Acts'

This analysis proposes that the narratives are constructed around three phases (or 'acts') of the narrators' lives. The use of the term 'act' in this study does not imply that the interview content is fictional, but a useful structural framework within which one can understand the lived experience. Although emergent themes often crossed the boundaries between acts, interestingly they followed the conventions plot-driven stories (Kenyon and Randall, 1967) and mirrored most basic of hero-centred narratives within fairy tales (Le Guernic, 2004). The 'hero' (participant/narrator) begins their story from a position of weakness (Act 1: 'Life before Services'), then for the middle part oscillates between positions of strength/dominance and weakness/being dominated by an antagonist (Act 2: 'Entering the Mental Health System'). As highlighted by Plummer (2001 - Table 3 – Page 57), the third character in any story would be the witness to the conflict between protagonist and antagonist. I quickly came to the realisation that by listening to the participants' narratives, asking questions at appropriate junctures, transcribing the interviews and undertaking this analysis, I became quite a powerful witness as the researcher. My influence on the interview has been initially explored in 4.2, but will be revisited in greater depth at the end of the chapter. The story concludes with the hero being placed in a position of strength (Act 3: 'New Directions').

#### **4.3.1.1      Act 1 – ‘Life before Services’**

Almost all participants referred to some form of early life difficulties that had a significant impact on their psychosocial development (although some stated that they had come to this realisation in their adulthood). The emergence of significant mental health crisis, experienced by self or a significant other (Mike is the spouse of Beth) for some was linked to a trigger ‘event’ (the birth of a child, bullying in the work place or a partner’s refusal to have another child). This was not to say that mental distress had been absent prior to this event (Beth reported almost debilitating low mood at the time of her ‘A’ level and undergraduate degree examinations), but afterwards a referral to mental health services had been made. Others reported a gradual decline in mental well-being since early life, punctuated by adverse experiences, but there not necessarily being a single trigger. It is important to note that reference to ‘early life’ does not necessarily refer to childhood in the context of this study. Indeed, all bar one of the participants’ mental health difficulties did not reach a level of crisis warranting a referral to services until well into adulthood (for three, not until approaching middle age). The exception was Jess, the one narrator to have accessed support from both child and adolescent mental health services (CAMHS) and adult mental health (AMH). At the time of interview, she was recalling the earliest experiences of mental distress, which had occurred within the previous 10 years.

Fitting with the hero-centred narrative, all narrators bar one (Mark) presented themselves as being subject to tragic events and the power and dominance of others, whether it be individual, family systems or institutions, putting them in positions of weakness. However, equally strong is the sense of survival through these difficult times, which by default or design engenders empathy in me as the listener to their narratives. Before getting into the detail of how their mental health crises came about and their experiences of care, I found myself rooting for them.

#### **4.3.1.2      Act 2 – ‘Entering the Mental Health System’**

For most, the second act incorporated a narrative account of their care within services and the path into service user involvement work, which initially could be seen as broadly linear. In reality the two were often intertwined, partially explained by the fact the recovery from a life defining episode of mental distress is in itself non-linear process. As highlighted in 1.3.5 (Page 6), the recovery model approach is underpinned by the understanding that one may plan for and live meaningfully with a level of distress and altered functioning. In tandem with this, as discussed at the start of this chapter, the middle section of a hero-centred narrative will oscillate between the hero being in positions of strength or dominance, and weakness or being dominated. A key example would be Orla’s narrative, where she describes a significant relapse in her mental health after having undertaken service user work for some years. She was detained under the Mental

Health Act (1983, revised in 2007) for treatment and her service user involvement work was temporarily halted.

#### **4.3.1.3      Act 3 – ‘New Directions’**

The final act of a story employing a hero-centred narrative, would see the protagonist emerge as stronger, wiser and hopefully victorious over previously dominant forces. I was aware that mental health services, whilst powerful and potentially counter-productive in some people’s recovery, are not a force of evil to be defeated. Their function is to care for people when they are at their most vulnerable in terms of mental health. Therefore, the analysis in this final part of the chapter focuses on the narrators’ ability to assert one’s own power when recovering and working in powerful institutions. An example of this would be Jess’ decision to refuse to tell her story for professional audiences and only engage in activity that would utilise the range of knowledge, skills and abilities she had to offer.

#### **4.3.1.4      The Dilemma of Acts and Thematic Analysis**

Having introduced the life story approach as key in this study and set out the overarching ‘acts’, the early drafts of this chapter saw me attempting to present the analysis of my findings within this structure, identifying similar and unique themes within each. It became clear that whilst useful in enabling me to tell a story, the exploration of transcending themes potentially became fragmented, leaving the reader unclear about the relative strength of individual themes.

The alternative is for the analysis to address themes in turn and identify those which cross the boundaries of the acts, which is broadly what I have done within the remainder of the chapter. The narrative analysis is divided under the thematic headings and sub-headings. The approach selected is not a perfect, as a number of themes merge into one another and new false boundaries are possibly created. However, I have mitigated as far as possible the impact of false thematic boundaries by acknowledging their presence at appropriate points in the discussion.

### **4.4 Overarching Theme 1: Survival**

As highlighted in 1.2 (Page 2), the notion of being a ‘survivor’ of mental health crisis and care is very much the perspective of service user commentators (Campbell & Rose, 2010; Chassot & Mendes, 2015). There has also been a proliferation of personal survivor narratives published over recent decades (Wield, 2006 and Bedillion, 2011 are two contemporary examples); to my knowledge, at least two people I have worked with in my professional career have put their stories to print. It is perhaps unsurprising therefore, that ‘survival’ was an overarching theme within the narratives of my participants. The sub-themes identified were ‘the tragic turn’, ‘the

pragmatics of surviving', 'the avoidance of shame and appearing weak', 'playing the game to survive' and 'rescued by others, rescuing others and rescuing self to survive'. Table 5 below highlights in which of the narrative accounts the sub-themes were identified (shaded in green), which will be explored in greater depth within the remainder of this section.

**Table 5: Theme and Sub-Themes of 'Survival'**

Overarching Theme	Subthemes	Beth	Mike	Simon	Orla	Ruth	Mark	Elsa	Maggie	Jess	Geoff
SURVIVAL	4.4.1: The Tragic Turn										
	4.4.2: The Pragmatics of Surviving										
	4.4.3: Resistance to Shame and Appearing Weak										
	4.4.4: Rescued by Others, Rescuing Others and Rescuing Self to Survive										

#### 4.4.1 The Tragic Turn

As with many hero-centred stories, the opening act (1) often involves some form of tragic event or series of events to engender the sympathy of the reader or audience (Le Guernic, 2004). This was reflected in a number of the narratives. Elsa's narrative in particular, contained an obvious sense of pathos, with detailed description of a series of tragic events, from her experience of childhood abuse and adult subjugation, to abandonment by her husband, subsequent collapse of the family unit and finally her experience of bullying at work. Each event recalled contained greater emotionality of expression than the last, with a poignant moment that would prompt her referral to mental health services;

When the bullying started I went to my GP and I said what was happening  
and I said "*I need to know, um, I want to be assessed because there's  
something in me that's causing this. I need to know how to respond to things*

*healthily. I don't think I responded healthily because, you know, I'm always bullied".*

(Elsa- Page 31)

Other accounts, where experience of hardship as children and adults was described, emphasis was placed on a single tragic occurrence or a short period of time where life took a different direction. For Beth, post-natal depression after the birth of her only child (generally perceived as a happy event), was followed quickly by the loss of a highly promising career in education and the death of a sibling. Mike, as Beth's spouse, experienced the 'loss' of his wife (the first of many occasions over the years) whilst managing his own mental health and keeping the family unit together. Orla's tragedy was her spouse's refusal to have another child;

"I lived my life according to his rules. And the one thing that I desperately, desperately wanted, because it was the one thing that made me feel fulfilled were the children."

(Orla – Page 1-2).

Beth and Orla were not the only narrators whose tragic turn of events involved anguish of having children. Ruth recalled how after having her eldest child she experienced unsuccessful rounds of IVF treatment and the subsequent trauma of a surrogate mother terminating her pregnancy with twins (they later had twins through another surrogate). It was the miscarriage of a fourth child and hysterectomy that impacted on her mental health to a point where she was referred to adult mental health services for the first time;

"...I was too hysterical on the ward. They decided that they weren't going to discharge me from hospital, because I was just too hysterical and got into, went into complete pieces. So, um, they wanted to refer me [to community mental health services] before they discharged me from hospital."

(Ruth – Page 13)

Maggie experienced post-natal depression after the birth of her son and his significant health difficulties with childhood asthma, but felt she could not tell anyone;

"Because Christians have joy and peace. That made, that meant there was something wrong with me. And, so there was a lot of shame; I couldn't tell people... when you give birth to a baby, you've got this perfect baby, you can't imagine anything wrong with them. So, when it was verbalised, I, I had trouble dealing with that... I didn't want people to know I was depressed; I felt ashamed. And I asked my husband not to tell people."

Geoff experienced the break-up of his marriage and threw himself into his work as a company general manager, until he experienced a mental health crisis. Jess equally threw herself into work at school and college, only for it to be arrested by inpatient admissions to both adolescent and adult mental health units. Simon's low mood began to significantly impact his life after he was seriously physically assaulted and then later lost his job for sickness absence. All three expressed their distress in the form of self-harm and attempts at suicide, prior to and during their engagement with mental health services.

The one interview that did not include a tragic turn of events, was Mark's, where his personal story was limited to "I've been a recipient of mental health services for around about 25 years" (Mark – Page 1). Being cautious about inferring phenomena that is not present, but knowing that significant mental health issues are invariably traumatic, Mark's lack of verbalisation does not preclude the tragic turn from his experience.

This sub-theme of survival was prominent in the first act. The interviews took place over a period of approximately a year and when I listened to the tragic turns in individual people's lives, it was sad and at times shocking (Ruth's accounts of losing multiple children in pregnancy perhaps impacted me the greatest), but ultimately part of one's life course. Only after the interviews when transcribing, analysing and drawing together the stories, did the full scale of tragic experience become apparent. Of the nine narrators who shared their personal details within their account, two have experienced sexual abuse, three physical abuse or assault, six emotional abuse or neglect, three post-natal depression, four the breakdown of their marriage relationship, four the loss of a professional career and one the tragedy of multiple miscarriages. Some of these experiences preceded the onset of mental health crises, whilst others were the result of them. Only three of the ten narrators did not mention an act of self-harm that potentially would have ended their life (Mike, Elsa and Mark). The impact of these experiences is discussed in greater depth throughout this chapter.

How survival was achieved and recounted did differ between participants, but could be divided into three broad approaches; being pragmatic – one *must* survive, the resistance of shame or appearing weak and being saved by more able others (or doing the saving). Most adopted multiple approaches.

#### 4.4.2 The Pragmatics of Surviving

The pragmatics of survival, a ‘head-down and play the game’ approach to challenging life experiences through Acts 1 and 2, was a commonality for all the narrators, whether this be in the way they raised them in the interview or the approach they adopted in the situation described.

As indicated in 4.2.2 (Page 87), gender potentially influenced the pragmatic tone of the interview narratives. Mark, who revealed virtually nothing about his personal story, was unsurprisingly very business-like, as was Mike when describing visiting Beth in a mental health unit, Geoff when recalling a suicide attempt and Simon when giving an account of being seriously physically assaulted. However, some female narrators would adopt a similar air. Ruth is a prime example;

“...I secretly wanted to be pregnant with a little girl and I had a little girl. Um, but she died and because of the scarring in my uterus I couldn’t actually miscarry. I went into labour and was in labour for a week and couldn’t manage to, couldn’t manage to pass the baby. And in the end my womb actually perforated, and I ended up having an emergency hysterectomy, and was very ill in intensive care afterwards to miscarry the baby.”

(Ruth – Page 13)

In contrast to the heightened emotionality of Beth, Elsa, Orla and Maggie’s accounts, Ruth’s even tone of speech, suggested a detachment from the trauma of this event. Jess was similar when describing encounters with self-harm and attempts at ending her life. Of course, this could have been to elicit an emotional reaction from me as the interviewer, to fill the emotional vacuum created at that moment of the interview. However, I am also conscious that both Ruth and Jess were known to me as expert by experience colleagues prior to the research and had given their account to professional audiences on many occasions, so ‘professional’ demeanour was preferred. A third possible explanation was the self-protective function of avoiding having to relive the trauma for the benefit of others’ curiosity; pragmatism.

The pragmatics of surviving within the narrative content permeated almost every interview. Orla described a strategy of internalising the resentment she held towards her husband and increasing her use of alcohol to “numb the pain” (Orla – Page 2). In a household where she was frequently bullied and abused by parents and siblings, Elsa would try to make herself as inconspicuous as possible (“I was such a mouse” – Elsa- Page 9 & Page 11).

For both Beth and Mike, their approach appeared to be to dissociate from the difficulties around them and focus on achieving (through education or professional training). Beth recalled completing both her Baccalaureate and Open University degree examinations in the midst of

periods of significant mental distress. After completing her final degree exam at home, Beth stated “(I) put the pen down in my exam and then I went to bed for 5 months.” (Beth – Page 10). When asked how he managed during Beth’s crisis periods, Mike’s moving response was;

“I think for me this was this, this sense of it will get better, you know. It’s just a case of we’ve got to get through this. It might take a long time, but it will get better.”

(Mike – Page 6)

Mike changed career pathways several times over the years, including undertaking teacher training and commencing a PhD (which he later stepped-off). However, Mike would struggle to feel comfortable in a role and moving onto something new seemingly re-energised a sense of purpose (eventually he would become formally involved in mental health carer support).

As previously highlighted, Ruth’s experience of being pregnant and having children had significant consequences for her mental and physical health, temporarily halting her blossoming career as a nurse and educator. However, she returned to nursing at a later point “to do enough hours to keep up my PIN number” (Ruth - Page 8). This modest response actually covered a number of different nursing and research roles that she undertook on a part-time basis, whilst raising her first son. Maintaining her identity as a nurse and mother was significant in maintaining a level of mental well-being through some distressing life experiences.

Ruth was not the only narrator who utilised their professional identity as a tool of survival. As previously discussed, Geoff became a “workaholic” (Page 2) in his management role and Simon would move around the country to find work. Although younger, Jess focused on perfecting her schoolwork as a way of surviving during adolescence. Importantly, it is here that light may be shed on Mark’s narrative;

“I’ve worked inside [mental health] services for about 17 years. Um, some of that time as a member of staff providing frontline services and as a manager later on. Um, and my current role, I’m part of the local area management team.”

(Mark – Page 1-2)

As an interviewer, I believed that Mark was setting out his credentials as a mental health professional, more so than a person with a history mental health crisis. This tone for the remainder of the interview and coupled with the reticence to reveal any personal information, perhaps indicated a pragmatic approach to survival always taken or more likely, his desire to play the role of fellow professional, exchanging views on service user involvement mental health services. The discursive approach employed by Mark very much links with Armes’ (2009)

‘professionalism’ tactic (becoming a service user professional within an organisation to instigate change – see 1.5.3 – Page 20).

In all positions within the mental health system (user, carer or expert by experience), Mark, Beth and Orla all commented that continuous direct challenges to those in power was fruitless.

Instead, one had to use the political astuteness of a professional in choosing the battles to engage in. Beth felt that her role as a service-user coordinator was to convey the importance of ‘playing the game’ to other service users in order to achieve tangible improvements to services;

“I think, what was really clear about the work I did with people was... it wasn’t just all about moaning, cause if you just moan, nobody listens. And so, it was okay, we’d have a little moan, a little moan then it was like this is the, this is the task, task orientated, work orientated.”

(Beth - Page 33)

Similarly, Orla quickly realised within her Peer Support Worker role, she would need to shift her approach for it to work;

“...of course, when you start there, first you can’t go blazing in and; you have to work as part, that’s the conflict; you have to be part of the team, but at the same time you have to be different and not to fall into their way of thinking.”

(Orla – Page 45)

Although reluctant to share his own story, Mark recognised the power of service users sharing theirs in order to impact on the thinking and behaviour of professionals;

“I think when people tell their stories that people’s defences are down, as it were, that people take in the information in a different way, so, perhaps messages that wouldn’t have got in, you know, got through the filter, as it were, they do.”

(Mark – Page 19)

It is no coincidence that all three here were formally paid employees of a mental health organisation. Inevitably there would be an expectation to align with the institutional values and practices, but also the potential for them to use the organisation’s need to be seen as listening to the service user voice to push forward their agenda for change. As discussed further later in this chapter, it is Beth’s exasperation at “toeing the party line” (Beth – Page 34), which prompted her eventual exit (a switch from ‘professionalism’ to ‘pride’ – rejecting the dominant hierarchies and functioning outside the system).

These three formal employees, however, were not alone in recognising the pressure to behave in a certain way to survive in the system as an expert by experience. Elsa provides a poignant example;

“And after I’d done the training and signed the contract and everything, they (*the organisation*) changed it and said I wouldn’t be paid and they kept changing it you see... Every time I raised it they said *‘look what we’ve done for you; you wouldn’t be doing any of this.’* It was that veiled threat that if you rock the boat, you know, you won’t be working for us anymore.”

(Elsa – Page 42-43)

It could not be clearer that one had to ‘play the game’ in order to be called back to engage in future involvement work. Like, Beth, Elsa would take the decision to walk away eventually. Although not as a result of conflict with the institution, Jess’ decision to move on from her involvement work was influenced by having “got a bit sick of telling my story” (Jess- Page 26). Essentially, she chose to opt out of playing the game of being a professional service user.

This awareness of needing to ‘play the game’, was arguably learned from people’s time as a user of services, where professionals held the power to restrict one’s freedom on the grounds of their mental health, or conversely reject them completely if they failed to comply. During one inpatient admission, Beth threatened to self-discharge;

“I said ‘no, I’m just going to go home’ and they were about to section me. And this healthcare support worker whispered in my ear *‘if you, if they section you, you won’t get into the States’*. And I must have mentioned somewhere that I liked travelling. She had this sort of quiet word in my ear and so I wasn’t sect[ioned], you know, I played ball.”

(Beth – Page 16)

Maggie asked for a change of therapist, as she felt that they were not working well together, and was subsequently called to a meeting with a different therapist;

“I was like *‘shit! This is God-woman as far as DBT’s concerned. She’s written the book, she’s done this, that and the other, all the training. Whatever she says now, that’s it; end of. There’s not going to be a chance to disagree. There’s not going to be chance to discuss. Whatever she says, that’s going to be the outcome.’* And basically, she told me I wasn’t suitable for DBT and they washed their hands of me.”

(Maggie – Page 30)

The poignancy of Maggie's recollection is the idea that if one asserts power by refusing to play the game (receive therapy in her case), the organisation can hit back by withdrawing its care. One is then alone in their experience of survival and recovery.

#### 4.4.3 Resistance to Shame and Appearing Weak

As discussed later in this chapter, the burden of subjugation and shame is pervasive across many of the narratives in both Acts 1 and 2. There is noticeable overlap between the resistance to this subjugation and shame with the pragmatics of surviving, as there is with accepting the burden of responsibility (see 4.5.1).

Beth's move away from the toxicity of the family home at 16 to an international school was referred to as "a life saver" (Beth – Page 2) where she "flourished" (Page 5). Beth would later go on to complete a Bachelor's and Master's degree (and more recently a PhD), which set her further apart from her parents and siblings, with their more modest educational achievements. Elsa's acts of resistance were a little subtler; she described in some depth an occasion when she was a young child and travelling in a car with her mother and mother's friend;

"I talked non-stop and I knew it was irritating her and she couldn't hit me because somebody was there. But it was like my only opportunity to get back (*at her*)"

(Elsa – Page 4)

Despite the image of a mouse previously presented, Elsa revealed a side to her that, on occasion, would not accept the cruelty of others towards her (later in the interview she would describe herself as being "like the *Duracell* battery, I'd just keep on keeping on" – Page 33). However, the predominant approach throughout her early life was to keep the shameful things a secret from the outside world, usually at the behest of her parents. A vivid example is presented from when Elsa was 8 years old;

"I suppose I must have been about eight and my father was, er, shooting the dog, (be)cause it was worrying, he used to keep lambs and he shot, but he shot me. But they never took me to the doctor and I was told not to tell anyone about it."

(Elsa – Page 11)

Elsa later spoke of being hit with a belt by her mother for crying after the incident, because revealing pain (showing weakness) was not tolerated. Only during an x-ray of her hand in 2012 was a small bullet detected in her wrist by a health professional.

For Maggie, as part of a strict Christian Brethren church, she had been taught that there was something significantly wrong with someone who experienced mental distress and sinful to access professional support for emotional issues, “because Christians have joy and peace” (Maggie – Page 6). Maggie went on to use the word ‘shame’ to explain why others in the brethren community must not know that she had thoughts of ending her life, despite her experiencing what was later diagnosed as post-natal depression. She was able to avoid the perceived shame for some time by opening up to her GP about her low mood, which was met with a supportive and empathetic response (the GP would eventually refer her to adult mental health services).

Ruth’s avoidance of shame or appearing weak presents itself at several points in the early part of her interview and is alluded to when she discussed not being allowed to show emotions in public, through fear of “showing them (*parents*) up” (also see 4.5.1.3 – Page114; The Need to Please/Accepting the Burden of Responsibility). She goes on to remark that she had to be quiet in order to avoid drawing attention to herself, “which was quite hard” (Ruth – Page 2). It is well documented in the literature that a coercive parenting style and the pressure to achieve (imposed by self or others) can be precipitators of an eating disorder (Lask & Bryant-Waugh, 2013), therefore it is unsurprising that Ruth went on to develop difficulties in this area. However, the avoidance of shame, did not cease, even when she was admitted for treatment in a general hospital;

“I did manage to get my ‘A’ levels on my own, (be)cause I was out of school, so I managed to

carry on studying and actually carried on and did those. ‘(Be)Cause I was determined not to fall behind, so I did everything at the usual time, if that makes sense?’”

(Ruth – Page 3)

The motivation not to fall behind her peers is perhaps another indicator of her fear of disappointing those around her, particularly parents, to the point where academic study carried equal or even greater value than her physical and mental health. Similarly, Mike’s sense of responsibility as the child in the family without complex needs is very clear;

“You know, unseen, unheard, you know. Do well at school so that I wasn’t, you know, the, the, cause the focus was on him a lot of the time.”

(Mike – Page 2)

Jess recognised that achievement of high academic standards did not come naturally, so in response she “started working really, really hard, um, kind of to the detriment of my health really.” (Jess – Page 2). Here again is an example of avoiding the shame of perceived underachievement, but there being a sacrifice in the form of deteriorating health. For Geoff the

situation was reversed, where he felt pressured to follow his father's footsteps in going to work at a shipyard, a position that would require a great deal of physical effort and demonstrate strength in a very masculine way. What he actually wished to do was attend university, which he eventually succeeded in doing as a man in his 40s.

As previously discussed, Mark's setting out of his credentials as a mental health professional and reluctance to speak about his own lived experience could have been pragmatic survival, but equally may have been borne of the desire to appear robust with me as both a mental health professional and researcher.

Although not an outright exception in the area of resistance to shame and appearing weak, Simon's early narrative presents in a different tone. He speaks candidly about being the victim of domestic abuse (Simon – Page 6) and violent assault in the community (Page 10-11), struggling with a long-term physical health condition (Page 8) and the impact of all these on his mental health (Pages 12 and 14); all of which had been experienced by other narrators in different ways. What differs with Simon is there is not a strong sense of pride at having achieved despite his hardships (he completed a 4-year degree in Forestry and applied it within several employment positions). However, I am conscious that in contrast with the other participants (with the exception of Mark), Simon naturally did have a very even tone to his voice, as well as the pronounced stutter.

The narrators' experience of significant mental distress or crisis would help shape the attitudes, behaviours and exercise of power by professionals, both within their experience of care and when they undertook involvement work and is discussed throughout this chapter. Their resistance to institutional power and dominance, to either avoid subjugation or shame or reassert one's own power, is specifically explored in 4.6.3. However, at this point it is useful to mention two who took a different approach in their narrative to the others; Mark and Mike. Their distinctiveness makes some sense, as these two narrators both referred to themselves as a 'service refuser'. The term 'service refuser' and 'service refusal' does appear in the literature, but only when authors are describing the behaviour of mental health service users. Nowhere was I able to find literature in which people used the term to describe themselves. Mark deflected from discussing his own experience of mental health crisis and both he and Mike offered a more socio-political narrative regarding the way in which services can impact on mental health recovery, rather than their personal insights. By refusing the mantle of 'service user', they have resisted any potential subjugation and shame that can come with it.

#### 4.4.4 Rescued by Others, Rescuing Others and Rescuing Self to Survive

Being rescued by others, as a facet of survival within the first act, was perhaps the most explicit within Beth and Mike's narratives, as a married couple. Across their relationship of almost 40 years, Beth referred on a number of occasions to Mike being her rescuer in times of great mental distress and intervention by mental health services ("Mike was always my advocate" – Beth, Page 15). Both husband and wife separately recalled an incident where Mike is seen to 'save' Beth's life, by preventing her from leaving the house;

"...it sort of culminated in me one day deciding I wasn't going into school [where she worked], I was going to... er kill myself. And for some reason Mike didn't let me go that day. He barred, he actually stood in front of the door and barred the door and said '*you're not going, you're not going to work today.*'"

(Beth – Page 7)

"...there was a particular time and actually it was probably actually this week, erm, 18 years ago, that I stopped her getting, going out of the house. I didn't know why, I know that if I'd let her go, she would have killed herself, and it would have been successful, I'm sure."

(Mike – Page 5)

Mike's ability to recall the week this incident happened 18 years before (a coincidence in the timing of our interview) gives an indication of the profound impact it had on him and his relationship with Beth. Mike was modest in his perspective on the role of advocate/rescuer, highlighting "the marriage vows are sickness and in health..." (Mike – Page 7).

For several others being rescued by others became more relevant in later acts of their story and usually came from either mental health professionals or fellow experts by experience (Maggie, Elsa, Orla and Geoff). The relevance for Geoff is particularly important, as rescue had clearly come through his acceptance into the professional fold at the Recovery College, providing him with a new sense of belonging and momentum in his life;

"Morale in this team is extremely high and we are very resilient.... yes, there is a sense of we swim together or we drown together"

(Geoff - Page 20)

The need to belong is explored in depth later in this chapter, but at this point it is important to note its role in survival for some.

Although not immediately obvious, transitioning into the role of rescuer would also have a part to play in people's survival narratives. Orla very much portrayed her Peer Support Worker role as being one that rescues both professionals and people in mental distress;

"I feel I'm there giving all these professionals hope." (Orla – Page 13)

"because I had come along and said, what I usually do to get them [people admitted to the ward] to talk me, is to say *'I've been in a place like this. I spent fourteen weeks in [a local acute mental health ward]. I know how you feel being locked up in a place like this'*, and that immediately, when they find out you can empathise with them, they open up."

(Orla – Page 17)

Similarly, Beth and Mark in their involvement coordination roles would offer people with experience of mental health crisis an opportunity to find purpose. Although they did not really see themselves as rescuers, but more as facilitators;

"...some of the, the service users I worked with in (*the mental health trust*), they, they do lots of other involvement, in all sorts of different ways now.

(Beth – Page 32)

"I endeavour to find spaces or create spaces for people who use services to have their voice heard." (Mark – Page 2)

Equally Ruth and Jess portrayed themselves as facilitators, but were more open about the personal benefits it brought;

"It was the confidence, self-esteem, the feeling useful; the feeling that I might potentially be helping other people as a result of my suffering. And that it gave, it gave a meaning to what I'd actually gone through and what I'd actually suffered and experienced."

(Ruth – Page 22-23)

"...I think that [involvement work] contributed to my wellness actually. Um, you know, also talking to people who had been through a similar thing, and also just feeling you could use your, for want of a better word, negative

experiences to benefit others, benefit services, um... and I guess find a sense of purpose or meaning in, in what you've been through."

(Jess- Page 17)

The impact of Ruth's involvement work was independently verified by Maggie, who named her as the encouraging voice to ask the mental health team for a different therapist (to my knowledge, Maggie was not aware that Ruth was another participant in the research).

A further dimension of rescuing others was the act of self-sacrifice for those close to them. In consistently modest fashion, as highlighted earlier in this section, Mike saw his meeting of Beth's significant support needs as part of the marriage commitment, rather than rescuing; the reluctant hero. In a similar way, Elsa came to the aid of her own son who was in crisis with drug addiction and daughter who experienced her own mental health difficulties, making unaffordable financial sacrifices to secure professional help ("I just didn't get any help anywhere. It was bizarre. Unless I paid for it." - Page 34-35). Maggie, despite being in the midst of her own mental vulnerability was able to come to the aid of her youngest son (Zac) in London, who himself was experiencing a mental health crisis;

"So, I went and stayed with him for that weekend. And on the Sunday, I had to take him to King's College Hospital, um... and he was admitted into the Maudsley. And from that time onwards, um, I was at the time to keep me safe, picking up my medication once a week... So, I would travel up to London, spend time up there... visit Zac at the Maudsley."

(Maggie – Page 23)

Once Zac's crisis had abated, the impact of her sacrifice was quickly felt;

"Zac got well and I plummeted. It was like '*who am I, now my sons are grown up and don't need me anymore*'. And probably overdosed again, which sounds glib, and every time that was gonna be it."

(Maggie – Page 23)

Whilst the act of rescuing others would take its toll for Maggie and others once the crisis had died down, the distraction it provided at its height served a self-rescuing function.

The act of self-rescue in order to survive has significant overlap with the pragmatics of survival. Elsa would seek care where it was available, but the tone of her narrative suggested that true survival came in the form of achieving the small things for herself (such as maintaining personal

hygiene, changing and washing clothes or cleaning the house). This has possibly arisen from her experience of bullying and rejection throughout her young and adult life across a number of settings; trusting others carries a risk. There are some similarities with Simon's narrative, where not once in the interview did he refer to another person acting as his rescuer; all positive steps within his early life and recovery were seemingly instigated by him. This did create a sense of isolation in Simon's story, more so than any other narrator.

#### **4.4.5 Summary of the Survival Overarching Theme**

As indicated in Table 5 (Page 82) and throughout this thematic discussion, survival is what draws this group of people together. By the end of their narratives (Act 3), the sense of self-actualisation differed between narrators (sadly some have subsequently experienced further mental health crises). However, the fact that almost all were able to share their personal narrative with me at that point in time was testament to their motivation to survive. Potentially key to this pragmatic approach is the ability to resist shame and present as stronger than they actually are in the face of dominant forces. Equally, being able to rescue self and others, or have access to those who could act as rescuer is a core part of the survival narrative.

### **4.5 Overarching Theme 2: Institutional Power and Dominance**

As discussed in 1.5.3 (Page 18), the psychological model of empowerment at an individual (micro) level can be achieved through personal growth in relationships and an increased level of self-confidence (Rogers, 1961; Masterson & Owen, 2006), and is very much generated from within (non-constant sum conceptualisation). It therefore follows that if one is not exposed to positive, nurturing relationships (through early abuse or trauma), or freedom from the impact of significant mental health issues, then the level of self-confidence and sense of empowerment when interacting with powerful institutions will be limited. The term 'institution' here is considered in the broadest of senses, to encompass not only formally organised institutions, such as educational and work settings or health services, but also social ones, such as culture, community, family and relationships. Institutional power and dominance here can be distilled down to six sub-themes of 'abuse, rejection and shame in early life', 'early identity and the challenge of fitting in', 'the need to please/accepting the burden of responsibility', 'the pros and cons of being a mental patient', 'the allure of professional patronage', and finally 'fragility of status and identity as an expert by experience'. All sub-themes are once more linked to the relevant narrators in Table 6 (Page 96). There is obvious overlap in the language used to describe some of the sub-themes, the rationale for distinction between them is discussed in the following sections.

**Table 6: Theme & Sub-Themes of 'Institutional Power and Dominance'**

Overarching Theme	Subthemes	Beth	Mike	Simon	Orla	Ruth	Mark	Elsa	Maggie	Jess	Geoff
INSTITUTIONAL POWER AND DOMINANCE	4.5.1: Abuse, Rejection and Shame in Early Life										
	4.5.2: Early Identity and the Challenge of Fitting In										
	4.5.3: The Need to Please/ Accepting the Burden of Responsibility										
	4.5.4: The Pros and Cons of Being a 'Mental Patient'										
	4.5.5: The Allure of Professional Patronage										
	4.5.6: Fragility of Status and Identity as an Expert by Experience										

#### **4.5.1 Abuse, Rejection and Shame in Early Life**

The influence of early experiences of abuse and neglect on the presence of shame and mental well-being is well documented in the research literature (e.g. Ellenbogen et al, 2018), with higher levels experienced if multiple types of violence were reported (Aakvaag et al, 2016). Emotional abuse, domination, rejection and abandonment by either family figures or institutions appeared to be a common experience for six of the ten narrators in their 'Act 1', with some reporting accompanying physical and/or sexual abuse (Elsa, Beth, Orla, Maggie, Simon and Geoff). Most revealed this only briefly and in a 'very matter of fact' way ("my Dad was angry...very short-tempered and... sometimes quite abusive" – Simon – Page 7; "lots of violence...lots of psychological abuse, which I thought was very normal until I left" – Beth – Page 1). Almost exclusively these remarks would come very early in the interview, due in part to my opening

question being to ask for information on their background. However, other factors may also have contributed to this phenomenon, not least the possibility that they have processed traumatic events through the course of therapy and also told their story' to professional and peer audiences on multiple occasions. Several were able to make clear links between their earlier experiences and later mental health difficulties ("one develops coping mechanisms in childhood that become really unhelpful in adulthood" – Geoff – Page 1). Maggie reported having not realised she had been abused as a child until it was pointed out by her GP in adulthood; "I remember him saying "*Maggie, this is abuse.*" I totally freaked out with those words..." (Maggie – Page 6).

An additional consideration with this group of people when looking at the way in which abuse experiences are presented is the fact that they had told their 'story' to numerous professional and peer audiences, as both a service user and expert by experience. As a person in recovery from mental health crisis and needing to be seen as such by others, any in-depth reference to abuse could serve either to undermine their credibility or just be too threatening to their mental well-being to revisit on a continual basis. Orla referred to both physical abuse within the family and sexual abuse from outside within the opening minute of the interview, almost as if it was something she needed to get past in order to continue with her account properly (as suggested above).

The exception to this cursory presentation of abuse experiences, came through Elsa's narrative, where she explained in some depth how she grew up in a harsh physical and social environment (1950s-1970s Australia) and felt rejected and humiliated by parents, siblings, wider family and the church (nuns overseeing her secondary education). Poignantly, Elsa remarked that her mother never referred to her by her given name, instead being called 'that lass' by her mother and on occasions where mum showed overt affection in front of outsiders, she recalled being frozen with shock. She reported being bullied within the family, by the nuns at school and other children and made this powerful remark early in the interview;

"...cause one of the things I've had is a lot of bullying, um, from a very early stage, so, I've always known there's something in me that invites it and I get very.... contrite and I'll try to please you even more." (Elsa – Page 7)

Articulated self-blame is also a well-documented narrative of those who have experienced abuse (Swannell et al, 2012; Lemaigre et al, 2017) and perhaps explains Elsa's self-positioning as the architect of her unhappiness in later life, whilst at the same time acknowledging the cruel behaviour of others.

For some narrators, there appeared to be a sense of feeling let down by key figures or institutions in their lives, which perhaps would constitute neglect or abandonment rather than targeted

abuse. The key figures invariably were close family members; parents, grandparents or spouses. Beth, with some pride recalled her successful achievement of a scholarship to an international school in another part of the UK, but reported feeling homesick in the early days;

“...when I was in my first term, I was homesick, ‘(be)cause we had been this very close knit family and I desperately wanted her [mother] to say come home, and she didn’t. Because she wan[ted], she thought if I ever came home, I’d never leave [home town] again.”

(Beth – Page 5)

Although Beth framed this in a positive context (she ended up flourishing at the school and meeting her future husband), even stating that it was the best thing her mother could have done for her, the tone suggested a feeling of being pushed away (Beth refers to “my abandonment issues” at a later point in the narrative – Page 48).

Institutional failure was met by the (now adult) participants with a sense of anger and injustice, certainly when their function was to protect and nurture. For Elsa, the church, represented by the nuns at her primary school, was cruel and vindictive, seeking opportunity to humiliate her;

“they wouldn’t let me go to the toilet. And I used to sit there crying with my hand up, crying. We sat on great big long benches and in the end, I’d wet myself. And I, so I had to take spare knickers to school and I can remember, I can still remember the smell.”

(Elsa –Page 5-6)

When her mother went into the school about the wetting, Elsa recalled the nun saying that she had been doing this deliberately. Elsa knew who would be believed of the two, as to her Catholic family “nuns came above Jesus!” (Elsa – Page 6). Maggie, who had grown up and married into the Christian Brethren Church, with her family were invited to stay by a community in the United States when her mental health first declined. They had been promised that the community would meet the cost of travelling out there, but when they arrived the money was not there to reimburse, they were told that she and her husband had not ‘prayed hard enough’. After taking her first overdose, members of the congregation in their UK home told her she would be going to hell for her actions (Page 10). At the time of interview, both women were no longer part of a faith community.

#### 4.5.2 Early Identity and the Challenge of Fitting In

As discussed in 1.5.2 (Page 20), Stryker's (2007) Identity Theory, one's social position is often designated by others, then accepted and internalised by the individual. However, Stryker (2007) posits that one's personality traits can also influence social cognition and relational behaviours, potentially directing designation. Although temperament (our inherent traits) has its place, personality is constructed through their exposure to our environment (nature and nurture). As discussed in the previous section, the abuse, rejection and shame in early life (Act 1 - e.g. Elsa's natural 'invitation' to bullying others or Maggie's perceived judgement by her church community) and possible need to please (e.g. Jess' perfectionism or Mike's drive to make his parents proud in a way his disabled brother could not), perhaps led to the belief that they did not fit with the world around them (Orla referred to herself on several occasions as being "a square peg in a round hole" – Page 1).

Orla, Elsa, Beth and Geoff pointed to their working-class background being at odds with a desire and/or ability to educate themselves to a higher level, possibly to pursue an alternative life path from that of their parents. A comment made early in Beth's interview highlights a dichotomy in her familial position;

"I did the International Baccalaureate... I grew up being told I wasn't wanted, but to counter that I was always the one that had all the family hope."

(Beth – Page 3)

This continued for Beth into adulthood; whilst her mother and siblings all remained in the local area, she was the one to stay away at university after college and live in a different part of the country during her early career in education. Only when her mental health difficulties forced her into retirement on health ground and her sister became terminally ill, did she return to live locally.

Ruth's account of her early life provided consistent examples of her struggling to fit in with the world around her. She reported that as a child of 10, she gave up after school activities to focus on her academic work, something that she intimated her parents were behind. As an adolescent she developed Anorexia Nervosa and spent a number of time periods in hospital, inevitably separating her from her peers. As a student nurse in London, her sense of being out of place continued;

"...if you went to any of the university social events, you had to travel quite a bit...  
It wasn't consistent with shifts. And I also found that a lot of the students, other students lived all round London, so every single weekend, they disappeared off...

it was quite lonely I didn't really get a very, very active social life."

(Ruth – Page 4)

Although Ruth was to achieve academically, become part of a professional group (nursing), marry and have children, these efforts to form an identity and fit in were taken away in varying degrees by her mental health crises in adulthood.

Similar to Ruth, Simon's narrative created an impression that he struggled to fit in until he entered mental health services. His formative years were punctuated by several family moves, dependent on his father's military postings. Although a majority of his primary education was undertaken in the private school system in one geographical area, when his father left the army, the family were forced to move out of quarters to private accommodation in another town. He and his brother also entered into the local authority education system;

"I was in a city that I didn't know, I was at a new school with new people, then going from a very strict public school to (*name*) Middle School, that was a massive shock... at the public school the boys were well behaved, whereas at middle school it was like chaos."

(Simon – Page 4)

Although Simon achieved academically and would eventually enjoy a four-year degree at university in another part of the country, the lack of settlement appeared to continue. Long-term physical health issues limited his ability to work in forestry, so he spent some time moving from place to place undertaking part-time paid and voluntary work (eventually he moved locally and lived with his mother). A significant underlying message from Simon's narrative was that he struggled to fit in, but also form a clear sense of identity in the important years of adolescence and young adulthood.

Linking back in with the theme of power and dominance and despite many of the narrators achieving educationally and professionally (Beth, Mike, Orla, Elsa, Simon, Mark, Geoff, Ruth), some marrying and having children of their own, a perceived lowliness of status remained for a few. As indicated previously, Maggie and Orla spoke of being subservient to their spouses, to the point where they almost did not have a separate sense of identity. With a husband who flew across the world as part of his work, Elsa fulfilled the role of full-time mother to her two young children until he made the decision that they should attend boarding school. With this role taken from her, her husband then informed her he was leaving the relationship;

“...he’d been living with someone for a year in Ireland and, so he’d put them [the children] in school so he could leave.”

(Elsa – Page 25)

After recounting this episode, Elsa asked to pause the interview so she could visit the bathroom. Although not visibly distressed, the timing of this pause was noted by me at the time. The sense of loss experienced by Elsa, whose adult life to that point had been to follow her husband and care for their children, was palpable.

The early identities of many of the participants possessed a fragility (Orla, Elsa, Simon, Maggie and Jess), or did not easily fit with those around them (Ruth, Beth, Mike and Geoff). The burden of becoming a ‘user’ of mental health services, whilst unpleasant in most narrators’ experiences, perversely perhaps gave them a firm identity and status later in life. Of course, this was not the only identity that those in power could offer; professional patronage could lead to an identity as ‘expert by experience’.

#### **4.5.3 The Need to Please/Accepting the Burden of Responsibility**

The link between self-subjugating behaviour and the development of mental health difficulties, such as depression, has been suggested within the literature as part of a range of maladaptive schemas (Eberhart et al, 2011; Davoodi et al, 2018). Of the ten narrators, eight indicated this had been a significant part of their life experience, both in the early years (Act 1) and sometimes during their interface with mental health services (Act 2).

Orla identified within the first few minutes that her self-subjugating behaviour within her marital relationship was as a trigger for her descent into mental health crisis;

“I really wanted a third child and my husband wouldn’t have it. And I’d spent my life doing everything he wanted, I mean literally; almost becoming him. I almost became a clone of him. I thought he was the perfect individual, I held him up on a pedestal...”

(Orla – Page 1)

Mike talked about the need to please and be “the perfect child” (Mike – Page 2) for his parents and at school, as a contrast to the anger and frustration of his brother (who had epilepsy and other complex needs). Ruth, whilst praising her parents’ care for her as a child, talked about their strict rules regarding public behaviour;

“I was never allowed to, um, show them up. So, I was never allowed to cry in

Public. I was never allowed to show strong emotions in public. I was never allowed to do this, that or the other in case I let the family down."

(Ruth – Page 2)

Despite reportedly significant emotional and physical abuse instigated by her parents, Elsa too was required to behave in public, at one point describing herself as "a dogsbody and people pleaser" (Page 44) in both childhood and adult life.

The academic expectations upon Beth were very much attributable to family, her mother in particular. Similarly, Geoff referred to childhood coping mechanisms that became unhelpful in his adulthood, citing the following of his father's footsteps and working in a shipyard, which was not his desire, but "what was expected of me" (Geoff – Page 1). His eventual mental health crisis came in his 40s after becoming "a workaholic" (Page 2).

For Jess, the expectations came not from inside the family, but from external institutions;

"I went to quite an academic secondary school, um, where kind of they, they really wanted us to get sort of top marks in things. And where it took me a bit longer to achieve that, I started working really, really hard, um, kind of to the detriment of my health really. Um, so I would stay up till the early hours of the morning, um, and just sort of try to get my work as perfect as it could be."

(Jess – Page 2)

Interestingly this expectation and her response caused frustration for her parents, to the point where they would switch off the mains electricity to prevent her from working late into the night. The most relevant point within this quote is Jess' causal link between her perception of others' expectations and the deterioration of her mental state.

Perhaps the most global portrait of external institutions weighing heavily can be found in Maggie's narrative, where she both grew up and married into the Christian Brethren tradition.

"my purpose in life was to basically be a wife, a mother and to lead people to Jesus and go to Heaven, And, that, that was it, that was my function and, it was very... when it's all you know, you don't question it..."

(Maggie – Page 4)

For Maggie, she was later to experience the consequences of defying expectations, by experiencing a mental health difficulties (Page 6) and leaving her marriage (Page 19), with all support systems ceasing to be available (bar mental health services).

#### 4.5.4 The Pros and Cons of Being a ‘Mental Patient’

Several narrators provided a rich narrative around their personal experience of power dynamics, sometimes positive, often distressing. Jess recalled the point at which she discovered she had been given a psychiatric diagnosis, after previous unsuccessful attempts to find out this information from her community mental health nurse (CMHN);

“...when I was then admitted to an adult psychiatric unit, um, and... I think I harmed myself and I needed to be taken up to the hospital to be treated and in the ambulance, um, the paramedic asked a member of the nursing staff who was accompanying me what my diagnosis was and then she said *“Borderline Personality Disorder”* and I sort of was like “*what?*” So that was how I found out...”

(Jess – Page 11-12)

Here is an example of health care professionals not only deciding regarding the diagnostic label someone should be given, but also when and how this information is then communicated to the person experiencing mental distress. However, once a diagnostic label was given, it then had the potential to be the lens through which professionals understood communication from the narrator. Maggie, having had an appointment cancelled at short notice when her psychiatrist took annual leave, expressed her unhappiness at their next meeting. It was, however, interpreted differently;

“I became the difficult person. He became then, he focused on anger every time in our times together. He’d focus on anger when he wrote to my GP.... Well, that was me being angry at him for cancelling an appointment. It became like the behaviour of a disorder, rather than me being like, ‘*well everybody feels like that don’t they?*’ So, it was just different, you know, just different...”

(Maggie – Page 26-27)

Orla provided a vivid analogy to explain the experience of inpatient admission;

“I was like in a, one of those storage lockers, taken out of society, because I was a danger to myself. Nobody wanted me out in society, was willing to look after me. Was just stored in there in the hope that I would eventually become

safe. I have to say I still got the psychological therapy, I was luckier than most people..."

(Orla – Page 3)

The image of being placed in a storage locker, reveals the perceived objectification felt by Orla and the power of services to dictate when she would be safe enough to move out into the community (Beth twice used the word "released" to describe the experience of being discharged – Page 11). The final part of Orla's remark is also quite revealing, as she identified herself as being fortunate, possibly even grateful, to access formal psychological therapy, rather than it being the standard part of someone's care.

Beth's account most clearly articulated potentially coercive side of institutional power; as highlighted in 4.4.2 (Page 98) she referred to having "played ball" (Beth – Page 6) in response to the threat of a section of the Mental health Act.

When considering the initial transition into user involvement work, all bar one of the participants reported started off in an informal way, by either invitation or volunteering their expertise. Once again, Mark was less forthcoming regarding this transition for him, but had stated that he had been a health service manager prior to accessing mental health services, which may have more directly opened up the opportunity to undertake the paid service-user co-ordinator role. At the time of interview, the participants could be divided into two broad groups; those who engaged in involvement work on an ad hoc paid basis (Mike, Simon, Elsa, Ruth, Maggie and Jess), and those who were formally employed for their expertise by lived experience (Beth, Orla, Mark and Geoff).

Interestingly, having moved into a new engagement with services (involvement work), the experience of domination, objectification and coercion appeared to resonate with a greater number of participants. Beth referred on several occasions to feeling like she was "wheeled out as a service user and moved back into the cupboard until the next time" (Beth – Page 7); a comment which resonates with Orla's above. However, she indicated that tokenistic participation in early involvement activities suited the limited cognitive function she had at the time (due to mental distress).

As one of the formally employed participants, Beth mentioned she had to be "toeing the party line" (Beth – Page 24) within her work and came to a realisation at the end of her employment that she had been complicit in finding service users to be present and add credibility to the organisational activity they were involved in, without it necessarily being meaningful for the individual;

"...it would be, say you were being interviewed for a job next week and suddenly thought '*Oh bloody hell, we need a service user on that panel*', and

then they would, I would get these phone calls sort of saying “*Oh you know, we want, we want a one-legged lesbian service user who [laughs], and we want them tomorrow.*” And so, where do I magic these people up from? ...It was, you needed the warm body.”

(Beth – Page 17)

When she did leave the organisation, a colleague undertaking a similar role in a different geographical area (who turned out to be Mark), reportedly told her “you’ve got your voice back” (Beth – Page 24) This suggests a stifling effect on her ability to challenge the status quo, despite reportedly engaging with higher level figures within the organisation on a regular basis.

Orla’s experience as a frontline worker in mental health care did not indicate a pressure to ‘tow the line’, however, this could be indicative of her specific role as a Peer Support Worker in front line care, as opposed to the co-ordinator role undertaken by Beth and Mark. However, the experience of power asserted by professionals perhaps took a more benevolent guise;

“And there’s one particular nurse there, an older person, who’s extremely supportive of me when I was in hospital as a patient. She’s one of the people I remember as being a huge part of my recovery. But she’s next to impossible to work with now. She keeps, every time she sees me, saying ‘*well I’m really worried about you getting unwell*’ and it’s getting very boring at this stage... She also challenged me on my notes, {be}cause the training we got as peer support workers is to look for the positives in people; so, my notes are very positive. ‘*Oh, we don’t write our notes that way*’ she said, and she went changing my notes, but now she can’t, because we verify our own notes now.”

(Orla – Page 44)

Maggie’s experience with her psychiatrist taking leave was of legitimate anger being interpreted through her diagnostic label. Here with Orla, despite being formally employed, she is viewed through her previous mental health crisis or the ‘lesser’ training as a Peer Support Worker. However, Orla’s remark ‘it’s getting very boring at this stage’, belies her resistant attitude towards these assertions of power. Orla vehemently challenges the perception of being ‘unqualified’, citing her lived experience as appropriate qualification. For example, when a rejected interviewee questioned her position on the interview panel for a professional programme (at a university);

“...she made a big assumption that I had no qualifications or anything, which shouldn’t matter anyway, you know, if I never even had a GCSE. What I’m

assessing is her suitability to actually deal with service users. I, I don't look at anything from an academic, (be)cause I'm not qualified to do that."

(Orla – Page 13)

Mark, in keeping with the tone of our interview, took a step back from the personal in his comments regarding institutional and professional dominance. He highlights the power of the institution to employ the Mental Health Act;

"...the Mental Health Act is still, looms large, you know, people are detained for, you know, if you're very unhappy and very depressed, you know, you come into hospital, you've got a sentence, which is basically thirty days to life; you don't know when you're going to be discharged"

(Mark – Page 7)

In response to this clear imbalance of the power relationship, at several points Mark refers to his role in 'creating spaces' for people to have their voice heard by the institution that is mental health services;

"...there are existing forums for people to be heard in or sometimes it might be necessary to create a new space for people to be heard, particularly if the organisation wishes to know about a particular issue. So, it may be, sometimes I come under pressure myself to provide the actual voice and if time is short, given that I'm part of a community of service users, I've often got a general idea of the sort of range of views that, that might be out there..."

(Mark – Page 2)

Although this comment demonstrates the drive to create spaces for people to reclaim a level of power within their mental health care, there is an interesting reflection on his role as Service User Involvement Coordinator. By suggesting he is under pressure to provide the service user voice at short notice, something he often has to fulfil himself, there is a risk that tokenism creeps in and he becomes merely a tool of the institution and consciously or not, once again reinforces the power imbalance.

Geoff recounted a point early in his service user involvement work, when he first became involved in recovery training;

"At that stage I was doing mainly the stereotypical service user involvement, which was rocking up at a training session and delivering a 10- or 15-minute recovery story and answering a few questions..."

(Geoff – Page 5)

This experience would tie in with the accounts of Beth, Elsa, Jess and Mark and the idea that 'rocking up' to tell one's story was often the entry point to the world of service user involvement work. Although alluded to by a number of the participants, Geoff is one of the most explicit in calling out the tokenism of involvement work at times, suggesting that services would ask the people "who were most compliant..." *We've asked the person with the least radical views and he think it's okay.*" (Geoff – Page 20). Again, this resonates with the 'toeing the party line' type remarks made by Beth and Orla

Like all the other participants, Geoff eventually moved beyond this to the point where he would use his lived experience to inform his involvement work, rather than limit it – "that is a different level" (Geoff – Page 20). Geoff continued to be very positive about his role as a recovery trainer, highlighting the equality of status and co-production of learning materials and teaching courses – "{when} you have equal status; something really cool happens" (Geoff - Page 21). However, the terms on which he entered paid employment, indicates the fragile nature of his equal status. After initially being employed on a temporary 3-month contract, this was extended by a 6 months, then by another 3 before he secured a permanent contract. The importance of the role even during the initial temporary period, with Geoff inserting the word "catastrophic" (Geoff – Page 17) if it had not worked;

"If that had failed, it might have been the last time I tried anything in my life"

(Geoff – Page 17)

For Geoff the decision of the institution to continue employing him literally became life and death, which gives a sense of the power held, even if the intentions are worthy (inclusive working with those who have lived experience of significant mental distress).

Mike, Simon, Elsa, Ruth, Maggie and Jess engaged in formal involvement work on an ad hoc basis or for voluntary sector organisations, which for most carried the benefit of being flexible in how and when they undertook activity for statutory services or higher education institutions. This potentially was helpful if their mental health deteriorated, as captured here by Elsa;

"I've told them, like (.....) with (...), I've told her *'these are the signs of me when I'm not doing so well'*... people that I work with they know what my warning signs are, so that if they saw them, then, you know, then they would

*say 'I don't think you're well enough to work' and I, and I would know to... I think it makes it easier for people to say no to you."*

(Elsa – Page 48)

None of the participants reported feeling unfairly excluded from involvement work because of their mental state, happy to defer to the wisdom of professionals. Whilst the professional judgement would appear to be made with the well-being of the participants at the fore, it does indicate the ongoing deference several had to the expertise those who were now collaborators or even colleagues (Elsa, Orla, Ruth and Geoff).

However, the ad hoc nature of their work, did at times make a small number of participants feel at the mercy of the organisation, captured by Elsa in 4.4.2 (Page 98). When a person is working with an institution who has provided care (at times against their will), invited them to enter the world of involvement activity, possibly offering remuneration or even formal employment, the ability to challenge and change the balance of power care for the better can be impacted.

#### **4.5.5 The Allure of Professional Patronage**

With the exception of Mark (who did not discuss the detail of his personal experience), and Mike (who could not remember the details, but suggested that it had happened through Beth becoming involved herself) the participants were able to recall how they first entered the world of service user involvement work (Act 2).

Beth's is of particular note; describing her recovery as "a series of quotes" (Beth – Page 11), she recalled the first time a Care Coordinator came out to visit her;

*"...the first thing she sort of said to me was 'there's nothing out there for you, people like you'... when I look back, what she meant was she didn't want me to go to day services and sit and drink coffee for the rest of my life. But I don't think she quite knew what to do with me either..."*

(Beth – Page 11-12)

Although Beth reported feeling angry at this remark and refusing to work with the individual, she also perceived being marked out as different from many other service users; someone who would be stifled by long-term engagement in mental health day services. It is almost immediately after this Beth's narrative describes how a carer's support worker alerted Mike to a local service user network she could become involved with, prompting a visit from the coordinator of the network;

"I was at the point I'll give anything a go. Quite...no sense of agency or anything in there and [coordinator] came round. Came here, she was sitting where you are. And she said '*There's lots you can do*'. And so, from the point started my involvement journey."

(Beth - Page 13)

Although by her own admission, Beth was still very fragile in her mental health, someone in a position of authority (SU network coordinator) had offered the hope of her being more than she was at that point. Similar accounts of the entry into user involvement work were offered by Orla, Geoff and Ruth, who were offered the opportunity to become the member of service user consultancy group within the organisation (for which they would receive training), which was being set up by a psychologist. This psychologist would also be Orla and Geoff's individual therapist, and as Geoff observed;

"She had me in mind... it was quite clever of her actually... what she did there was give me a little bit of hope for the future, that there is something beyond this therapy".

(Geoff – Page 10)

Similarly, Ruth was part of a therapy group, but had "shown quite a flair for actually developing the skills and learning them" (Ruth - Page 11), to the point where she began to teach them to others in the group. Although no one professional is mentioned, she referred to being put forward to become a member of the service user consultancy group.

Here are four of ten narrators, who were seemingly identified and invited by a professional to engage with service user involvement work, with three going on to formal employment within the same organisation. Mike and Mark aside, the remaining four participants appeared to rely more on their own initiative to become involved. Maggie was alerted to involvement opportunities by a student social worker with whom she had worked whilst he was on placement; an external reference group for the social work programme at a local university. Her motivation derived from distress experienced after receiving, possibly well-meaning, but ill-conceived comments the student had made to her about her mental health. Similarly, Elsa's drive was to speak out, albeit for others rather than herself;

".... I just thought somebody has to speak up, you know, I can't speak up for myself, but I can speak up for other people. So, I joined Rethink and I started doing things for (*local NHS trust*) and I just thought, anything that came up,

I'd do or I will do. I mean even if it means driving to (*county town*) just for an hour or something."

(Elsa – Page 41)

There is a notable difference in tone between Maggie and Elsa's comments, with Maggie demanding to be heard in an academic environment, whereas Elsa almost grateful for the opportunity to speak where health care professionals might listen. This potentially raises a question about setting and the confidence with which people can speak for themselves and others' lived experience – a university would never have the power over a participant's life that a mental health service provider (who, for example, can legally detain someone against their will for treatment). This idea is supported by both Simon and Jess' experience. The early life accounts given by them described a lack of self-confidence and worth, yet Simon graduated to being a 'buddy' to new attendees at a local day centre after he himself had been there for 6 months (he eventually became the Buddy Coordinator for the service) and Jess used her own initiative to engage with large mental health charity for young people;

"I went on their website and saw that they were kind of looking for young people and thought '*yeah, why not, given it a go*'".

(Jess - Page 16)

From there, further involvement opportunities arose for Jess at both a local level (she too joined the service user consultancy group) and nationally. Both initially pursued involvement opportunities that sat outside the organisations that had proved their care (although later would eventually undertake ad hoc work within them).

In 3.3.2.12 (Page 76) narrator demographics was briefly discussed, highlighting the commonalities in ethnicity, educational attainment and social class. Fitzgerald & Hurst's (2017) systematic review revealed that healthcare professionals exhibit similar levels of implicit bias as the wider population in relation to characteristics including race/ethnicity, socio-economic status, age and mental 'illness' amongst others. Although a direct link cannot be made at this point, due in no small part to the purposeful sampling strategy employed within my study, it is interesting that white, well-educated middle-class people with mental health difficulties have perhaps enjoyed greater opportunity to engage in formal service user involvement activity, irrespective of whether they or a professional instigated the idea.

However, patronage of professionals when undertaking involvement work, particularly for those formally employed, demanded a cost in the longer-term. In her role as an involvement coordinator, Beth reflected;

"I found that increasingly... my voice as a service user representative was shut down and that we were constantly told to follow the party line... we were always reminded that we were representing [the NHS trust]."

(Beth – Page 23-24)

As a colleague undertaking the same role in a different geographical area, Mark commented;

"...I suppose over the last 25 years I've seen some things have got better, but then they're really quite small, but bits of progress, as it were and, and as I say, the main challenges, the sort of things that people originally protested about before they were potentially co-opted into services, are still there."

(Mark – Page 6)

Both comments suggest an acceptance that one must compromise their stance on particular issues in order to continue to benefit from the patronage of the organisation. Eventually for Beth this proved to be too high a cost and she left the organisation. Mark continued, despite arguably having more radical views on mental health and the system of care; his justification for operating within is neatly surmised here;

"I think it's universally accepted that involving people is a good idea and it can potentially, you know, there's still progressive potential in it..."

(Mark – Page 6)

Orla, as one of the other paid employees at the time of interview, indicated that the authority of the person offering patronage was key in getting one's voice heard;

"The person who was chairing the panel, that's what made the difference. And I, my view of it was the higher up you went in the service, the more they wanted to soak up all the information from the service user. When you came down to a manager of a ward, they had their own agenda."

(Orla – Page 12)

This suggests that for some participants patronage was not something that was always passively received, but could be actively sought, if one had access to those holding the greatest power within the organisation.

#### 4.5.6 Fragility of Status and Identity as an Expert by Experience

One possible explanation as to why some participants would later seek identity or status through activity away from the services that had once treated them (Act 3 - discussed in 4.6 – Page 125-140), is the continued fragility of one's position within it. This was certainly the case if a narrator shifted back and forth between their involvement role and actively accessing care. Beth recalls an incident just two years prior to our interview when she experienced toxicity in her Lithium regime;

“I’d been really moaning about it beforehand because in the past if you are on Lithium you used to get your bloods done and... the guy that took your bloods would get the results and really anal, you know, and in the service redesign all that went. So, you’d get your bloods done but you never knew if it was okay. And I’d been saying to people ‘*You know, you know, this is, this isn’t, this isn’t good*’ because the therapeutic range it was so, you know it’s so, the line between me being okay and being toxic was right on the edge. Anyway, I became unwell and ended up in [a local acute hospital] and I come, I had toxicity of 2.7? And, yeah, my Psychiatrist said ‘*You shouldn’t be here, you really shouldn’t be here...*’ you know, cause at 2 it should be fatal. And, but she said, ‘*Right, but we want to put you back on Lithium, because we can measure your levels*’ [laughs]. So, I went back on Lithium.’

(Beth – Page 42)

The wider context of this statement is that Beth had been in her formal employment as an Involvement Coordinator for approximately 2 years and has previously suggested, had the ear of powerful figures at the top of the organisation. However, despite her protestations regarding the new system of blood testing and near fatal consequences, the eventual outcome was for her to be put back onto the lithium medication (Beth was taken off this medication just a few weeks later after another episode of toxicity). Much later, when Beth did assert herself within treatment, she would be discharged from the service. Her decision to leave the organisation in her formal involvement role would follow relatively quickly;

“...we were always reminded that we were representing (*the Trust*) ... when I was asking those why questions my, my boss was constantly saying ‘*Its above you pay grade, above your pay grade*’. And so, I went from being this, this.... quite, I felt quite influential to being nothing, even down to when I asked if they would support me in my PhD, my boss said ‘*No, it’s above your pay grade to do a PhD*’. And I thought ‘*fine, I will, I will come out of it and I will...*’

you know, I don't want to be part of that organisation anymore.

(Beth – Page 35)

Key within this extract is the phrase 'influential to nothing'; such was the power of the organisation and the fragility of her position within it. As previously highlighted, Beth spoke of being 'robbed' of her career in education by deteriorating mental health and eventual retirement on medical grounds. Beth did not provide a timeline for this shift in her service user coordinator role, but there was a real sense that history had repeated itself. Whether Beth's narrative truth reflects the actual course of events is inconsequential; for her there was a narrative of the organisation bestowing power and position then removing it at will.

Given the mirroring of their formal involvement coordinator roles, it is useful here to look at Mark's perspectives on the fragility of power and status, which predictably did not include reference to his personal experience, but that of service users whom he would recruit to undertake involvement activity;

“...we can invite say formal service, you know, formal or semi-structured or service users back to do, say to audit services for instance and do ward walkabouts and things. Then they'll write a report and they'll be free to be, you know, say their bit, but there'll be an extent to which they'll need to be circumspect about what they say and, you know, they'll want to be, they'll want to be positive, because they want to be invited back to do more reports.”

(Mark – Page 8)

This extract reinforces Beth's point about the organisation's ability to remove one's power as an expert by experience if they do not like the message one is giving and arguably mirrors the power professionals have within the professional-service user relationship. Later in the interview Mark highlights that;

“...in any relationship the person that's doing the helping will always be in the more powerful position than the person being helped.”

(Mark – Page 28)

As highlighted earlier, Beth reported being discharged from services on the basis that there was nothing more they could do for her (after she challenged the treatment plan). Maggie recounts being informed that she was unsuitable for a particular type of therapy after requesting a different therapist from the one allocated; “they washed the hands of me” (Maggie – Page 30). This is

important because it highlights a rigidity in the relationship between professionals and service users or experts by experience; the former will always be the helper, whilst the later will inevitably remain as the helped. Whatever sense power and status a person feels when engaging in involvement work is gifted by organisations and can never be assumed to be permanent, very much aligning with the constant-sum conceptualisation of power discussed in Chapter 1 (1.5.3 – Page 18). The realisation of this for the Individual can lead to disappointment and disillusionment, as illustrated by Orla;

“...we also have supervision; we’re each given a certain mentor on the ward, er, from a professional staff. I have a Band 5 nurse, but it is very poor, at the supervision, in my opinion. I’m lucky I have the day a month; she’s always rushed. She doesn’t come from the same place as me...”

(Orla – Page 18)

There was a sense throughout Orla’s interview that whilst she enjoyed her role as a Peer Support Worker, the lack of parity with staff who had a professional training background was a source of resentment, particularly when she found herself challenging some on their professional behaviour. Although there was no sense of resentment from Geoff, he recalled having to surrender his sickness benefits in order to take up a temporary Peer Trainer post at a recovery college. This temporary contract was extended twice more before he had the opportunity to apply for a permanent post (which he did and got – Geoff – Page 20). Whilst presumably the option to return to claiming benefits was available should the job have not been extended, for him it would have been more significant;

“If that had failed, it might have been the last time I tried anything in my life”

(Geoff – Page 20)

The fragility of one’s status was not, however, limited to those formally employed. Elsa’s ongoing dispute with the organisation over payment for her ad hoc work is interesting;

“I’ve recently stood up for myself, which is very rare for me, with the person who supervises me, because I haven’t been paid for a few things from over a year ago and I feel that, I’m not, I don’t care if they never use me again, I’m not being treated this way; just not having it.”

(Elsa – Page 41)

The phrase “I don’t care if they never use me again” implies that challenging the organisation could result one’s exclusion from working in it, reminiscent of Beth’s ‘toeing the party line’ remark

Whether this is actually the case is secondary to Elsa's perception that it could and inevitably maintains a significant imbalance of power.

It is perhaps inevitable that these dynamics exist when the individual is working (formally or on an *ad hoc* basis) in the same organisation in which they were treated and for one to truly exert power, the message perhaps needs to come from outside. This will be discussed further within Chapter 5.

What becomes clear is that for a number of narrators, early life experience in these areas has in many ways been reinforced through their experience of accessing services for mental health crisis and recovery, as well as their work as an expert by lived experience. Presented at this point is a rather bleak picture of the care offered to people with mental health difficulties and questions the benefits of subsequent involvement work, however, this would be incomplete. The third overarching theme and arguably the final act in the narrators' stories largely presents a view of restoration and hope for new directions in life.

#### **4.5.7 Summary of the Institutional Power and Dominance Theme**

As articulated in 4.4.5, it is survival that draws this group of people together. With survival comes a struggle for power between the individual and the institution that dominates them at a particular point in their lives. In early life the struggle centred on the institutions of family, marriage, religion and culture. As their descent into mental health crisis began, these former dominant institutions were swept away in favour of something more pervasive powerful; the mental health system and the professionals who operated within. Key here is the fact that despite in the change in role the narrator's may undergo (patient to expert), their identity, from the perspective of the dominant institution, did not significantly shift. They were still the 'mental patient'.

### **4.6 Overarching Theme 3: Asserting Power and Forging a New Identity**

This overarching theme incorporates three sub-themes; 'The Benefits of Involvement Work – Healing and Validation', 'Finding a Sense of Belonging?' and 'The Emerging Hero - Resistance and Action' and is linked to the relevant narrators in Table 7.

**Table 7: Theme and Sub-Themes of 'Asserting Power and Forging a New Identity'**

Overarching Theme	Subthemes	Beth	Mike	Simon	Orla	Ruth	Mark	Elsa	Maggie	Jess	Geoff
ASSERTING POWER AND FORGING A NEW IDENTITY	4.6.1: The Benefits of Involvement Work – Healing and Validation										
	4.6.2: Finding a Sense of Belonging?										
	4.6.3: The Emerging Hero - Resistance and Action										

#### **4.6.1 The Benefits of Involvement Work – Healing and Validation**

The benefits of user involvement work are clearly articulated by eight of the ten participants in Acts 2 and 3; the exceptions being Beth and Mike.

Orla recalls the first time she shared her lived experience of mental health crisis with a large audience;

*"I said 'I'll do everything, but not standing up in a group in front of a whole hall of people' and she [psychologist coordinating the service user consultancy group] said 'fine', but my first assignment I was given was speak at a conference and I was so nervous, I will never ever forget it. And I had visions of falling across the stage... But I was fantastic, it, it was one of the most positive experiences of my life."*

(Orla – Page 6-7)

After this comment she went on to recall an experience of receiving negative feedback during a brief period as a teacher in her 20s, after which she had vowed never to stand in front of a large audience again. Later in her narrative, Orla reported feeling a sense of fulfilment in her role as a peer support worker;

*"I come out every day so, feeling so satisfied with what I've done and feeling I've done something worthwhile."*

(Orla – Page 42)

From the trauma of mental health crisis and detention in a hospital, Orla's involvement work had enabled her to both address negative past experiences and move forward with a renewed sense of purpose. The sense of enrichment is echoed by others; Simon reporting an increase in confidence and self-esteem, which has enabled him to challenge himself in other areas of his life (such as learning Chinese Mandarin and visiting China many times) and Ruth mentioning feeling listened to and validated on at least six occasions throughout her narrative.

Maggie not only spoke of personal enrichment, but also the opportunities involvement work had given her to influence professionals and improvements in mental health services;

“It’s just been such a privilege. From it I’ve been able to do, go on different conferences, which has not just made me richer, but I’ve been able to pass that on to other people and get them thinking and reflecting and researching, and to start to explore. But I was trying, thinking my goal, was thinking, well this is it. Be involved in mental health services, because this is where I feel it really is needed.”

(Maggie – Page 33)

This sentiment is shared by Elsa, also intimating the importance of validation by professionals;

“I treasure it, greatly value it. I greatly value the opportunity to have an input and to share. I really appreciate it when I’m accepted as an equal.”

(Elsa – Page 55)

This view was echoed by Jess, who identified the positives of influencing panels and professional applicants when involvement in staff recruitment interviews. Mark reflected that historically the organisation targeted service users who would give them the answers they wished to hear, but in his view “at least locally things have changed” (Mark – Page 3). Geoff takes this view further as part of a recovery college, where courses and materials are developed and delivered jointly between professionals and people with lived experience (“We’re not here for an opinion, we’re here to do the work”, Geoff – Page 23). For him personally the impact is profound;

“For the first time in my life, probably, I have that sense of utility. I have that sense of I’m doing something worthwhile.”

(Geoff – Page 28)

As the exceptions, Beth and Mike were the only participants married to each other, although their lack of comment regarding the personal benefits of involvement work perhaps differed. As discussed earlier in this chapter, at the time of interview Beth had only recently left her paid

employment role within the trust, and not in the most positive of ways from her perspective. Her frustrations with the organisation regarding the value of service user involvement very much came across in the tone of the interview. It was perhaps inevitable that Mike, whose path through the mental health system had been as Beth's 'supporter' (Mike preferred this term to 'carer'), would also struggle to espouse the personal benefits of service user involvement work within a large organisation. Interestingly he did not limit this to comment to statutory care providers, such as the NHS, but also powerful third sector organisations. In describing his part-time work within a national mental health charity;

"...it was a very sort of hierarchical, sort of centralised bureaucracy, you know, it was quite... although it's in the charity sector, it very much operates as if it's a big company with headquarters in London and they set all the standards, all the paper work and all the systems and sort of disseminated out to people who are actually doing it. And it, it just felt a system I couldn't work in."

(Mike – Page 15)

Although Mike's statement is clear here, I was cognisant of his lifelong sense of struggling to fit in (see 4.5.2.1 – Page 116), which indicated he may never reap personal benefits from working within a large organisation (he would later compare the national charity to engineering firms he had worked in – Page 15). For him to experience personal benefits from involvement work, it would need to look quite different.

#### **4.6.2 Finding a Sense of Belonging?**

As highlighted in 4.5.2.1 (Page 116), the early identities of several participants possessed a fragility (Orla, Elsa, Simon, Maggie and Jess), or did not easily fit with those around them (Ruth, Beth, Mike and Geoff). I also posited a question as to whether a mental illness diagnosis gave them a firm identity later in life. This is certainly indicated by some at various points in their recovery narrative, but the majority appeared to have left the diagnosis behind. Instead most appear to have developed new identities or attempted reclaimed former ones within the system, or have chosen to step out (Acts 2 and 3).

Beth, who in her pre-mental health crisis life was on the fast track to achieve great things in secondary education, spoke with pride about her joint project work at a director level as an involvement coordinator;

"I was working with these people, so I had quite a... it wasn't a long chain of... I was asked by the Director of Operations if I would review care plan from a service user... And so, I did all the training for the new care coordinators. I did

all that training, [be]cause I need to actually go through the process. And basically, I wrote a report saying it is not fit for purpose and, and as a result they basically threw out care planning and started again."

(Beth – Page 29)

However, this move "across to the dark side" (Beth – Page 23) did present difficulties at times, as she could be regarded with suspicion by service users;

"I was on a two-and-a-half-year psychodynamic group and it took quite a while for the other service users to accept me, [be]cause they thought I was a mole, [be] cause I worked for the trust. Yeah, why would I need, if I was working, if I worked for the trust why did I need to be in therapy?"

(Beth – Page 45)

Beth's challenge in being accepted by both service users and professionals is not unique amongst the participants, but her desire at the time to be viewed as both an authentic user and professional colleague is perhaps the strongest.

Similarly, for Ruth, as a former senior healthcare professional and academic, her desire to be recognised for her professional knowledge and skills was clearly evident;

"...this one service user started telling about how she was highly suicidal at the moment. Um, and it was actually really quite hard, [be]cause if I just told her '*don't, don't do anything, just use your skills*' like a member of staff would have been able to do, the whole benefit of her sharing her experience, [be]cause she thought I'd understood would have been really, really undervalued. So, it was actually quite a difficult role to play between bridging that you understand what it's like to be a service user, but yet having that professional role as well, in that you actually have to, obviously, take the staff role on as well. It actually was quite a challenging role dealing with that."

(Ruth – Page 32)

For Orla and Geoff, the distinction between the professional and service user roles was less evident, despite almost three decades as a civil servant before her mental health crisis and subsequent role as a Peer Support Worker. Possibly because of her job remit, her narrative presents her as a service user/person with lived experience first and foremost, almost shunning notions of being 'the professional', as shown here;

"You know, and they said to me '*oh, we've, we've just revolving door patients'* and I keep reminding them '*I was one of them*' and I said, then they said to me '*you're in the minority.*' But I'm not; I know loads of people that have gone on and recovered from mental health difficulties and they're nowhere near, they're not working for mental health services, they've got on with their lives, you know..."

(Orla – Page 53)

The final sentence of Orla's extract, though possibly a turn of phrase, perhaps also points to a sense of safety and belonging being an expert by experience in the mental health system, in contrast to those who experience recovery and do not return ("they've got on with their lives"). In Geoff's case, the sense of utility he experiences in his recovery college role was highlighted in 4.5.1.2 (Page 113). He does go on to qualify this with an anecdote about a service user who was brought to him for advice about applying for a voluntary position. Geoff was informed shortly before our interview that the person had successfully secured that role, prompting this comment;

"...that is worth more to me than my pay cheque at the end of the month"

(Geoff – Page 30)

Clearly the sense of achievement and impact on his self-esteem, has engendered a feeling of belonging within the recovery college environment. In contrast to Beth's experience in her role, here Geoff is able to be open about his lived experience of mental health difficulties (like Orla is employed for that expertise), but also feel he is engaging in genuine co-production with professional colleagues in the team. He did, however, confess to "being in a bit of a bubble" (Geoff - Page 25), not knowing what co-production was like outside of the recovery college.

Similarly, for Simon and Elsa there was satisfaction with staying in that mental health system to offer their expertise by experience and maintain relationships with people who understand that experience. The sense of belonging is not really articulated in Simon's case, although he spoke with some sadness about friends outside, who have rejected him when he has been 'ill' with depression. For Elsa, there was a palpable sadness about not fitting into wider society;

"I don't know I'll ever be able to be in the world again and that makes me sad"

(Elsa – Page 50)

Whilst recognising the collegiately experienced with service user peers engaged in involvement work, Maggie and Jess both hold hope to belong in a world outside of the mental health system;

“I’d rather build friendships; let that grow and then move on and move out.”

(Maggie - Page 58)

“I think the participation involvement stuff is certainly a stepping stone to me getting to where I am now and I imagine that in the next few years it will probably tail off a bit just as I, yeah, get more things in my life and perhaps build new experiences that aren’t necessarily just around mental health and my personal experience of mental health.”

(Jess – Page 26-27)

Mike’s reluctance to be pinned down by labels was apparent through the narrative of his adult life and involvement with services with Beth. At several points he indicated feeling uncomfortable with the label of ‘carer’, as at times he had his own mental health difficulties. He recalled the time a peer support project facilitator role was first advertised where Beth was employed;

“...it was interesting because it was her [Beth’s] boss was, was kind of in, the boss of the person recruiting [to the facilitator role] and had said ‘*Oh, which is he; a carer or a service user?*’ and I think I was quite angry I suppose at the time, because it was kind of ‘*well I’m both, well I’m not, no, I’m not a service user, I’ve never been a service user*’”.

(Mike – Page 14)

Eventually he would settle on being described as a ‘peer’, because it broadly encapsulated people who had lived experience of mental health issues, but also wished to support others going through similar experiences or improve services. The issue of labels was a strong feature of his narrative; more so than any other participant.

It became clear to me that for a majority of the narrators, service user involvement work created or restored a sense of identity and belonging that did not reject the label of ‘service user’, but attempted to resist the power imbalance that may come with this status. For Geoff, Elsa, Ruth, Orla, Simon and Mark this could be achieved whilst remaining in the system. For Beth, Mike, Jess and Maggie it would mean moving on. This is discussed further in 4.6.3 (Page 131).

#### 4.6.3 The Emerging Hero - Resistance and Action

If one subscribes to the Foucauldian notion of power and domination (discussed in 1.5.3 – Page 18), this group of people would be generating power through knowledge and learning about

themselves in recovery and the system in which they operated (as a service user and expert by experience). However, acquired knowledge and learning must be accompanied by action in order to challenge the attempts by institutions (health care organisations and professionals) to reassert their dominance.

It is unsurprising that within episodes of care meaningful individual resistance was limited for some, given the level of mental distress experienced. Elsa recalled once again introduced the mouse analogy, when describing a therapy session with a counsellor;

"...she'd take phone calls during the sessions and the worst thing was, and I just thought she's just got, just doesn't treat people with any respect, I mean... I went there one day and she was just streaming, sneezing all over me. I was such a mouse and I just there thinking '*my God, I, I can't get*'... I couldn't fight anything off."

(Elsa – Page 40)

At this time Elsa was struggling with significant physical health issues, as well as her mental well-being. This anecdote highlights her sense of feeling trapped in the presence of someone in a professional position (even if they were not behaving professionally). Both Beth (Page 15) and Orla (Page 17) likened the experience of inpatient care to being a prisoner, with the threat of punishment (sectioning under the Mental Health Act) should they refuse treatment or attempt to discharge themselves. Again, the self-reported fragility of their mental well-being at these times and possible impact on cognitive function, would have an inhibitive impact on any resistance. At a time of significant vulnerability, there was no indication of resistance to professional authority within the accounts of Simon, Ruth, Jess or Geoff.

However, resistance explicitly featured in three of the narratives. Mike, who with some pride described himself as someone who refused or avoided services, firmly ascribing the identity of 'service user' to Beth. At one point, when describing his own mental health struggles whilst Beth was experiencing hers, he stated that one of them had to "stand up....be counted" (Mike - Page 6), essentially staying strong and challenging services on her behalf when required. This again feeds into the sense that he had embraced the fact that he did not fit in, which as previously discussed, had been a feature throughout most of his life.

Maggie's appropriate challenging of her psychiatrist (see 4.5.1.2 – Page 109) demonstrated an unwillingness to accept what she felt to be inconsiderate behaviour, even though she was vulnerable in her mental health. Interesting here, was the psychiatrist's subsequent response; to focus on her 'anger' in future sessions. Similarly, Beth refused to work with a number of different

community care coordinators until she found one with whom she could form a mutually respectful working relationship.

Mark, even more so than Mike, had been removed in his tone and described himself as a service refuser' (Page – 1). However, as he did not discuss any aspect of his care, it is not possible to understand his behaviours whilst accessing services.

Meaningful challenge to the dominant authority of professionals and the system in which they operate very much aligned with the articulated trajectory of their recovery for several of the narrators. Beth, Orla and Elsa reflected that the tokenism experienced within initial involvement activities would not be tolerated by them in the present day. Elsa had got to a place where she stated she might walk away from working with a NHS trust, whom she felt were trying impose changes to an agreed contractual arrangement;

*"I just got to the point where I thought 'I don't care, I've got to do it my way and, you know, if they don't like it, they don't like it.' Um, so that's what I've done."*

(Elsa- Page 42-43)

Although ultimately Elsa did not walk away from her involvement work, the contrast between this statement and the 'mouse' extract in (Page 131) is clear. The development of Elsa's confidence and sense of agency is perfectly captured at another point in the narrative;

*"I'm not being treated this way; just not having it. And.... I get stronger and stronger and stronger."*

(Elsa – Page 41)

The sentiments here are echoed across several of the interviews. Orla reported no longer being "a 'yes' woman" (Page 10), consistently reinforcing the message that her personal recovery came above all other parts of her life, including peer support activities.

For Maggie, the opportunity to demonstrate strength was recognised from the very beginning of her involvement work, in response to the ill-conceived comments by the student social worker, (briefly mentioned in 4.5.2.2 – Page 119);

*He said 'Maggie, you'll never, you don't realise how many negative boxes you tick as far as social work is concerned.' He said 'you're a woman, you're on your own, you're in your middle-age, you've got no support, you're dependent on benefits, you've got, you've been long-term mental health service user'. And I went 'huh, yeah, you're right' and giggled. And afterwards I thought 'Shit. This is what people think of me every time I go into a doctor's office.'*

*Every time I go to my psychiatrist'..."*

(Maggie – Page 27)

The same student told her about a service user reference group in social work education at the local university;

*And I thought 'right mate. I'm going to get involved with that, because no student is ever going to do that to anybody again.'"*

(Maggie – Page 28)

From this point Maggie's involvement activity enabled her to share her story in its rawness, with professionals who were open to hearing it. However, the diagnosis and status of patient were never far away; she recalled attending a developmental meeting for the professionals within a community crisis team (under whose care she had previously been) and feeling very upset afterwards;

*"...I couldn't put my finger on what was going on. But what was going on in actuality was that it felt like I was in a ward round. And not just that, because they, you know, afterwards, they then discussed me... So, it was like, it was very much a 'them' and 'us' thing. It was very much about them, how it made, it was good for them and there was nothing about me."*

(Maggie – Page 47-48)

This sense of feeling useful for one's story and responding to that was very much echoed by Jess, recognised the importance of personal benefit from involvement work and telling her story, but also the need to resist organisational activity that lacked genuineness;

*"And I do try to avoid sharing participation work that's more about kind of just story sharing now, because I just, I don't know, I think there does have to be, in a selfish way, there does have to be something in it for you, whether that's a feeling you get afterwards or something like that. And I just feel that I've got a bit sick of telling my story and, I don't know, I think it's lost its... kind of, not value, but it, it's lost a sincerity that it had at the start."*

(Jess – Page 26)

The accounts here point to a rejection of the patronage bestowed upon them by the organisation and a move to generate one's own power; a feminist approach (1.5.3 – Page 20). It was not lost on me that the above accounts all came from female narrators and that the narratives offered by the four men may differ in tone. Mark and Mike, as it has been noted, asserted the mantle of 'service

refuser' from the very beginning of their interviews, which could suggest a feminist notion of rejecting benevolence and generating one's own power. This would appear to be the case for Mike;

"I feel that, that the whole kind of secondary mental health service, that it's so arbitrary anyway, whether, you know, when they accept you and when they discharge you is all up to them, it's not up to you as an individual and, I think ultimately it gets in the way of recovery."

(Mike – Page 17-18)

More than any other narrator Mike spoke about rejecting what statutory mental health services had to offer and promoted the value of peer support and the role of the third sector;

"I think a big part of it, you know, is often you just need a bit of support from somebody who can listen and understand and I don't think it's a healthy way to get that support from professionals if it's possible to get it from peers, you know."

(Mike – Page 25)

This avoids the very masculine approach of battling for a share of the power held by paternalistic mental health service providers. Revisiting the work of Armes (2009) (see 2.3.2 – Page 35), looking at how service user activists cope with pressure to formalise involvement work, the stance of Mike and the others here would most align with 'pride'; rejecting hierarchies and standing out as having expertise by experience. Mark's narrative would initially seem to echo the tone of Mike's, highlighting the increasing importance of social media in giving people a voice that is free from regulation. However, he also refers on five occasions to his role in 'creating spaces' within the organisation for those accessing services to share their perspectives;

"I think it, what started as activism outside services, there was sort of a move to be active inside as it were and service users' views being elicited. And I think, you know, spaces for people to be involved inside services will just continue to grow."

(Mark –Page 11)

The suggestion Mark makes here would seem to counter Mike's perspective; the flow of people into involvement work within the organisation has the potential to increase the influence of the service user voice over the type of service offered. Again, within the context of Armes' (2009) work, Mark appears to advocate rationalization (reluctantly engaging in dominant ways of working in order to ensure continued service user involvement and advocacy) for the people he

recruits and professionalization (becoming formally employed within provider organisations to gain professional status and achieve the service user agenda) on a personal level.

Geoff's narrative appears to sit within the professionalization approach, speaking with pride at the parity of esteem achieved within the recovery college environment between himself as a service user trainer and the professional trainers ("We're not here for an opinion, we're here to do the work" – Geoff – Page 24). Ruth and Simon's narrative would seem to align with the fourth of Armes' approaches; 'reformism' (sticking with the values of service user involvement, however long it may take).

I am conscious that the discussion so far in this section assumes the narrators in my study would consider themselves service user 'activists', as in the Armes' study or part of a larger service user movement through their work. The interviews revealed that whilst a few explicitly did, most did not describe it in those terms. However, that was not to say that they failed to recognise the power a group of people sharing a sense of purpose.

As the first participant, the interview encounter with Beth influenced the approach I would take to the subsequent interviews, refining some of the questions asked. She was the only participant to describe herself using the term 'activist';

"I was always so proud of my roots, you know, we came from a very staunch Labour background... I was always knocking on doors as a kid, getting people out to vote. I marched for the miners, did all the Barclays... you know when no one should use Barclays Bank [be]cause of apartheid..."

(Beth – Page 7)

Despite the destructive power of mental health crises within her life and the well-documented frustrations at feeling powerless within her Service User Coordinator role, at the end of the interview Beth remained proud to be an activist;

"...when I look at what some of the other people are doing on their PhDs, quite a few of them, their projects been given to them. And I think actually in my, when I can feel proud I actually I'm doing something I really want to do and hopefully it will make a real difference. And, I suppose not being funded you think '*Well actually again you're fighting against the tide*'".

(Beth - Page 51)

Mike, perhaps unsurprisingly shared a similar outlook to his wife. As a – as a service refuser, talked little about self (more about Beth), but spent the final quarter of the interview discussing his perspectives of mental health services and he need for change, starting with this quote:

‘.... I suppose, you know, we’re, we’re erm, we don’t know what we are capable of until we, until we do it. Erm, and, you know, a lot of it, a lot of it is undoing some of the, the sort of reinforcement that services have provided, you know, the institutionalising. Although we don’t, we got rid of the buildings, we’ve still got institutions, people institutionalised in the community.’

(Mike – Page 28)

Mark used the term ‘activism’ eight times during his narrative, but never to describe his own work within the organisation, despite being introduced by Beth as a real activist before I had met him for his interview and introducing himself as a ‘service refuser’ (Page 1) within the first 30 seconds. Almost Mark’s entire interview referred to change at a macro level, but also an acceptance of an eternal power imbalance between someone needing help and those providing it;

‘if you have power and you’re wise, you know that your power needs to be checked or scrutinised and, you know, and held to account as much as possible. So, that’s one of the things, you know, arguably is missing is accountability in mental health services.’

(Mark – Page 27)

Simon held a firm perspective that as a group of service users, the accountability mechanisms were there;

‘It’s not individuals doing their own thing, so, and as, as a group of people with an actual label... you’re seen as part of an organisation, um, it gives your voice more power, more authority, more thunder, more importance, so people can’t say you are just a service user, because now as soon as you become as part of a movement, they don’t see you as a service user, they see you as a part of the organisation. So, you speak on behalf of the organisation, you, you’re not just saying what you think, you’re, you are actually saying what many people think, so.’

(Simon – Page 25)

The use of the word ‘thunder’ is prominent here, particularly from a narrator who had described a life time of being vulnerable as an individual (physically and mentally). Similar could be applied to Ruth;

‘So, that actually did feel like it was a, um, quite a major movement of actually getting involved in that and actually really sort of worming our, worming our way in. And I think that’s something that we were able to do because we were a group, rather than doing it just because you were an individual.’

(Ruth – Page 37)

Other narrators recognised the power their experience might have to inspire others in their own recovery, but perhaps shied away from declaring they were part of something bigger than themselves. Despite being known for her forthright demeanour as a Peer Support Worker within the organisation, Orla conveyed a realist tone towards the end of her narrative;

‘I know the number one thing is my own health... I am not single-handedly or even with a whole load of peer support, transform, but hopefully I can make a little difference and that’s good enough for me now.’

(Orla – Page 60-61)

This stance, to prioritise one’s personal well-being and recovery over large scale challenging of the mental health system, is echoed across a number of the narratives. Towards the end of the interview Elsa made a poignant statement;

“...this is a difference of opinion I have with the psychologist, is that he feels I’m compromising too much; I’m accepting a very limited life. But actually, what I’m finding in that limited life is contentment. I don’t have expectations, so anything’s a bonus.”

(Elsa – Page 50)

Although there is a sadness in the ‘limited life’ accepted by Elsa, given the traumatic life history she narrated, finding contentment could be seen as a victory and testament to her ability to survive. This testament to survival is echoed by Maggie, but the sense of hope was perhaps greater;

“I just want to keep looking after me, making sure those things [connection and relationship with others] are in place, so it doesn’t become my life again. So, my identity isn’t as an ill person. And I don’t know until, I don’t know how

that will happen when it's still got those outside influences. But I hope it will, you know, I hope it will. And that, that's what I'd like."

(Maggie – Page 59)

Two of the narrators openly rejected the idea of being either an activist or part of a user movement;

"Recovery is more than a movement, it's a paradigm. It's a way that you view things rather than being some sort of movement. I don't believe that recovery, now, needs to be based in activism of any kind." (Geoff – Page 30)

"No to be honest. Um... I mean I know I'm aware of the recovery movement and all that stuff going on. I've never thought about me being part of that. Even with the sort of national work, I've never, no." (Jess- Page 32)

Overall, personal recovery from the trauma of mental health crises and the ability to shape one's future appeared to be a much stronger narrative theme than activism. This future for some did not necessarily mean further involvement work. Beth's acrimonious departure from her formal service user involvement role has already been well documented in this chapter, but the following extract perhaps points to the inevitability of moving on;

"...involvement should be, should be one aspect of recovery. And I suppose the idea was, in (*the trust organisation*) was to support people to develop the skills, their new skills... The majority (*of involved service users*), okay, you know, you might get paid for what you do, but it's not a living, and so it should be one part of anyone's journey to and hopefully get back out there and doing whatever."

(Beth – Page 40)

Clearly Beth recognised the value of getting involved as an expert by experience, but also that it was a stepping stone to a recovered life away from the mental health system, which she would eventually achieve herself. Jess echoes this, pointing to the combination of a WRAP (Wellness & Recovery Action Planning) course, securing part-time paid employment and volunteer work as encouraging personal responsibility;

"I thought '*actually, you know what, this is something I want to do*', rather than being told and that did make a difference, of how just I thought about things and my sort of, I don't know, agency and all that."

Ruth actually used the phrase 'stepping stone' when summarising involvement work (Ruth – Page 38). Having worked with Ruth for several years and witnessing the professional way in which she would conduct herself within the academic environment, moving on with her life would involve reclaiming the status and identity that had been lost to mental health crisis. At the time of the interview she aspired to regain her registration status as a nurse, but like Elsa was aware that she had not yet moved on in the way that some of her involvement peers had done.

Simon saw his future as being in the mental health arena, but in a formal paid employment role as part of an independent service user network, rather than within a service providing organisation. He also expressed a desire to return to academic study and undertake a Master's degree related to mental health care.

#### **4.6.4 Summary of 'Asserting Power & Forging a New Identity' Overarching Theme**

When deciding the title of the overarching themes and sub-themes I was conscious that they did not represent a satisfactory conclusion in the way that a final act of a story usually would (the hero victorious and forces of evil vanquished). The reality is that for each of the narrators, their 'story' was ongoing; the interview with me was only ever going to be a checkpoint to reflect on what had happened so far. As the time lapse between the interviews and final draft of this thesis is some 4 years, much has happened in the lives of those whom I have been able to maintain contact with. As is the nature of mental health recovery, some have seen a deterioration in their mental well-being and further access of services, others have maintained the status quo, whilst a few have continued on a journey of personal development away from the system.

In terms of the impact their service user involvement work has had, for almost all it has been recognised as an important part of one's recovery, offering a sense of belonging purpose when one has been fragile in their mental health and ongoing opportunity to reclaim lost identities and form new ones. Although few would define themselves as activists or identify as being part of a user movement (certainly formally), all have exhibited behaviours that fall within Armes' (2009) discursive tactics of resistance. This will be discussed further in Chapter 5.

#### **4.7 Revisiting the Storytelling: The Use of Tropes to Convey Key Messages**

In Table 3 (Page 57) I highlighted the key areas of interest when adopting a life story approach (Plummer, 2001), not least the way in which the story told by the narrators has been constructed

for me as the researcher. At the beginning of this chapter I discussed the plot (for many, a hero-centred narrative divided into acts), characters (protagonist/narrator, antagonist/ dominant institutions and witness/me as researcher), and genres/structures (overarching and sub-themes). One element that has been touched upon within the thematic analysis, but not specifically focused upon is the use of tropes; imagery and metaphor across the story arc. It was clear that some narrators used many tropes in their story (Beth and Elsa), whereas others used very few, if any at all (Ruth, Simon, Mark, Jess and Geoff). Everyone's story will be unique to them, with sub-themes having been clustered under overarching themes. Therefore, key identified tropes were grouped in the same way and are briefly discussed.

#### **4.7.1 Survival Tropes**

Surprisingly there were few survival tropes employed by the narrators, although it is arguable that one's actions and behaviours in response to dominant institutions could be couched as survival mechanisms. Whilst many were understated in their description of tragic events, the trauma of their mental health crises and subsequent recovery, a few employed quite grandiose terms. Beth referred to the fact that her "world collapsed" (Page 10) when she experienced her first crisis; Geoff foresaw an end to his Peer Support role as being "catastrophic" (Page 17). In espousing the seriousness of their crisis (or risk of), it emphasises the achievement of having survived. For Beth it was within the first minute of the interview that she had declared herself a "survivor" of the mental health system (Page 1-2). Geoff celebrated the sense of security and achievement working within the system afforded him, confessing to "being in a bit of a bubble" (Page 20).

As previously discussed surviving or being listened to within the mental system required a degree of political astuteness and the ability to learn how to behave in a particular way. Beth framed this as having "played ball" as a service user (Page 16) and "toeing the party line" as an employee (Page 34). Elsa employed the phrase "rocking the boat" (Page 43). Maggie felt the consequences of challenging, by being told she wasn't suitable for Dialectical Behaviour Therapy (DBT – "they washed their hands of me" – Page 30).

#### **4.7.2 Institutional Dominance and Power Tropes**

Perhaps unsurprisingly, the dominance and coercive power of institutions (family, the church, mental health system), produced a number of tropes across the narratives. As alluded to earlier in this chapter, the objectification of narrators when either accessing care or engaging as a service user consultant came across several times. It was Beth who referred to being "wheeled out as a service user and moved back into the cupboard until the next time" (Page 18), echoed by Orla's

description of being a patient; “I was like in a, one of those storage lockers, taken out of society” (Page 3). This sense of being hidden when not useful was reiterated again by Beth, claiming that when mentally ‘unwell’ service user experts would be “often forgotten, hidden, buried.” (Page 26).

The mechanisms by which institutions exerted their power and dominance is also richly described in several narratives. Mark referred to the Mental Health Act, which “looms large” for a potentially indefinite period of time, under which treatments such as Electroconvulsive Therapy (ECT) (which Maggie described as feeling like her “mind had been raped” - Page 19) can be administered. Orla referred to inpatient admission as “being locked up” (Page 17) in a similar way to a prison detainee and Beth discussed being “released” rather than discharged from her first inpatient admission (Page 15). Maggie reflected at one despairing moment in her experience “uh, *will I ever be free of mental health services.*” (Page 50). Jess described hospital as “a holding place” with little in the way of therapeutic input (Page 10).

#### 4.7.3 Asserting Power and Forging a New Identity Tropes

Whilst the imagery and metaphor to describe dominant institutions is powerful, equally so are those associated with asserting one’s own power and moving on to forge a different life. Interestingly, this is never more powerful than in the narratives of both Beth and Mike. Since leaving the organisation as an Involvement Coordinator, Beth used terms such as “a new lease of life”, reigniting interests and relationships from the past (Page 48). Mike’s extract below is even richer in its descriptive language;

“I’m alive now and not just surviving, you know, um things like I try and wear  
bright clothes, bright colours, because I realise that for a long time I was  
camouflaged.” (Mike - Page 29)

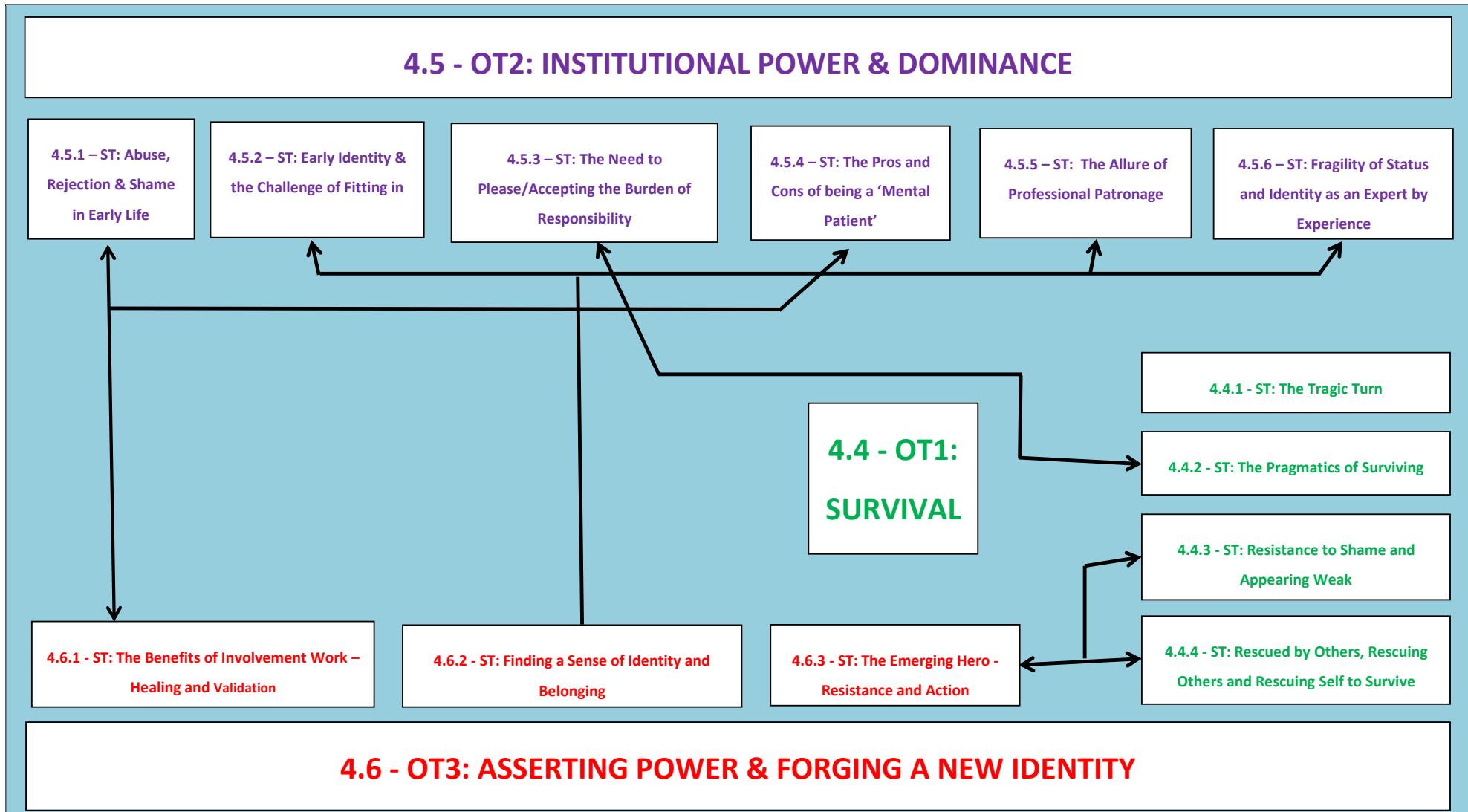
By contrasting the image of being previously being camouflaged to wearing brightly coloured clothing at the time of interview perfectly represents the move from surviving life to thriving in life (he would later refer to a “midlife awakening” as opposed to a “mid-life crisis” – Page 30-31).

However, carrying the greatest weight is perhaps Simon’s ‘thunder’ statement (Page 127), which is said with such boldness compared with the earlier parts of the narrative. This provides testament to the positive impact of service user involvement work, encapsulating a rise in self efficacy, as well as a sense of belonging when previously one did not easily fit in.

## 4.8 Chapter 4 Summary

As discussed at the beginning of this chapter, there was no ideal way to present the analysis of my interviews without creating some false barriers. My aim was to minimise this by acknowledging the 'acts' of the narrators' stories, but discuss along thematic lines (overarching and sub-themes). Figure 4 (Page 133) seeks to minimise the barriers further, but highlighting where sub-themes link with one another and are drawn through the overarching themes. Tables 5, 6 and 7 provide some indication as to the strength of sub-themes across the ten narratives. Threaded through Chapter 4 and focused on in 4.7, the powerful use of tropes supports the narrative of survival and battling powerful institutions in order to secure a sense of freedom and greater self-knowledge by the end. This collective information will form the basis of my discussion in Chapter 5.







# Chapter 5      Discussion

## 5.1      Introduction and the Research Questions

As discussed in Chapters 1 and 2, the study research questions and review of the literature, focused on three key areas; exploring the narratives of service user involvement activity, the experience of power within relationships when undertaking involvement activity and where the experience of such activity fits within an individual's recovery from mental distress. As highlighted in 2.3 (Page 35), the gap in the literature addressed by this study is the contextualising of involvement work within the narrators' life 'stories' and more specifically their experience of recovery and identity change. This chapter addresses each of the subsidiary research questions in turn, synthesising the literature with the analysis in Chapter 4, in order to answer the primary research questions.

The subsidiary questions are considered first in sections 5.2 to 5.7 and are summarised below:

**Subsidiary research questions:**

- i) What barriers have service users faced to effectively participate in the planning, delivery and recruitment activities within mental health provider organisations? (5.2)
- ii) To what degree do the concepts of power and empowerment concern mental health service users who have engaged in the 'work' of involvement? (5.3)
- iii) To what extent do service users view themselves as part of a broader social movement, alongside other groups that have been historically marginalised or oppressed? (5.4)
- iv) To what extent have service users been able to successfully overcome any barriers and if so, what approaches have they taken? (5.5)
- v) How has the experience of user involvement work impacted on the recovery of service users? (5.6)
- vi) How do the narratives of service users participating in this project inform the future policy and practice of involving of experts by experience in the planning, delivery of and recruitment to mental health service providers in the UK? (5.7)

## 5.2 Barriers to Effective Participation

### 5.2.1 Barriers to Effective Participation

Effective participation within the context of this study is measured by the individual's perceived personal sense of purpose and achievement (being listened to and feeling valued), rather than the agenda of health care organisations being objectively met. The critical interpretive review in Chapter 2 highlighted a number of benefits and barriers to the involvement of people with lived experience (user consultants) in the shaping of services at all levels, but very much focused on the health care organisation agenda. The lack of focus on the user perspective was highlighted as a gap in the literature, which this study hoped to address. What has emerged from the data analysis in Chapter 4 is some degree of overlap between the two, which is now explored.

The first and most prominent shared barrier to emerge from both the literature review and data analysis could be summarised as the challenge of 'fitting in'. Service user consultants in the literature reported feeling a sense of isolation, possibly being the only service user representative in a setting with professionals and managers (e.g. Crawford et al, 2003; Hitchen et al, 2011). Often, the user representatives felt they did not understand the unwritten rules, languages and behaviours of engagement, which one had to adopt in order to be credible (Lowndes & Roberts', 2013, third wave institutionalism – see 2.3.2, Page 47). Some professionals questioned the representativeness of service user consultants in making decisions regarding the future direction of care provision (e.g. Crawford, et al, 2003), despite evidence to suggest that they were (e.g. Rutter et al, 2004; Rose et al, 2010).

Within my study, a majority of the narrators (9/10) reported a sense of not fitting in with the world around them from an early age, resulting for some in a need to please to elicit praise or avoid punishment and abuse ('Early Identity and the Challenge of Fitting In' - 4.5.2, Page 99). This can be reinforced when becoming a mental health patient, where fitting in with the rules and expectations of the clinical environment and appeasing professional expectations, would decide whether or not they might be detained under the Mental Health Act (2007) (e.g. Beth and Orla) or conversely whether or not they were offered therapy (e.g. Maggie). It is therefore unsurprising that some may experience a sense of anxiety about how they can be credible as a representative of other service users (look and behave like someone who has experienced mental health crises) and meet the perceived expectations of professionals and managers (look and behave like a professional). This would align with findings in the literature (e.g. Restall et al, 2013; Rebeiro et al, 2016). Although someone may be in a setting where they could potentially influence change, this sense of anxiety and possibly conflicting expectations may paralyse or stifle their voice. If one

finds their voice and assertively challenges, professionals in the room have the fall-back option to dismiss those views (and accompanying passion) as a residual symptom of mental illness.

This anxiety is not without foundation, given that resistance by professional staff (e.g. Bennetts et al, 2011; Restall et al, 2013) was another barrier to emerge from the literature. Within the narratives in this study the theme 'The Pros and Cons of Being a 'Mental Patient' (4.5.4 – Page 103) is very much linked with resistant behaviours and attitudes, particularly if the narrator was working alongside people whom had previously been involved in their care, or if they were to question or challenge established culture and practice. Having the lived experience of mental distress and accessing services undoubtedly qualified them to feedback on improving provision, As established by the narrator demographics (3.3.2.12 - Page 66) it was clear that members of this group were well-educated and articulate, some with professional lives before their mental health crisis. This should have been advantageous when assimilating into the professional health care culture and language, however, the burden of proof was on them to overcome the barrier of being seen as the 'mental patient' (e.g. Robert et al, 2003; Rutter et al, 2004 - discussed further in 5.5). The following shared barrier does not help in this task.

Elstad & Eide (2009) highlighted the importance for service user respondents that professionals recognised and supported them if they identified a deterioration in their mental well-being whilst undertaking involvement activity. This was supported by several of the narrators in my study, who had gone so far as to tell others the signs that their mental health was declining and giving permission for them to withdraw them from any activity. I am conscious that my research did not seek to elicit the views of mental health professionals, thus preventing them from engaging on this issue, however the literature suggests that concern about the additional support requirements of these user consultants was prominent in their minds (e.g. Doherty et al (2004). Whilst encouraging to see that professionals are cognisant of this group's mental well-being, wishing to minimise risk of harm, and the consultants themselves are grateful for this, what it does is to reinforce the role of professional and patient, with the power imbalance that results. Once again, it is within the gift of professionals to erect a barrier to meaningful involvement, albeit with the best of intentions.

Considering my discussion in 2.4 regarding the influence of neoliberalism on the provision of UK mental health care, particularly the focus on individualism and self-reliance, the phenomena described in this section are logical. If one has yet to leave the relatively safe confines of the mental health system, even if the only engagement is as an expert by experience, does that signal a level of dependency that equates with weakness, and therefore does this mean that paternalism towards this group will never be wholly removed? After all, the individual is

contributing to the improvement of services, but is potentially still considered a burden to those services (if still accessing support) and could remain on welfare benefits if their involvement role is not substantive.

### **5.2.2 A Barrier for the Organisation, Not for the Individual**

The final identified barrier within the literature review, the under resourcing of service user consultants, could be linked to the sub-theme 'fragility of status and identity as an expert by experience' (4.5.6 – Page 112), but not in a significant way. There was only one clear example where resourcing was highlighted from a narrator perspective; Geoff's rolling short-term employment contracts at a recovery college. The lack of strong presence of this barrier is not particularly surprising; with the ever-increasing requirements for service providers and research groups to demonstrate evidence of user and carer involvement (e.g. CSIP, 2006; NICE, 2019a), robust processes for remunerating user experts are essential (NICE itself recently published a guide on lay member payment and expenses for those becoming involved in its own committees, panels and groups – NICE, 2019b). It should also be noted that the under-resourcing issue, as highlighted in the literature review, was identified by service managers and not through grievances raised by user consultants (Bennetts et al, 2011). This suggests that budgetary challenges have the potential to act as a barrier to user involvement, or possibly act as a reason to avoid it.

### **5.2.3 Summary**

A major barrier faced by service users to effectively participate in the planning, delivery and recruitment activities within mental health provider organisations appears to be their firmly established status as a patient, with all the trappings afforded by our neoliberal present. This identity, which is reinforced by the organisation's ongoing duty of care and the individual's willingness to defer to the judgement of professionals regarding their mental health status, can hinder the knowledge and skills they are able to contribute. At this juncture it would be remiss to take the duty of care agenda as the only explanation of resistance by professionals to user involvement activity. Others are considered in the discussion of power and empowerment (5.3).

## 5.3 Understanding of Power and Empowerment

### 5.3.1 The Constant and Non-Constant Sum Conceptualisations of Power at a Personal (Micro) level

Section 1.5.3 (Page 20) and Figure 2 (Page 22) provided alternative understandings of power and empowerment, centred on the constant sum and non-constant sum conceptualisations. I speculated that the former would underpin the narratives in this study, whereby the power held by mental health professionals and services would be used to empower the narrators. At the micro level of empowerment, narrators as experts by experience retain the 'consumer' status they had as patients; at the macro level, social empowerment would be evidenced through the creation of opportunities to engage in involvement work as a group or network, facilitated by health care organisations under local and national policy and guidance. This differed from the latter, non-constant sum conceptualisation, where narrators would possess a sense of determination and personal control (psychological self-efficacy) at the micro level and at the macro level take ownership of the user agenda as a collective to directly challenge discrimination or inequality. My speculation was proven to be correct.

The literature review, focusing on experiences of power (2.3 – Page 35), provides context for the emerging barriers discussed in 5.2 and would appear to confirm my earlier assertion. Here Lowndes & Roberts' (2013) 'third wave' institutionalism comes into play; if one adopted the overarching narratives, practice and behaviours of the mental health professionals, they would enjoy continued access to involvement work and the benefits that entailed (social, emotional and financial). The data analysis in Chapter 4 and discussion in 5.2 revealed a strong desire by the narrators to fit in, when historically they had felt 'like a square peg in a round hole' ('Early Identity and the Challenge of Fitting in' - 4.5.2 – Page 99). Involvement activity offered them the opportunity to feel like they belonged, as a colleague with expertise by experience ('The Allure of Professional Patronage' – 4.5.5 – Page 108). Whilst the engagement in such activity also brought benefits for their mental health recovery ('The Benefits of Involvement Work – Healing and Validation' – 4.6.1, Page 116) it served to reinforce the power position of professionals, who could cease to employ people if they 'rocked the boat', as discussed in 5.2.1.

The specific research question here was to what degree do the concepts of power and empowerment concern mental health service users who have engaged in the work of involvement? Gosling (2010), asserts;

We are not empowered from the outside, we have to snatch power back and this is crucial to Recovery.' (P31)

Out of context, this comment would indicate a call for communal action; empowerment at a macro level (Figure 2, Page 20), however, Gosling (2010) is explaining the meaning of recovery from a lived experience perspective and 'we' actually means 'I'. This is important, highlighting mental health recovery very much as a unique experience; one person's 'journey' differing from another's in receipt of the same diagnostic label (Anthony, 1993). By promoting service user involvement work as a tool of recovery, as identified in a number of the narratives, encouragement or patronage by professionals has the potential to engender empowerment at the individual (micro) level. As shown in Figure 2 (Page 22) under the constant-sum conceptualisation of power, experts by experience remain consumers of the benefits involvement work has to offer, highlighted in the literature as possibly reinforcing the elevated position of professionals and managers (Fryers et al, 2001; Ostler et al, 2001). Under the non-constant sum conceptualisation, the individual's involvement work generates personal psychological benefits, and is therefore more aligned with Gosling's (2010) concept of self-empowerment. However, as highlighted in section 1.5.3 (Page 20), critics have suggested that little transfer of real power may actually take place (e.g. Wright, 1995; Ryles, 1999). This is evident throughout the narratives (see 4.6.1 & 4.6.2 - Pages 116-121) with the narrators articulating the development of new skills, as well as reclaiming former skills and identities, but identifying the pitfalls ('The Pros and Cons of being a Mental Patient' – 4.5.4 (Page 99); 'The Allure of Professional Patronage' – 4.5.5 (Page 108). Section 4.7 (Page 130-132) explored the tropes employed to convey key messages related to power and empowerment, revealing a meta-narrative of challenging dominant institutions to work towards freedom and greater self-knowledge. In a personal sense the concepts of power and empowerment are often well understood by people engaging in this type of activity.

The above does leave an open question about the narrators' concerns regarding power and empowerment at the grassroots community level or societal (macro) level, given that recovery and professional patronage potentially focuses on micro level empowerment. This is discussed in greater depth in 5.4, but at this point it is appropriate to revisit Arnstein's (1969) Ladder of Citizen Participation, introduced in 1.4 (Page 14) and discussed as part of the critical interpretive review in Chapter 2. The findings of my study indisputably align with the notion that universal citizen (or service user) control of services is a long way off in UK mental health services. The question to be answered here is where along the lower rungs of the ladder do my findings suggest the narrators are engaged with by professionals and services? Power and empowerment at a micro level will rarely, if ever, result in reaching the rungs of citizen power. Unless one generates individual power through raising and developing a regional, national or even internal public profile, a person on their own can only aspire to reach 'placation' (being placed in an advisory position, but power holders retain the right to decide). Some involvement activities will prove to be exemplars of non-

participation (the base of the ladder), whereby what the individual does is designed to educate or ‘cure’ them, rather than giving a meaningful voice. Examples of both are seen throughout Chapter 4.

Voronka (2016) offers a relatively benign description of power as being “neither good nor bad, it just is, and can be used in a multiplicity of ways” (Page 193). Whilst in principle nothing that is said here is in dispute, it fails to capture the misuse of power that can occur (Voronka’s ‘bad’), particularly in the context of mental health survivors/experts by experience. Voronka (2016) does point out the conflict between the neoliberal biopolitical nature of the mental health system and the social justice discourses, such as the recovery movement. However, as alluded to earlier in this thesis, the appropriation of recovery as a tool for treatment will inevitably curtail those more radical discourses.

### 5.3.2 Summary

Concerns over power and empowerment, from the perspective of the narrators, is very much contextualised within one’s personal story of recovery and therefore, at a micro level. Whilst this potentially brings a number of benefits for one’s recovery, it also serves to reinforce the power and dominance of professionals and neoliberal institutions, limiting the meaning and impact of any participatory activities. Whether or not people can hold concerns for power and empowerment at both a micro and macro level will be further explored in section 5.4.

## 5.4 A Social Movement of Mental Health Service Users?

### 5.4.1 The Constant & Non-Constant Sum Conceptualisations of Power and Empowerment at a Macro Level

A standard question I asked all narrators was whether they considered themselves to be part of a larger user movement in mental health. The responses to this are discussed in Chapter 4 (‘The Emerging Hero: Resistance and Action’ - 4.6.3 - Page 121), but what emerged was a recognition that they could be, but that this was not the greatest concern for many of them. In reality just one of the ten narrators presented what could be termed as a vision for communal grassroots action in shaping the development of future services (Mike); a vision which will be explored later in 5.4. The remaining narrators recognised being part of informal and formal networks of people who had experienced mental health difficulties and accessed services, from which they drew strength and a sense of community. However, this was often described in relation to inspiring their own personal recovery and them being positioned to inspire others (‘Rescued by Others, Rescuing

Others and Rescuing Self to Survive' – 4.4.4 - Page 92; 'Finding a Sense of Identity and Belonging' – 4.6.2 - Page 118). This firmly places any empowerment experienced here as being socio-structural, rather than grass roots in its origins; organisations have created mechanisms (such as service user training and consultancy groups, or Peer Support Worker teams) through which people with some commonality of experience can significantly influence the services or education being delivered (e.g. Crawford et al, 2002; Doherty et al, 2004; Treichler et al, 2015). Again, the transfer of power to such groups or networks and the scope of their activity are controlled by the organisation itself. This is strongly supported within the literature (e.g. Horrocks et al, 2010; MacDonald et al, 2014). Link once again to Arnstein's (1969) ladder, there is a suggestion that experts by experience may enjoy the higher position of 'partnership' on the ladder, which allows for a degree of negotiation and trade-offs with those holding the power (see Figure 1 – Page 16).

The one study in the literature review which arguably focused on the experience of grassroots communal action (and therefore the non-constant sum conceptualisation) was Rose et al (2016), appropriately titled '*Service user led organisations in mental health today*'. A key outcome of this study was that of the five user-led groups followed by the research team, the one that had ceased to operate was the one which had refused to adapt to the institutional rules and norms of the managerial discourse. As previously established within this study's narratives, those that refused to conform on an individual level were aware of the consequences; being 'cut adrift' from the organisation. It is therefore unsurprising that grassroots communal action, the generation of power and influence from the outside, was little in evidence within my findings (the only example provided by Simon in his 'thunder' dialogue – see 4.6.3 - Page 127).

#### **5.4.2 Summary**

The discussion across 5.3 and 5.4 point to concerns regarding power and empowerment very much leaning towards the individual (micro) level, rather than going beyond to the collective (macro level), which could be viewed with a sense of disappointment. As alluded to in 5.3, the stifling of activism, as a means to generating power at a grassroots level, serves the interests of institutions that traditionally have held power and are able to disseminate it to users/survivors as they see fit (the constant-sum conceptualisation – 1.5.3, Page 20). If a person is offered the opportunity to form an identity as an 'expert by experience', with its undoubted benefits to self-esteem, the sense of belonging and personal recovery that mitigates some of the risk of a relapse in their mental health, there is less of a need to identify as an activist or be part of a socio-political movement that challenges the status quo.

At an individual level, there is perhaps more cause for some optimism for a select group of survivors/experts by experience. Those with the ability to articulate themselves in a language understood by organisations, are able to generate a sense of individual agency and increased self-confidence/esteem. In turning to the tactics employed by experts by experiences to overcome barriers to involvement activity (5.5), it is reasonable to suggest that they too will be individual in nature.

## **5.5 Overcoming the Barriers**

### **5.5.1 Introduction**

In addressing the question about how service users have successfully overcome barriers to involvement, such as those discussed in 5.2, the literature offers limited insight. Most have sought to highlight the problems and barriers and then make future recommendations about how organisations might act to remove them (e.g. Weintstein, 2010; Rose et al, 2016). It is here that Armes' (2009) themes of *individual* discursive resistance to the formalised pressure of dominant professional groups provides a useful framework for understanding the relative success people have enjoyed in overcoming barriers to effective participation. The tactics employed by the narrators in this study have been thoroughly explored in 4.6.3 (Page 121), but are summarised here.

### **5.5.2 Reformism and Rationalisation**

To a degree 'Reformism' (working jointly with non-user/survivor allies to achieve their agenda) and 'Rationalization' (reluctantly engaging in dominant ways of working in order to ensure continued service user involvement and advocacy), have been the most common methods of overcoming participation barriers encountered by the narrators in this research. This has been discussed in the context of third wave institutionalism (see 2.3, 5.3.1, 5.3.2). By adopting this approach, survival as an expert by experience is assured.

### **5.5.3 Professionalism**

Although linked to the first two discursive tactics (working within organisations to instigate change), becoming a user professional represents a step up in status and perhaps has a more marked influence on one's identity. For a number of narrators, particularly those with professional lives pre-mental health crisis, this represented restoration of what had been lost. This was a strong theme within Chassot & Mendes' (2015) study; 'identity and identity

reconstruction'. In both their findings and my own, some are able to question the established notions of mental 'illness', or more specifically the assumption that one can never hold an identity outside that of the 'mental patient'. Returning to Identity Theory (1.5.2 – Page 20), it clearly outlines the notion that people will have positions determined for them by others, which must be accepted and internalised (such as being the service user). However, it also posits that one can hold multiple identities and organise them into a hierarchy of importance, depending on the given situation. In terms of addressing the barriers to involvement, for some there was an opportunity to lift the professional identity to prominence, whilst holding onto the lived experience identity to legitimise their involvement activity. If successful, one is placed in a more robust position to instigate change within the organisation and challenge the perspectives of others, if done so in an appropriate manner (e.g. Chassot & Mendes, 2015). At the time of interviewing, this service user professional status was held by four of the ten narrators, three of whom had clearly linked to the maintenance of their mental well-being (Ruth, Orla and Geoff).

It should be noted that achieving the status of service user professional as a means of overcoming barriers, potentially can have the opposite effect. As one becomes institutionalised within the network of professionals, adopting the requisite language and behaviours, they potentially move further from the body of service users they are there to represent, in the eyes of both fellow service users and professionals. Within the theme 'social experience of involvement', Chassot & Mendes (2015) reported that some participants had their legitimacy as a service user questioned, mirroring the experience reported by Beth. Equally Beth's assertion that the organisation she worked for wished for the service user part of her expertise to disappear is supported by the third wave institutionalism contextualised within MacDonald et al (2014). If one can accept this possibility and mitigate the risks, arguably as Mark was able to do, survival in the system is secured. However, if it proves unbearable, as in the case of Beth, it is time for an alternative approach; 'pride'.

#### 5.5.4      **Pride**

This approach, rejecting hierarchies and standing out as having expertise by experience, was identified in the smallest proportion of narrators in my study (Beth, Maggie and to a lesser extent Jess). For the first two, the getting to this point had involved a degree of distress, feeling ignored or even abused by the organisation they were involved in. For Jess, it had not been a negative experience that had prompted her to move away from several service user commitments, but a desire to move on with a life away from services altogether. Similarly, Maggie sought the freedom and opportunity for a different life, but this decision was very much rooted in the re-traumatising experience of continued interaction with mental health services, as both an expert and patient.

For all three this shift away brought a greater sense of personal freedom and self-determination, even if it removed the opportunity to directly influence mental health care. Beth stands out as the one narrator who outwardly rejected the system in order to reclaim her voice (as always philosophically supported by Mike as her husband).

Except for Armes (2009), the historical research literature is unsurprisingly quiet when it comes to 'pride' discursive tactics. As noted by Nelson et al (2006), research on user-led organisations has almost exclusively focused on the personal, self-help benefits for individuals involved, rather than social justice and systemic change.

By stepping outside the system, there is a potential draw towards the critical theorist and activist circles, joining organised groups such as 'Mad in the UK' (Mad Pride ceased to exist in 2012) or online collectives such as 'Recovery in the Bin' ([www.recoveryinthebin.org](http://www.recoveryinthebin.org)) who will publicly embrace their experiences and identity as a 'mad' person. As intimated by Mark in 4.6.3 (Page 121), the relatively unregulated role (by services at least) of social media is becoming increasingly used to convey an alternative perspective on mental distress, the treatment people receive and the concept of recovery itself. However, these alternative perspectives are not yet loud enough to be consumed at a population level in the way that other social media movements have (the 'Me Too' movement is perhaps a useful current example – [www.metoomvt.org](http://www.metoomvt.org)). For individuals this creates a risk of being labelled a fringe radical, whose message should be viewed through the lens of mental 'illness'. The potential result, certainly whilst service user involvement activity is managed by the organisations providing care, is that people on the outside will never be heard. It is perhaps the knowledge of this reality that motivated Mark to continue within his Involvement Coordinator role? However, for those who struggle with the compromises one must make to be heard within an organisation (such as Beth), the potential creation of another barrier to involvement and loss of power is a worthwhile sacrifice against the regaining of an authentic self. However, as discussed in 2.4 (Pages 41-43), this is not necessarily the end of the story.

The emergence of psychopolitics and mad studies presents an opportunity for collectives of survivors/service users, academics and workers within the mental health system to be formed. As McKeown et al (2014; Page 282) state;

"...the recognition of shared interests and contradictory positions between services users and workers pens up possibilities of more nuanced negotiation of identity issues and the appreciation of the experience of mental health and service use or care work from each other's perspectives."

This is discussed further in the final chapter.

### **5.5.5 Summary**

The ability to overcome barriers to user involvement work, self-imposed or placed by organisations, would largely appear to be predicated on one's ability to play a political game. By having an awareness of the rules and behavioural conventions, as well as being able to articulate oneself in an acceptable way, an individual can secure the attention of powerful others. In turn this may instigate positive change within services. For those who can accept and live with these terms of engagement, the added reward is the potential restoration of lost confidence, esteem or even professional status (as a service user professional). However, those who refuse the terms of engagement and step outside of the organisation, the sense of personal well-being and freedom can be equally rewarding, and the opportunity to be part of something bigger than themselves does not necessarily diminish.

## **5.6 Impact of Involvement on Recovery**

### **5.6.1 Introduction**

To answer how the experience of user involvement work has impacted on the personal recovery of service users, the similarly focused Chassot and Mendes (2015) study is an important comparator (Appendix A – Pages 196-206 and 2.3. – Page 35). Supported by other studies included in the literature review (e.g. Restall, 2013; Treichler et al, 2015), the authors identified three key themes; ‘Being able to make sense and reframe mental distress’, ‘The social experience of involvement’, and ‘Identity and identity reconstruction’. Chassot and Mendes (2015) had a similar number of participants (n=12), who were similarly narrow in terms of age range to my own research. These are now discussed in light of my findings and analysis in Chapter 4.

### **5.6.2 Being Able to Make Sense of and Reframe Mental Distress**

Chassot and Mendes (2015) found that being part of a group of peers (i.e. those who had experienced mental health crises) potentially enabled them to safely share painful or embarrassing experiences of distress, as well as constructing and reconstructing the meanings they attached to this aspect of their lives. There is alignment to my study; almost all my narrators were drawn together through a service user consultancy group, organised and administered by a mental health trust (Figure 3 – Page 66). From here confidence and skills were nurtured, enabling

them to share their story for the benefit of audiences of mental health professionals and service users who were at an earlier stage of their own recovery.

With the caveat that my research focus may have provided some guidance, the narrators demonstrated an ability to contextualise their involvement work, the positive and negative aspects, within their recovery from mental health crisis, and subsequently their overarching 'story'. The positives (see 4.6.1 - Page 126, 4.6.2 – Page 128 and 4.6.3 - Page 131) had the potential to inspire hope that their lives could be different from how it had been in former times, including the adversity experienced in early life. The impact on identity and identity reconstruction is discussed further in 5.5.3. Equally, on the negative side past trauma and fragility of self could potentially be exacerbated by continued involvement with the mental health system and the actors within it. Either way, what emerged at the end of many narratives was a reflection on the story told to that point, which will continue to change and involve in the future as new experiences are gained. As a researcher, I would not be so blinkered as to believe this is exclusively the result of participating in my study (as highlighted in this thesis, their stories had been told on many previous occasions. Therefore, the individual sense making, and reframing of their mental distress was a continuous process, which I briefly joined.

### **5.6.3 The Social Experience of Involvement**

As highlighted in 3.3.2.11 (Page 65) most relationships between the narrators developed and informal networks emerged from activity created and facilitated by professionals within the care providing organisation. From this all ten would find a sense of belonging (4.6.3 – Page 118). The participants within Chassot and Mendes (2015) were similarly explicit in their reporting of community and belonging within involvement work. However, there was also an acknowledged undercurrent of exclusion and rejection should one's experience of mental distress or diagnostic label not be deemed severe enough. This was not the case in my study findings, where peer relationships were viewed as exclusively positive and encouraging in the consultancy group (Beth was the only one to report negative attitudes from peers, but this was in the context of her formal Involvement Coordinator role). A possible explanation for this divergence may lie in the participant demographics, but this is difficult to establish with any certainty. Both Chassot and Mendes' (2015) and my study participants were similarly in the 'middle' age bracket, but ethnicity, level of education and background is omitted by the former.

As discussed in 3.3.2.12 (Page 66), the people in my study were of virtually the same ethnic background (white), of similar intellect and educational attainment, and had accessed the same service provider (Maggie was the one exception) for comparable expressions of mental distress

(low mood, anxiety, self-harm and attempts to end their life). No one articulated in their interview experiences of psychotic phenomena, although I recognise that this may be something they might choose to withhold from me as the interviewer. With the exception of Jess, even their ages fell within the same bracket (middle-age). So, whilst the sense of being part of a social movement with a shared mission or agenda (outside of that defined by the organisation) was lacking, what they had was the commonalities to be drawn together socially, irrespective of their lived experience. The fact that they had been afforded the opportunity to use their lived experience to engage in involvement work would arguably say more about the organisation and professional facilitating this. For all intents and purposes, it is a further demonstration of dominance and power; including only those people who will articulate and behave in ways that are acceptable to the organisation (Lowndes & Roberts, 2013), whilst offering a sense of community and belonging to improve their individual mental well-being.

#### 5.6.4 Identity and Identity Reconstruction

Identity and identity reconstruction, the final theme in Chassot and Mendes' (2015) study, is where there is the strongest alignment with my own research. This extract from their discussion provides a useful summary;

“Engagement, then, helped reconstruct spoiled identities, as they began to see themselves as fighters and agents of social change.”

(Chassot & Mendes, 2015 – Page 385)

The process briefly outlined in this statement accurately reflects the experience of most of the narrators in my study. In 4.5.2 (Page 99) I discussed the early identity of the narrators and the challenges many found in fitting in with the world around them. I linked this to Stryker's (2007) identity theory, which proposes that one's social position is often designated by others, then accepted and internalised by the individual. The descent into mental health crisis 'spoiled' many positive identities adopted by the narrators (spouse, parent, academic, professional), whilst the designated identity of 'mental patient' served to reinforce some of the negative identities ascribed in early life (outsider, inferior, deviant). When the opportunity for involvement came their way, so did the chance to restore some of what was lost and create a new narrative for their lives (extensively discussed in 4.6.2 – Page 118 and 4.6.3 – Page 121). The use of the word 'fighters' by Chassot and Mendes (2015) is important, as the capacity of the dominant institution to keep one in check is powerful.

Whilst Chassot and Mendes (2015) recognised the personal transformation experience that involvement work could provide, in the context of their study it was viewed as a by-product of the mental health movement's drive for social change on a larger scale. As indicated already in my discussion, the reverse would be the case in this study; social change was a secondary benefit of individual transformation. Even Mike and Mark, whose narratives presented the strongest case for a change in the way services might be delivered or people's voices should be heard, had a greater focus on the benefits of the individual experience. Despite some continuing fragility expressed by a few of the narrators, almost all sought to convey a sense of achievement and transformation of self in ending their 'story'.

### 5.6.5 Summary

This subsidiary question is one of the most important within my study; does the work of involvement actually benefit the personal recovery of the individual undertaking it? The findings and discussion have suggested that such activity has great potential to positively influence recovery from mental health crisis by enabling one to make sense of what has happened to them and regularly revisit its meaning in their life 'story'. Usually this will come via opportunities to share their narrative with professional and peer audiences. Alongside this, people may have the experience of meeting and forming relationships with others who have significant insight into their distress, through their own lived experience. As in my study, formal and informal networks of peer relationship can develop, providing ongoing support even after services have withdrawn. Finally, as often is the case with mental health crises and becoming a user or of services, identities and a positive sense of self can be spoiled or even destroyed. On a personal level, user involvement work has the potential not only recover lost identities, but create new ones. However, there also exists the risk that negative identities, such as that of the 'mental patient', can be reinforced through ongoing engagement with professionals and organisations.

## 5.7 Feeding Forward to Inform Policy and Practice

### 5.7.1 Introduction

The final subsidiary question moves beyond the individual experience and asks how the findings of this study inform policy and practice of involving of experts by experience in the planning, delivery of and recruitment to UK mental health services in the future. Again, linking back to Arnstein's (1969) Ladder of Citizen Participation (Figure 1 – Page 16), a question is posed as to

whether individuals or groups of people can ever reach the highest rungs of 'delegated power' or 'citizen control' in the future

### 5.7.2 The Cruise Ship Analogy and Social Capital

I ask the reader to bear with me, whilst I explain why I have introduced the cruise ship to a thesis about mental health service user involvement activity! The cruise ship is often very large, holding thousands of people who are there in different roles; the captain and senior officers oversee a safe and timely journey, the engineers ensure the ship moves, the hospitality and entertainment staff provide passengers with a comfortable and enjoyable experience, and finally there are passengers themselves, without whom the whole enterprise is rendered pointless. Systemically, each group of people (part) working in harmony together is required to make a cruise experience successful. If the cruise ship represents the mental health provider organisation, the Captain and senior officers would be the board and senior management and the crew would be the multiple professional groups delivering care. Finally, the passengers represent not only the people in mental health crisis, who engage in the service, but also those who choose to enter involvement activities (the focus of this study).

The difficulty with a cruise ship holiday (and why many may balk at the idea) is that the experience is controlled. Passengers are treated with respect, because they are paying for their holiday, and the positives or negatives experiences noted through feedback and evaluation. However, the ship will work to a schedule, berth at predetermined destinations and whilst out at sea offer passengers a finite range of activities (albeit usually quite extensive). If the passengers collectively demanded that the ship stayed longer at a place or berthed somewhere different, they would be refused. If passengers do not board prior to a designated departure time, they will be left behind. The same principles apply within the mental health system, where the power of neoliberalism enmeshed with a biomedical understanding of distress holds sway; experts by experience have a degree of individual agency, by offering feedback and evaluation on the current service being provided and informing the future direction of care delivery. However, if one is identified and invited by professionals to act as an expert by experience and possibly paid for their input, ultimately the organisation is controlling the experience. One can challenge or resist in an 'appropriate' way and their feedback may be taken on board if it does not fundamentally alter the status quo. One can be more vociferous in their challenging, but are at much higher risk of being ignored or excluded altogether (metaphorically left on the dockside).

To ensure complete control over one's holiday experience, the only way is to buy or charter your own boat. However, this is a costly endeavour that requires the availability of the necessary

resources. As Rose (2014) succinctly states; "...we have to tackle head on the fact that our society is intolerant of difference" (Page 218). However, in the world of the mental health service user, the ability to step outside of the system whilst maintaining a desire to change it for the better, requires social capital.

There has been historical debate regarding a definitive definition of social capital, particularly as to whether it refers to individuals or groups of people (McKenzie and Harpham, 2006). Arguably the most commonly applied definition within health sciences is provided by Putman (1993), who refers to;

"...features of social organization, such as trust, norms and networks."

(Putman, 1993 – Page 167)

Putman (1993) argued that social capital is made up of five key characteristics;

- Community networks, voluntary, state and personal networks
- Civic engagement, participation and use of civic networks
- Local civic identity – belonging, solidarity and equality with members of the local community
- Reciprocity and norms of cooperation, a sense of obligation to help others and confidence in return of assistance
- Trust in the community

If this definition is to be accepted, what becomes immediately clear is the lack of social capital for a person with a history of mental health issues, as part of a group who are often discriminated against and pushed to the margins of society (Rose, 2018; Campbell, 2019). In light of my discussion across Chapters 4 and 5 regarding the potential personal benefits and network of relationships involvement work has to offer people with lived experience of mental health crises, it becomes clear that the mental health system offers a contained form of social capital. As my discussion has demonstrated, by accommodating and working within the system, following the institutional rules and behaviours, an individual can feel a greater sense of empowerment and agency within their lives, without presenting any significant challenge to the status quo within services (micro level). It is suggested within the field of community health psychology that these 'accommodationist' approaches mask the way in which poor mental health is driven up by the conflicting agendas of service users and power-holding professionals (Moore et al, 2006). The result is a widening in the political power gap between individual and institution.

Community health psychologists who adopt a more critical/emancipatory perspective (e.g. Campbell, 2019) advocate more adversarial strategies by those in the weaker power position, in order to achieve change at a macro level. This is achieved by people uniting within and across marginalised groups (bonding and bridging social capital), and as with Armes' (2009) 'pride' approach to discursive tactics, necessitates stepping out of the domain of those holding the power position.

### 5.7.3 A Fundamental Shift in Service User Involvement Activity?

In 5.7.2, I argued that within services, user involvement activity will always be limited in terms of influencing meaningful change in policy and practice. I have suggested that in order to attain true social capital, as defined by Putman (1993), individuals and informal networks with lived experience of mental health crisis may need to step out of the mental health system and surrender the patronage offered by organisations and professionals. However, this leaves a gap in the system, where there is some degree of listening and accountability towards service users, as well as the need for an alternative way for the user voice to effect change from the outside.

Fortunately, there are emerging alternatives, which sit outside the service provider environment, and arguably embody some of the key strategies for mental health activism, as advocated by figures in the field of Mad studies (McKeown et al, 2014; Moth et al, 2016; Spandler et al, 2016). Moth et al (2016) offer a three-part strategy for mental health activism in the 21<sup>st</sup> century, centred around content, form and agency;

- Content – challenge the 'strivers versus skivers' rhetoric of the UK central government in and the austerity agenda. Seek to campaign for people to flourish in the context of 'distributive injustice'.
- Form – a transitional approach to change, emphasising swift action to resolve the most pressing social issues, but being underpinned by a new social logic (that moves away from neoliberalist principles).
- Agency – not in the individual sense, but cross-sectional alliances between different groups of people to counter individualistic 'divide and rule' social policy.

The authors go on to describe "the articulation of a politics of commonality and solidarity capable of respecting and valuing difference as an essential feature (Moth et al, 2016; Page 283). One such alternative approach is the mental health triologue.

The mental health triologue is not a new approach, evolving in late 1980s Germany and spreading mainly to other European countries, as well as the USA and China (MacGabhann et al, 2018).

Utilising the principles of Open Dialogue (where psychotherapeutic interventions are undertaken in the presence of the service user's family and social network – Razzaque & Wood, 2014), trialogues are a community-based approach, which gathers different stakeholders in the mental health system (those with mental health difficulties, families, friends, community members and professionals) in a neutral setting to discuss and develop a common language and understanding about a given mental health related issue. As a mental health nursing educator and citizen, I have attended trialogue meetings, coordinated by a local third sector organisation and found one of the most powerful aspects is the requirement that stakeholder titles (such as 'service user', carer' or 'professional') are left at the door before the meeting commences (Walker & Barber, 2018). The environment is equally important; usually a church, village hall or similar type of community space, which is owned by none of the stakeholders and therefore services to minimise any potential power imbalances.

Research studies looking at the impact of mental health trialogues have been more recent, emerging from Austria (Amering et al, 2012) and Ireland (MacGabhann et al, 2018). Amering (2012) points to the unconventional nature of the trialogue setting, the lack of didactic approaches (such as found in psychoeducation) and absence of strict rules observed in psychotherapy groups to explain the challenges of systematic study into the approach. However, MacGabhann et al (2018) were able to gather data from 7 trialogue groups and 48 individual participants. The findings suggested the following:

- Irrespective of cultural background and mental health role, knowledge and awareness of mental health was increased.
- The environment created within the meetings felt secure enough for people who ordinarily would be reluctant to share their experiences/views on mental health to do so, offering members from provider organisations a broader perspective.
- The meetings served to aid the deconstruction of pre-existing power dynamics within mental health.

These findings are key in light of my own, given that the narrators' aspirations were to offer their lived experience and perspectives on mental health care in order to inspire peers, educate professionals and possess a personal sense of purpose and achievement. As discussed in this chapter, the barriers to these aspirations always led back to the power imbalance between themselves and the professionals/institution, which trialogues have the potential to address.

It is important to consider whether such an approach fits with the more adversarial tactics to achieve social capital, highlighted by Armes (2009) and Campbell (2019). In some key ways it does not, as trialogues (or an adaptation of the approach) allow space for traditional power holders

(professionals) to remain. However, this is not necessarily a negative; people who have engaged with services (voluntarily or otherwise) may feel a sense of hurt and injustice around their experience, which requires the presence of professionals to hear about this (e.g. Spandler & McKeown, 2017). The opening up discussion and debate between has the potential to promote healing and change going forward.

Another potential issue is the fact that trialogues are locally focused in their membership and agenda for changing services, which precludes the creation of a national or international triologue 'movement'. However, as found in this study, many of those engaged in involvement work did not see themselves as being part of a broader social movement anyway.

The concept of trialogues is seemingly not without its issues to address; its locality focus being one. As acknowledged by MacGabhan et al (2018), the relative success of trialogues is reliant on engagement by service provider representatives, as those who are able to go away and implement change within an organisation. Because of this, they potentially serve to reinforce the limit to which people with lived experience of mental health crisis directly can influence improvements to care ('Consultation' on Arnstein's Ladder of Participation – see Figure 1 – Page 16). In relation to this, service providers are under no obligation to implement recommendations coming out of trialogues, even if delivered by their own staff. This firstly raises the question of organisational seniority in those attending as provider representatives at meetings, against the backdrop that all stakeholders are welcome and have an equal status. The informal nature of trialogues, one of its key appeals, also impedes its ability to act as an accountable body for providers, in the way that bodies such as Clinical Commissioning Groups (CCGs), The Care Quality Commission (CQC) and NHS England are in the UK.

The final issue relates to how such events are resourced, especially if they are to be held on a regular basis and in community buildings, who will generally charge for use. The administration of trialogues requires resourcing and as with many third sector initiatives, relies on statutory funding or their own fundraising activities in order to survive. To be truly independent, there is an importance that such approaches remain free from obligation to dominant institutions who hold the purse strings.

Trialogues provide a safe alternative environment in which those with lived experience can share their story, inspire others, be listened to and validated by stakeholders across the mental health system. However, in order to hold service providers to account for the care they deliver and promote the non-constant sum conceptualisation of power to achieve greater balance between people and the institution, something more formal is required to run alongside it. Arguably, this does exist in England in the form of Healthwatch. The result of the reorganisation of patient

involvement bodies in the early 2010s, Healthwatch England was set up under the Health and Social Care Act 2012 (HM Govt, 2012) to gather information on the experiences and concerns of people who accessed health and social care in their local community, and use this information to speak on their behalf. The organisation at its inception was hosted by the Care Quality Commission, but reported directly to the Department of Health and was divided into 148 local Healthwatch groups. However, the true power and influence Healthwatch possesses has been increasingly questioned in the intervening years, particularly after it was embedded within the CQC in early 2016, reporting to its chief executive, rather than the Department of Health (Hazel, 2016). Critics have also pointed out that Healthwatch was never given the level of resource, statutory powers or responsibilities held by previous incarnations, such as the Community Health Councils (People's Inquiry into London's NHS, 2014). If this is the case, then it would appear to face similar challenges to trialogues.

#### 5.7.4 Summary

In looking at how the narratives feed forward, the discussion in 5.7 has highlighted the concerns regarding the efficacy of user involvement 'work' being contained within the sphere of mental health service providers (the cruise ship analogy). Undoubtedly there are positive gains for both the individual with lived experience and the organisation (as highlighted in earlier sections) and opportunities for the former to influence the work of the latter. However, ultimately the organisation holds the power and dictates the direction in which it wishes to head. Alternative, community-based initiatives, such as mental health trialogues, provide social capital to those who are ordinarily disadvantaged in society (such as mental health service users) and begin to challenge the 'divide and rule' politics of neoliberalism. Importantly, as suggested by some of the key authors in the field of Mad studies (McKeown et al, 2014; Moth et al, 2016) such initiatives do not exclude the input of those seen traditionally as the power holders (health care professionals and managers). Alongside these there perhaps remains a need for more a more formal community-based body, organised by service users, to be wholly independent of national government bodies, as well as local service commissioners and providers, who can provide robust accountability processes; true citizen power.

### 5.8 Answering the Primary Research Question

This chapter so far has been answering the subsidiary questions to build up to addressing primary research question below. My intention here is not to tread over the same discussion, but draw together the key points; a summary of summaries.

**Primary research question:**

What is the participants' experience of power and empowerment when involved in the planning and delivery of mental health services and the role such experiences have had in their overall recovery?

As acknowledged in Mark's interview, when there is a scenario which one person is tasked with helping another, there will always be an imbalance of power. Though not articulated so directly, most other narrators in this study would appear to concur. As highlighted in 5.2, there is a duty of care held by services and professionals, embedded into organisational mission statements and codes of conduct, which cannot simply be switched off when the service user starts to work alongside. Equally, experts by experience may defer to the clinical expertise of the professionals around them, particularly in relation to their mental wellness, surrendering what power they do possess.

For those who have lost formerly held identities and lack a current sense of self due to the destructive force of mental health crises, involvement work can provide a sense of individual empowerment and hope for the restoration of self in the future, even with the challenges of negative professional attitudes, the need to be politically aware and the rollercoaster ride of mental well-being. However, a key word here is 'individual'; reflecting the underpinnings of the mental health recovery model, it is about 'me' and 'my' wellness. I would never criticise people's need at times of vulnerability to focus on themselves as the highest priority, but when it is promoted as the default of existence, there is a consequence for social capital. Although peer networks have been formed as a result of organisationally created involvement activity, providing support, advice and ongoing friendship, there is a stifling of the collective voice. When a group of individuals are contained within the dominant institution, where does the challenge to change mental health care for the better at a macro level come from?

It would be unfair to dismiss the possible impact people as individuals can have within an organisation and in some cases their ability to 'create spaces' for others to have a voice too. However, one's chances of success are currently predicated on the ability to demonstrate political awareness, understand the organisational agenda and behave in a way that is acceptable to the institution (needing to please). Failure to do this will result in exiting involvement work in that setting, which in the experience of several of my narrators has brought a rewarding sense of personal well-being and freedom. Nevertheless, the significance of this step should not be underestimated.

In terms of engaging in a community that exists outside the confines of provider organised service user consultancy groups and recovery colleges, alternatives do exist to provide social capital and the opportunity to change services for the better, either informally (e.g. trialogues) or formally (e.g. membership of a local Healthwatch group). As it stands, these fall short of the 'citizen control' envisioned by Arnstein's (1969) Ladder of Citizen Participation, but are progress in the right direction.

Returning to the recovery 'journey'; the opportunities to share one's 'story' and develop knowledge and skills through involvement work enables people to frame and reframe their lived experience, discarding previously held meanings and creating new, more positive ones. Discussed earlier in this thesis, as a researcher I have briefly entered their stories and hopefully been positive in some small way (or at least not destructive!). However, these stories will continue to evolve.

Chapter 6 will provide conclusions to the research in this thesis, discuss the strengths and limitations of my work, outline the contribution to knowledge it makes and offer recommendations for future research.



## Chapter 6 Conclusions and Recommendations

### 6.1 Introduction

This study adds to the wealth of literature surrounding the involvement work of people with lived experience of mental health crisis in shaping the future of care delivery, whilst uniquely contextualising such activity within the individual's overarching 'story'.

The key objectives were to;

- Present the experiences of people who have accessed mental health services and then gone on to service user involvement activity.
- Explore how the power relationships between the informants and professionals may have evolved in light of this changing role.
- Examine how the experience of service user involvement work fits within the informants' overall life 'story' and recovery from significant mental distress.

The key findings reveal the importance of user involvement activity in challenging or reinforcing the individual psychosocial experiences and identities held earlier in life, leading up to and during their first mental health crisis and entry into the care system. At its most beneficial, involvement work has enabled some people to reclaim professional identities that have been affected by mental distress, and for others, afforded them the opportunity to develop new knowledge and skills. For all it has led to the development of a supportive network of peers and a greater sense of self in the world. At its most counterproductive, engagement in such activity has been shaped or reinforced by negative schemas developed in earlier life, particularly the belief that one does not quite 'fit in', however hard one tries.

The study findings also confirm the presence of a very masculine concept of power and empowerment, whereby the dominant institution (mental health services and the professionals operating within it) retains the majority share of power and will give away enough to those seen as working in partnership, without there being a fundamental shift in overall direction (the cruise ship analogy – 5.7.2 – Page 152). This is supported by the individualistic nature of the recovery model of mental health and its application within care. As a consequence, I have pointed towards alternative ways of engaging mental health service users that embraces a more feminist, self-generating approach to power and potentially provides an independent framework, that service providers are meaningfully accountable towards. The conclusions of the study are briefly outlined in 6.2, serving as a reminder of the discussions summarised in Chapter 5.

## 6.2 Conclusions of the Study

### 6.2.1 The Positive Impact of Involvement Work on Recovery and Identity

The work of involvement has the potential to positively impact upon a person's recovery from mental health crises in a global sense of confidence and esteem building. If the activity involves revisiting one's 'story', this provides the person with an opportunity to review and change the impact and meanings of events, which is often the aim of psychotherapeutic approaches to working with mental trauma and distress (Feltham et al, 2017). This creates the possibility for not only recovering lost identities, but also creating new ones. However, there remains the risk that negative identities, such as that of the 'mental patient', can be reinforced through ongoing engagement with professionals and organisations.

### 6.2.2 Reflecting on the Social Construction of Mental 'Illness', Identity and the Creation of Barriers to Effective Participation

The establishment of one's identity as a mental health patient, first and foremost, is the entry requirement for involvement activity, but also the greatest barrier to influencing meaningful change. The benevolence of providing care to those devastated by 'illness' of both the mind and body, is written into all health professional codes of conduct (e.g. NMC, 2018), resulting in those with lived experience around the meeting table being viewed through the lens of their mental illness diagnosis, however professional they are in their conduct and behaviour, and genuine service providers are in wishing to hear the service user voice. For service users, an unkempt appearance maybe interpreted as a sign of self-neglect, whereas for a professional it is more likely to reflect the busyness of their lives. Robustly challenging or being passionate about a particular issue is perhaps seen as a sign of poor emotional coping skills, as in Maggie's experience. Again, Foucault's (1977; Page 304) remark "the judges of normality are present everywhere" seems pertinent.

The ability to be politically aware, knowing the rules and conventions of the environment one operates in as a service user representative, and being able to articulate oneself well, will enable an individual to challenge some of the key barriers up to a point. For those who can accept and live with these terms of engagement, the personal rewards in terms of increased self-confidence and esteem, as well as identity formation can be substantial. However, those who cannot accept these terms must step outside of the organisation to achieve a sense of personal well-being and identity, or risk an erosion to the progress made in their recovery from mental health crises.

### **6.2.3 Reflecting on Power and Empowerment: Individualism Versus a Social Movement of Mental Health Service Users**

The constant-sum conceptualisation of power dominates in a majority of organisations where mental health service user involvement activity takes place. Power is transferred to an individual or small group of service users by the dominant institution, but can be removed again should the feedback messages become too unpalatable. However, this eventuality can be avoided through the promotion of involvement activity as a therapeutic benefit of one's individual recovery. Articulate service users are able to generate a sense of individual agency and increased self-confidence/esteem. By focusing on that, one is empowered on a micro level, and therefore less concerned about being part of anything bigger than themselves or the small network of peers they may have worked and trained with (such as a broader social movement of mental health service users). As discussed in 1.5.2 (Page 19), the possibility that organisations may fail to acknowledge or understand the binding attachments that bring 'stakeholders' together, whilst focusing on the achievement of their set agenda (Crane & Ruebottom, 2011), further impedes macro level empowerment. This has the unfortunate (or fortunate, depending on one's perspective) consequence of reinforcing the neoliberal socio-political and economic ideals, whereby no group of marginalised people (this includes unsettled/radical professionals and academics, as well as mental health users/survivors) can easily form collective action to challenge the status quo (Sedgwick, 1982; McKeown et al, 2014; Moth et al, 2016; Spandler et al, 2016).

### **6.2.4 Feeding Forward to the Future Planning and Delivery of Mental Health Care**

This study has questioned the efficacy of user involvement 'work' being contained within the sphere of mental health service providers (the cruise ship analogy), despite the positive gains for both the individual and organisation (as highlighted in Chapter 5). Moving the power base into the community, with initiatives such as mental health dialogues, provide social capital to mental health service users, who are ordinarily disadvantaged in society. Such schemes do not exclude the input of traditional power holders (such as health care professionals), which to some critics may be deemed merely a change of geographical location, rather than an impetus for meaningful accountability and change. However, geography is important; by locating a forum for discussion in a neutral space, such as a church hall or community setting, immediately no one 'party' can claim ownership and a power on that basis. The measures to anonymise attendees' status and background, further assists in levelling out the balance of power (MacGabhann et al, 2018; Walker & Barber, 2018). For an individual, having one's views listened to and respected in such a balanced environment, should bring all the benefits of traditional, provider-led involvement activity.

There does remain a question over the need for a more formal community-based body, properly funded and resourced, and organised by those who have accessed mental health services. In the way that service provider organisations are accountable for their strategy and care delivery to semi-independent bodies, such as the Care Quality Commission (CQC) and local Clinical Commissioning Groups (CCGs), this type of body could sit alongside this.

### **6.3 Strengths and Limitations of the Study**

As discussed in Chapters 1 and 2, whilst there is extensive empirical literature focusing on mental health service user involvement and its effect on the organisation and delivery of care, there are fewer studies exploring the impact on a person's experience of recovery and virtually none contextualising this within their overarching life 'story'. Therefore, an in-depth study such as this was warranted.

A key strength of this study lay in its methodological approach – the life story interview. Whilst setting out the broad purpose of the interview (see Appendix E – Pages 227-232), the person being interviewed had the freedom to organise the narrative in a way that felt generally comfortable and communicated the story they wished to tell. At one end of the scale I had a participant who chose to reveal virtually nothing about their lived experience and instead focused on his views on involvement activity for almost the entire 70 minutes of the interview (Mark). In contrast, Elsa's narrative came in at 160 minutes, with a majority focus on her lived experience (with everyone else somewhere in between). Whilst both interviews were challenging in different ways, what they reflected were the various ways in which people were able to create their narrative and attach meaning to them.

The study has presented some limitations with regards to the sample size, geographical, organisational and cultural demographics of the people recruited for interview, not least by utilising a theoretical sampling strategy ('snowballing') (3.3.1 – Page 68). However, by engaging with this group of narrators, it has shed an important light on the supportive relational networks that can emerge among like-minded peers, with or without the sense of being part of a wider social movement. It has exposed the benefits to individuals in terms of creating a sense of community and reducing the sense of isolation that so often accompanies the experience of mental distress. The network of relationships in the group, outlined in Figure 3 (Page 66) also provides insight into the approaches service provider organisations might take to identify people for user involvement activity, and what limitations this has on the feedback they receive.

In my role as a researcher, I have brought in my experience as someone who has been affected by mental distress (although not accessed services), a Registered Mental Health Nurse of many

years, and a mental health nurse educator in a university setting. This has brought a number of potential benefits to the research process, such as an ability to reflect on my influence on the interviews themselves and within the analysis of the data, the access I have had to colleagues with lived experience or a background in academia (sometimes both!). However, with this comes the risk of what De Witt and Ploeg (2006) describe as undetected pre-understanding, when approaching the analysis, discussing the findings and presenting the conclusions. I have tried to minimise this through the small network of support described above, reflecting on relational ethics and reflexivity (see 3.2.2 – Page 66), and demonstrating rigour in my methodological approach to data collection and analysis (3.1-3.4 – Page 55-81).

The knowledge generated within this research study has never purported to be an objective account of service user involvement work, which would be inappropriate in addressing the aims and answering the research questions posed in Chapter 1. It is an interpretation of a group of people's subjective experience, which has been developed through a lens of reflexivity and continuous justification of my theoretical position. 6.4 considers the contribution this thesis makes to new knowledge.

## **6.4 Contribution of the Thesis, Recommendations for Further Research and Dissemination Strategy**

This thesis has referred at a number of points to the micro (individual) and macro (community and societal) levels, particularly in reference to power and empowerment. What has been demonstrated through my analysis in Chapter 4 and discussion in Chapter 5 is the potential disconnect in a person's mind between their individual recovery 'journey', which may impact upon the people who hear it, and the sense of being part of something bigger, that is a force for positive change in the way people in mental distress are cared for. The conclusions presented in 6.2 suggests a spectrum of activities that a person may engage in, which will be expanded further in this section. It is first important to revisit the theoretical considerations at the beginning of the study and what the research has added to that.

### **6.4.1 Is Arnstein's Ladder Still Fit for Purpose?**

Arnstein's (1969) Ladder of Citizen Participation, introduced in 1.4 (see Figure 1, Page ?) has often been applied to service user involvement activity, but not without criticism. Tritter and McCallum (2006) question its linear approach and singular focus on power as being handed over by traditional holders to service users (the constant-sum conceptualisation), as well as its perceived failure to account for the people's preferences (not everyone wants to become involved).

Alternatively, they call for multiple ladders which not only account for those individual wishes, but also the “dynamic and evolutionary nature of user involvement” (Page 165). Their criticisms carry merit; the ladder does emphasise a competitive dynamic between power holders (government, the NHS and service providers) and citizens (those with lived experience of services), with the pinnacle being full citizen control. This arguably upholds the market economy principles of neoliberalism and does little to challenge the biomedical model of mental health and illness (as one gets better, the professionals who decide what better looks like relinquish some of their control). In defence of Arnstein (1969), the ladder was originally developed for application to citizen involvement in town planning and not the psychopolitics surrounding the mental health system. However, the development of multiple ladders with different emphases is potentially useful in understanding modern mental health service user involvement activity at both a micro and macro level. Amendments could also consider integrating the non-constant sum conceptualisation of power, thus rebalancing the possible leaning towards the neoliberalist and biomedical (although one should not ignore these present realties in mental health care and wider society). For example, the upper rungs of the ladder could be reframed (left hand side of Figure 5):

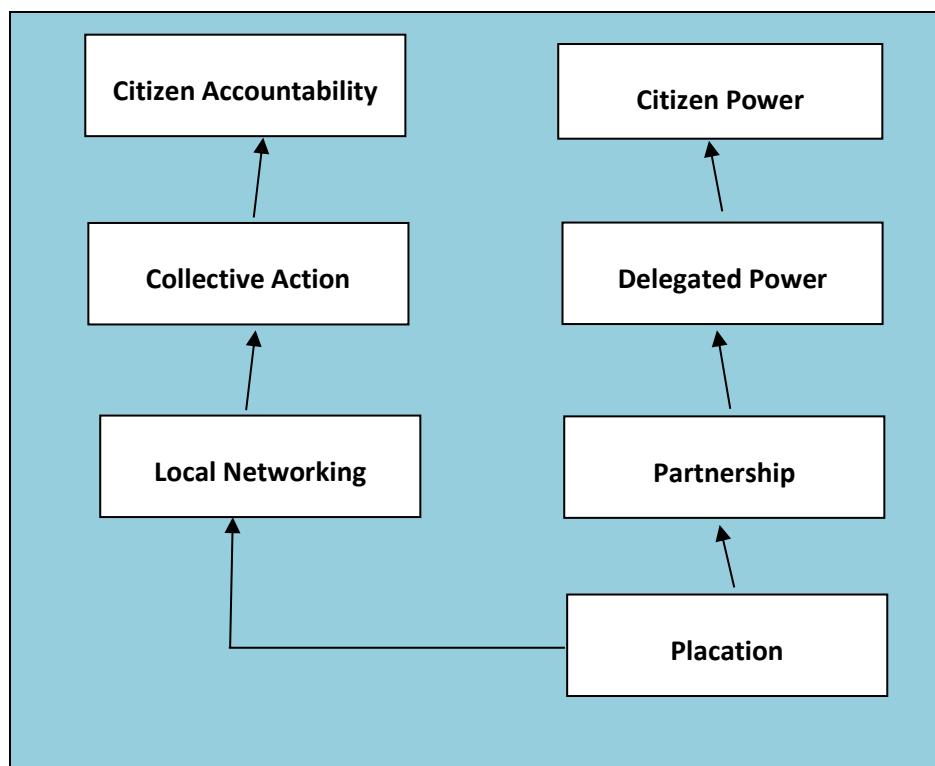


Figure 5: Alternative to the Citizen Power Rungs of Arnstein's (1969) Ladder

#### 6.4.2 Micro Level: Changing Individual Professional Attitudes

This study has highlighted the potential benefits of engaging in involvement work as part of their recovery from mental health crisis, not least in the reclamation of lost identities and the formation of new ones. However, negative attitudes and behaviours of some professional groups and even other service users present a significant challenge to achieving this. This supports the existing literature related to mental health service user involvement. In light of this, there is a call to explore further why those professionals who should demonstrate the greatest compassion and empathy for people with lived experience can potentially be the most discriminatory in their behaviour. Clues are presented in Chapters 1 and 2, related to historic institutionalisation of people in mental health crisis, reinforced by UK law regarding mental health (Mental Health Act, 2007 – HM Govt, 2007) and mental capacity (Mental Capacity Act, 2005 – HM Govt, 2005). This arguably leads to psychiatrists and nursing staff in particular to become the agents of social control, purported by Scull (2006) and Szasz (1960 & 2010).

As an educator in pre-registration nursing, I am acutely aware of the regulatory body requirement to facilitate student learning in relation to mental health risk assessment and management, and mental health law. Equally, however, this study suggests greater involvement of people with lived experience in the design and delivery of the curricula that not only emphasises the NHS values of compassion and respect and dignity (NHS, 2015), but also alerts learners to the risks of developing a ‘them and us’ mindset with service users, particularly when other pressures, such as staffing resource and risk averse practice come into play when in the practice setting. The Nursing and Midwifery Council (NMC, 2018), like many other regulatory bodies require evidence of user involvement in the development of curricula, but how that is operationalised in delivery of teaching and learning is down to the organisation providing it. A multicentre longitudinal study of the impact of user/carer involvement in pre-registration curricula on the attitudes and behaviours of students throughout their training and into the early years of their career as a health care professional would shed greater light on this.

This thesis not only focuses on the negative attitudes towards experts by experience, but also hopefully gives well-intentioned educators, professionals and service providers pause for thought when encouraging the people, they work with to engage in involvement activity. The following questions provide a useful guide:

1. Is a rationale for recruiting this person to support the restoration of confidence, esteem, and lost identities, or is it exclusively to satisfy the need of the organisation to hear a positive recovery story (tokenism)?

This highlights the need for balance between the service benefits and individual benefits and reemphasises the importance of robust preparation and debriefing processes being offered to those who are making themselves vulnerable by sharing their lived experience.

2. What knowledge and skills does an individual possess outside of their experience of mental distress and engagement with services, that could also contribute to an improvement agenda?

The second question primarily relates to the benefits for the individual, but actually can have an indirect benefit for organisations. If a person has a professional background in education (such as Beth and Ruth), their involvement work should perhaps be steered towards teaching activity within pre-registration training and continuing professional development activity for staff. If another has a background in the civil service (such as Orla), does their involvement activity focus on signposting advice towards community information and support resources in relation to benefits, housing and employment? These are just examples to emphasise the point and should not preclude people from developing new knowledge and skills as part of their involvement work (Orla's public speaking and Elsa's ability to stand her ground with powerful others are two prominent examples).

3. Is remuneration for people's time and energy limited to living wage hourly payments and a sense of achievement, or could alternatives be offered, such as academic study or a vocational qualification?

The third question is linked to the second; narrators such as Jess and Beth gave insight into a life beyond service user involvement, using the knowledge and skills developed whilst engaging in such activity. Certainly, for those employed for their expertise on an ad hoc basis, hourly pay can interfere with benefits payments and potentially cause additional mental distress. The opportunity to engage in vocational training or academic study would potentially negate this issue and serve to promote recovery and offer a direction for people beyond the mental health system. Courses offered by Recovery Colleges can be enormously helpful for those in the early stages of their recovery, but something more formal that is recognised by employers and educational institutions is potentially more helpful in the longer-term.

4. Is the person being approached because the demographic they represent aligns well with professional audiences (white, middle class, mature and well-educated)?

The final question in some ways is the most important; whilst people who can articulate themselves well and adhere to the rules and conventions of the professional meeting or forum is helpful in eliciting change from within the organisation, there is a greater risk of the third wave

institutionalisation occurring (see 5.2.1 – Page 138 and 5.3.1 – Page 141). This also excludes the voice of those who may not fit this semi-professional mould, but may have valid (and challenging) points to make. This leads on to the next area of contribution this thesis makes; the creation of shared community spaces.

#### **6.4.3 Micro-Macro Levels: Creating Shared Community Spaces**

Although a national and international social movement can effect significant change for disadvantaged social groups (such as those with lived experience of mental health crisis) at a macro level, in order to connect with the individual, local arrangements are needed for all to express their voice and feel that it is being listened to and given value (micro level). This thesis contributes to the body of literature that supports the widening of access to trialogues in local community settings (discussed in 5.7.3 – Page 154). Because trialogues are independent and welcoming of mental health stakeholders from all backgrounds, there is a further opportunity for a shared understanding of the challenges facing mental health care and a coproduction of strategies to change things for the better. The impact of such initiatives is predicated on a commitment from all stakeholders to engage in the process and a clear plan to present strategies and ideas to those responsible for the planning and delivery of services (Clinical Commissioning Groups and management boards within provider organisations). This is potentially impeded when organisations recruit and involve people with lived experience ‘in house’.

There remains a question as to who should facilitate triologue events and how they are to be funded? The ‘who’ is more straightforward; community third sector organisations, such as the Good Mental Health Cooperative ([www.goodmentalhealth.org.uk](http://www.goodmentalhealth.org.uk)) are well-placed to undertake this role. The funding is more challenging, as third sector organisations are almost always reliant on grant funding for local, regional or national streams, which are rarely permanent. Only a national government mandate for local health and social care providers to contribute to the funding of triologue, with no imposed conditions regarding the messages that come out from them would provide the secure longevity needed. Such longevity would then open up opportunities for further research into the engagement and effectiveness of trialogues in bringing together stakeholders and the influence this has on how professionals and service users relate in the care setting and on wider mental health care strategy.

#### **6.4.4 Macro Level: A System of Citizen Accountability?**

This thesis, albeit on a small scale, has highlighted the importance for people with lived experience not only to feel listened to, but also to believe that the work they engage in results in

meaningful change for others in mental distress. However, as power is often concentrated with one service provider organisation or group of professionals, aspirations for change can be sanitised to fit with the organisational agenda.

User input into the design and delivery of services should be sought from outside the provider organisation in the form of properly funded, independent bodies, led and organised by users themselves. This promotes the non-constant-sum conceptualisation of power (1.5.3 – Page 20 & 5.3.1 – Page 141) and aspires to the higher rungs of Arnstein's 1969 Ladder of Citizen Participation (or my amended version – see Figure 5, Page 133). It would sit separately from trialogues, which should retain its function as a safe and democratic community space for *all* stakeholders. As discussed in 5.7.3 (Page 154), arrangements akin to this have been in existence in the UK for a number of decades, but have been less effective than they could have been. There is a compelling argument for a review of the current powers held by Healthwatch England, with the view to placing them on the same statutory footing as the Care Quality Commission, rather than a subsidiary of it. At a local level, Healthwatch or a similar body would not only gather data from the provider organisations and other statutory agencies, but draw on the rich information coming out of events such as trialogues. In these environments, everyone has an equal voice and out of it should come agreed recommendations about how care could be improved, to which providers are legally accountable to deliver on.

#### **6.4.5 Macro-Meso Level: Collectivism, Psychopolitics and Mad Studies**

In 2020, during a global health pandemic, and after the killing by a police officer of an African American man in Minneapolis, world-wide Back Lives Matter protests (<https://blacklivesmatter.com/>), reflect the ability of diverse groups of people to come together around a single important cause. Engaging in activism via social media and mass protest events, governments and the news media have been forced to take notice and respond. Whether this translates to meaningful change in the way minority ethnic groups are treated remains to be seen, but its ability to draw people together is undisputed. In many ways, neoliberalism disadvantages both minority ethnic groups and people experiencing long term mental distress, by denying adequate welfare support and opportunities that may assist them to improve their lives (one is doubly disadvantaged if black and a mental health service user – Morgan et al, 2017).

The discussion at various points in this thesis about psychopolitics and the harmful impact of neoliberal policy and practice on the care of people experiencing mental health crises calls for a much wider activism than perhaps can be facilitated through local initiatives, such as mental health trialogues (although these are the places where such activism can be nurtured in their

infancy). As highlighted by authors such as McKeown et al (2014), Moth et al (2016), Rose (2016), and Spandler et al (2016), debate and activism must be as widely inclusive as possible, avoiding the trap of alienating entire professional groups, such as psychiatrists, nurses, social workers and others, who themselves can experience a sense of depersonalisation and powerlessness (Moth et al, 2016). As the same authors suggest; “mental distress is arguably the primary form of industrial injury in twenty-first century capitalism” (Page 279). The field of Mad Studies draws together survivor and professional academics to identify commonalities between different actors within the mental health system and formulate a strategy for reshaping a wider understanding of mental distress, including how class and ethnicity intersects with psychiatric forms of oppression. Importantly, this can then lead onto discussion of how we respond to mental distress as a society. Is it from this field that positive change might come, and if so, how is the whole spectrum of people experiencing discrimination on the basis of their mental health engaged?

#### **6.4.6 Dissemination Strategy**

The dissemination of my work has been a continuous process since the early stages of the doctoral ‘journey’ in 2011/12. My preliminary research proposal formed part of a co-presentation with my Second Supervisor entitled *In and Out of the Asylum: The narrative of the patient journey from lunatic asylum to ‘hospital at home’*, which was delivered at the National Psychiatric Nursing Research Conference, at Oxford University in September 2012. The focus and methodology employed within my final study is very different from this early conference, sitting firmly within the fold of historical studies (in my early 20s I completed a Bachelor of Arts degree in History). The historical context within which I place the mental health service user experience in Chapter 1 reflects my thinking in these early days.

My next and first solo conference presentation, at the European Social Science History Conference in Vienna (April, 2014), reflected a completed literature search and plan to adopt a qualitative oral history/life story research methodology in interviewing a small group of people who were involved in services as experts by experience in mental health. Entitled, *Patients, Professionals, Politicians and the Public Purse: The Rise and Professionalisation of the UK Mental Health Service User Movement from the Mid-Twentieth Century*, this was the first iteration of the title presented at the beginning of this work.

My most recent conference presentation was again at the same as first, but now called the International Mental Health Nursing Research Conference, in Cardiff, Wales (September 2017). Having completed the research interviews between 2014 and 2015 and working towards

completing my upgrade thesis, I was able to present my preliminary analysis and findings, which would identify the three overarching themes presented in this work.

Now I am at the final stages of my doctoral studies, I will look to present my finished thesis at future conferences. As a completed work, however, I am now clear that there are a number of different types of conference with a range of audiences who may be interested in listening to what I have to present. These are outlined in the *Summary of Dissemination Strategy* (Appendix I - Page 262). In order to reach a wider audience, I will also be looking to publish a summary of my research within identified relevant journal publications, also outlined in the summary.

#### **6.4.7 The Future Research Agenda**

In light of my research and engagement in the literature surrounding people with lived experience who engage in mental health service user involvement activity, I briefly consider the research agenda to focus on the following key areas:

- The potential benefits and harms of mental health service user involvement work, that focuses on individuals and their recovery from mental health crisis and not on their contribution to the organisational patient and public involvement (PPI) agenda. Although this study begins to address the gap first introduced in Chapters 1 and 2, more is needed.
- The longevity, membership, and impact (on individuals and local services) of mental health trialogues. As discussed in 5.7.3 (Page ?) and 6.4.3 (Page ?), such initiatives have been in the UK for a few years, but the measure of their relative success in these areas requires further investigation. How do such groups draw together shared interests and live with contradictory positions between those who attend, to ultimately improve the experience of support for those in crisis and beyond?
- Assessing the impact on service provision of local/regional citizen ‘assemblies’ that reflect the patient councils of old, as well as the purpose of the modern Healthwatch England, but sit independently from the CQC.

### **6.5 Final Reflections**

Dr Theo Stickley’s (2006) article is provocatively titled ‘Should SU involvement be consigned to history?’, discussing the issues from a critical realist perspective. In his conclusion he states;

‘If we continue to work within existing models of service user involvement, then change that is wrought within mental health services will only ever be mediated by those in control of services, to comply with their agenda.’

(Stickley, 2006 – Page 577)

I could not be in greater agreement, 14 years after this article was published. As a mental health nurse and educator, it is sad and frustrating that my work reiterates these observations, however, I also feel hope. Having completed her research doctorate, Beth returned to employment with a different mental health service provider, taking a leadership position within patient and public involvement research. Mark's discussion regarding the power of social media to challenge the status quo in mental health services may in the future prompt a service user revolution and permanent change in care for those in mental health crisis. As a programme leader in pre-registration at a different university from where I started this thesis, I am in a position to influence academic colleagues and the nurses of tomorrow about the true meaning of listening to the service user voice and co-production in planning care.

Over the nine years of my doctoral studies, the process and more importantly the people encountered, have had a profound effect on my perspectives regarding mental health care, my role as a registered nurse and the learning I facilitate with the nurses of the future, which will stay with me for the remainder of my career.



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## Appendices



## Appendix A: Summary of Selected Works for Critical Interpretive Review

Author(s), Year, Country of Publication & Title	Key Findings/Concepts
<b>Simpson &amp; House, 2002 (UK)</b> <i>'Involving service users in the delivery and evaluation of mental health services: systematic review'</i>	<ul style="list-style-type: none"> <li>Employing service users led to clients having greater satisfaction with personal circumstances and less hospitalisation.</li> <li>Providers of services who had been trained by SUs has a more positive attitude to users in general.</li> <li>When interviewed by SU employees, clients reported less satisfaction with the service they had received.</li> </ul>
<b>Crawford et al, 2002 (UK)</b> <i>'Systematic review on involving patients in the planning and development of health care'</i>	<ul style="list-style-type: none"> <li>Evidence supports the idea that involvement activity has contributed to service changes across a range of settings.</li> <li>Evidence base does not exist for the effects on user of services, care quality, satisfaction or health of patients.</li> </ul>
<b>Crawford et al, 2003 (UK)</b> <i>'User involvement in the planning and delivery of mental health services: a cross-sectional survey of service users and providers'</i>	<ul style="list-style-type: none"> <li>The main obstacle to user involvement, as identified by providers, was that those who took part were not representative of local patients.</li> <li>The main obstacle to user involvement, as identified by user groups, was staff resistance and 80% were dissatisfied with the current involvement arrangements.</li> </ul>
<b>Robert et al, 2003 (UK)</b>	<ul style="list-style-type: none"> <li>None of the 6 trusts sought to employ and train users as a means of developing total user-defined targets.</li> <li>Methods initially employed were limited – inviting a single service user onto a project board.</li> </ul>

<p>'Redesigning mental health services: lessons on user involvement from the Mental Health Collaborative'</p>		<ul style="list-style-type: none"> <li>Highlighted the 'colouring' of SU feedback by an ambivalent relationship with staff and staff findings that meeting all SU requests would prove incompatible with 'safe and appropriate care'</li> <li>There is a need for direct support of SUs to fully engage in project process through training and the removal of practical and symbolic barriers.</li> </ul>
<p><b>Author(s), Year, Country of Publication &amp; Title</b></p>		<p><b>Key Findings/Concepts</b></p>
<p><b>Summers, 2003 (UK)</b></p> <p>'Involving users in the development of mental health services: A study of psychiatrists' views'</p>	<ul style="list-style-type: none"> <li>All participants applied a positivist approach to thinking about SU involvement – this implied that improved services could be objectively and neutrally defined.</li> <li>Less emphasis on professional duty and user rights.</li> <li>Participants broadly split into three camps; '<i>optimists</i>' (n=7), '<i>rationalists</i>' (n=4) and '<i>sceptics</i>' (n=3)</li> </ul>	
<p><b>Crawford &amp; Rutter, 2004 (UK)</b></p> <p>'Are the views of members of mental health user groups representative of those 'ordinary' patients? A cross-sectional survey of service users and providers'</p>	<ul style="list-style-type: none"> <li>Four items rated as priorities by the random sample were also rated by the user groups, as were two of the lowest rated priorities. The authors suggest that this challenges the view that service user groups do not represent the 'ordinary patient'</li> </ul>	
<p><b>Doherty et al, 2004 (UK)</b></p> <p>'The consumer-employee as a member of a Mental Health Assertive Outreach team. Impressions of consumer-employees and other team members'</p>	<ul style="list-style-type: none"> <li>Employment of consumer HCAs did not appear to impact the well-being of other staff members.</li> <li>Staff recognised the benefit of consumer HCAs in being able to spend more time with clients assisting to engage with community services and providing a positive role model.</li> <li>50% of staff respondents expressed concern around professional boundaries, additional support requirements and role conflict in relation to the HCAs, which remained stable over the 28 months of the study.</li> <li>The HCAs' perceptions around the benefits of their work were similar to others staff, but felt that their own views were not considered equal with those of professional staff.</li> </ul>	
<p><b>Rutter et al,</b></p>	<ul style="list-style-type: none"> <li>That UI remained within the control of managers</li> </ul>	

<p><b>2004 (UK)</b></p> <p>'Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London'</p>	<ul style="list-style-type: none"> <li>• Providers retained control over the decision making</li> <li>• There was an expectation that users addressed Trust agendas and conformed to Trust management practices.</li> <li>• SUs had a broader agenda to improve the status and condition of people with mental health problems.</li> </ul>
<p><b>Author(s), Year, Country of Publication &amp; Title</b></p> <p><b>Hodge, 2005 (UK)</b></p> <p>'Participation, discourse and power: a case study in service user involvement'</p>	<p><b>Key Findings/Concepts</b></p> <ul style="list-style-type: none"> <li>• Boundaries governing the way such initiatives operate were strictly maintained, meaning the important structural issues were kept off the agenda.</li> <li>• Because of the above, the authors highlighted the importance of independent user-led local organisations, who could engage in the off-agenda issues.</li> <li>• The discourse within such settings are action orientated and instrumentalised, which results in the objectification of the lived experience.</li> </ul>
<p><b>Ramon</b></p> <p><b>2008 (UK)</b></p> <p>'Neoliberalism and its implications for mental health in the UK'</p>	<ul style="list-style-type: none"> <li>• Highlights the managerialist model of private industry now dominating the UK health and social care sector – autonomy of individual workers curtailed.</li> <li>• Points to a hybrid in the NHS of the liberal collectivist regime of universalism and the adoption of market economy principles.</li> <li>• Discusses the challenges with moving services into the third sector, which whilst more informal in engaging with those in mental distress, will often employ cheaper (less qualified) staff, be subject to insecure funding regimes (annual renewal) and less likely to challenge funding bodies if they disagree with the strategy and implementation of initiatives.</li> <li>• Individualism over-emphasised to curtail collectivist action and responsibility. MH service users are seen as social and personal failures in the 21<sup>st</sup> century.</li> </ul>
<p><b>Armes,</b></p> <p><b>2009 (UK)</b></p> <p>'Mission informed discursive tactics of British mental health service-user/survivor movement (BSUSM)'</p>	<p>Four discursive resistance tactics identified:</p> <ul style="list-style-type: none"> <li>• <i>Reformism</i>: joint work with non-user/survivor allies to achieve agenda.</li> <li>• <i>Rationalization</i>: 'If you can't beat them – join them!' – Reluctant engagement in dominant ways of doing business in order to safeguard SU involvement and advocacy.</li> </ul>

resistance to formalization pressures accompanying contractual relationships with purchasing authorities'	<ul style="list-style-type: none"> <li>• <i>Professionalization</i>: Users/survivors becoming formally employed to gain professional status and hopefully getting support to others that they would want.</li> <li>• <i>Pride</i>: Rejecting hierarchies, celebrating mutual support and openly challenging stigma.</li> </ul>
<b>Author(s), Year, Country of Study &amp; Title</b> <b>Elstad &amp; Eide, 2009 (Norway)</b> 'User participation in community mental health services: exploring the experiences of users and professionals'	<b>Key Findings</b> <ul style="list-style-type: none"> <li>• User participation can be viewed as one single process, from the level of individual service users through to user control over services.</li> <li>• Users felt it important that their needs for professional help should not be overlooked when involving themselves in participation work.</li> <li>• Both groups underlined that some Sus did not participate in decisions about activities and the social milieu of the centres, as well as those at an organisational level.</li> <li>• Concern expressed by professionals that unless user participation is properly defined, then it can become an empty phrase.</li> </ul>
<b>McDaid, 2009 (Ireland)</b> 'An equality of condition framework for user involvement in mental health policy and planning: evidence from participatory action research'	Inequalities identified were: <ul style="list-style-type: none"> <li>• Cultural resources (education and cultural repertoire of policy making)</li> <li>• Physical and mental resources</li> <li>• Time and economic resources.</li> </ul> This can result in: <ul style="list-style-type: none"> <li>• Lack of respect for social position</li> <li>• Lack of recognition for experiential knowledge</li> <li>• Lack of power or role on committees.</li> <li>• Isolation in position as SU representative, resulting in powerlessness.</li> <li>• Silencing of emotional expression.</li> </ul>
<b>Harding et al, 2010 (UK)</b>	Four categories emerged:

'Service user perceptions of involvement in developing NICE mental health guidelines: A grounded theory study'	<ul style="list-style-type: none"> <li><i>Drawing expertise from experience</i> – extended and complimented scientific contributions, by determining outcomes that had personal meaning.</li> <li><i>Overcoming stereotypes to demonstrate value</i> – this included challenging the ‘jargon’ of professionals to make the debate more accessible.</li> <li><i>Unwritten rules influence deliberations</i> – Although SUs saw the complementary role of experiential knowledge, there was a perception that quantitative evidence took precedence and group consensus were overruled by NICE.</li> <li><i>Social comparisons affect confidence</i> – SU members compared themselves to other guideline development group members, which could undermine their confidence.</li> </ul>
Author(s), Year, Country of Publication & Title	Key Findings/Concepts
<b>Horrocks et al, 2010 (UK)</b>  'Does strategic involvement of mental health service users and carers in the planning, design and commissioning of mental health services lead to better outcomes?'	<ul style="list-style-type: none"> <li>SU and carer involvement was a high priority for the trust examined, but its time was mostly dominated by discussing process and actions (power dynamics).</li> <li>Where improved outcomes were identified, these were for the individuals involved, rather than broader SUs.</li> </ul>
<b>Rose et al, 2010 (UK)</b>  'Perceptions of user involvement: A user-led study'	<ul style="list-style-type: none"> <li>Activists were more aware of user groups and forms of involvement, but perceptions of outcomes differed little between the two groups.</li> <li>The above suggests that activists and those more involved in SU work align in their views with non-activists.</li> </ul>
<b>Bennetts et al, 2011 (Australia)</b>  'Understanding consumer participation in mental health: issues of power and change'	<ul style="list-style-type: none"> <li>Managers differentiated ‘Consumer Consultants’ from consumers of services, articulating their value in driving and being the doers in participation, as well as providing education and training to staff.</li> <li>Identified nurses and psychiatrists as having the most negative attitude towards consumer participation and strongest orientation to the medical model.</li> <li>Barriers to the ongoing development of consumer participation were identified as staff attitudes, under-resourcing of consultants and the tokenistic approach to participation.</li> </ul>

<p><b>Hitchen et al, 2011 (UK)</b></p> <p>'Lone voices have an emotional content: focussing on mental health service user and carer involvement'</p>	<ul style="list-style-type: none"> <li>Users and carers found three main areas which made involvement difficult; professional language barriers, emotional impact and power imbalances between themselves and professionals.</li> </ul>
<p><b>Author(s), Year, Country of Publication &amp; Title</b></p> <p><b>Restall, 2013 (Canada)</b></p> <p>'Conceptualizing the outcomes of involving people who use mental health services in policy development'</p>	<p><b>Key Findings/Concepts</b></p> <ul style="list-style-type: none"> <li>Identified a balance of benefits (increased self-esteem, confidence &amp; personal satisfaction) and costs (feeling vulnerable and receiving negative reactions from others at meetings) at a personal level.</li> <li>Achievements can be made at a micro and meso level simultaneously, with transparency in decision making process related to policy minimising the tokenism of SU involvement.</li> </ul>
<p><b>Esposito &amp; Perez, 2014 (USA)</b></p> <p>'Neoliberalism and the commodification of mental health'</p>	<ul style="list-style-type: none"> <li>Asserts that mental health concepts are social in nature and therefore any attempt to classify/categorise is shaped by political and/or profit driven objectives (such as those from large pharmaceutical companies)</li> <li>People are encouraged to adjust behaviours and attitudes to suit the 'market' – happiness is equated with success in the marketplace (distress is not). Therefore, those experiencing mental distress are compelled try to integrate into society and employ the techniques of recovery to achieve this.</li> <li>Points to the individual being the focus (of deviance and intervention), rather than the society within which they live, fitting with the neoliberal ideology.</li> </ul>
<p><b>MacDonald et al, 2014 (UK)</b></p>	<ul style="list-style-type: none"> <li>Who sets and governs the agenda? <i>Meeting conduct and content</i> – agendas in all meetings were strictly controlled and offered little scope for debate/discussion were very limited. Some opportunity offered within more informal pre-governor meetings. Any strength of feeling expressed within meetings around specific issues were not reflected in the minutes.</li> </ul>

'Service user governors in mental health foundation trusts: accountability or business as usual?'	<ul style="list-style-type: none"> <li><i>Agenda setting</i> – SUs felt they were not actively encouraged to contribute agenda items, but this was more effective within the sub-committees.</li> <li><i>Relationships</i> – in 2 of the 3 trusts, SUs viewed such involvement work as a way of networking with key influential individuals within the organisation. In the third, communication was deemed poor, impacting on relationships.</li> <li><i>Representation</i> – SU governors were elected by the FT membership and some felt it was unrealistic or not even their role to fully represent all SUs, particularly if there was confusion around the appropriate forums in which broader SU concerns could be raised.</li> <li>Authors situated their analysis within Lowndes &amp; Roberts' 'third wave' institutionalism, whereby all institutionalism is underpinned by core concepts of rules, practices and narratives, which have a constraining influence.</li> </ul>
<b>Author(s), Year, Country of Publication &amp; Title</b> <b>Rose</b> <b>2014 (UK)</b>  'bThe mainstreaming of recovery'	<b>Key Findings/Concepts</b> <ul style="list-style-type: none"> <li>Makes links between the instrumentalization and mainstreaming of the original (user-led) concept of recovery to the neoliberalist values of modern society.</li> <li>Refutes the idea that recovery is about the individual, positing that people do not exist in isolation. Reflects on the importance of collectives to validate and reflect on lived experience.</li> </ul>
<b>Chassot &amp; Mendes,</b> <b>2015 (UK)</b>  'the experience of mental distress and recovery among people involved with the service user/survivor movement'	Three key themes identified: <ul style="list-style-type: none"> <li><i>Being able to make sense and reframe mental distress</i> – being part of a social movement enabled them to safely share painful or embarrassing experiences of distress.</li> <li><i>The social experience of involvement</i> – created a sense of community and belonging for the participants for most, although some reported that their legitimacy as a SU sometimes was called into question by others (i.e. were they truly representative?)</li> <li><i>Identity and identity reconstruction</i> – coming across discourses that challenged the established notions of mental illness, enabled some to question their previously held identity. Now had the opportunity to fight injustices in the system and become role models for other SUs (recovery of spoiled identities).</li> </ul>
<b>Treichler et al,</b> <b>2015 (USA)</b>	<ul style="list-style-type: none"> <li>Participants identified the importance of involvement at this level, but actual involvement was low overall (each aware of approx. 1 in 8 available opportunities).</li> </ul>

<p>'The relevance and implications of organizational involvement for serious mental illness populations'</p>	<ul style="list-style-type: none"> <li>• Most salient predictor of organisational involvement were feelings of community and a desire to contribute to that community.</li> <li>• Recommended the tailoring of involvement opportunities as key to increasing involvement.</li> </ul>
<p><b>Byrne et al, 2016 (Australia)</b></p> <p>'Lived experience practitioners and the medical model: world's colliding?'</p>	<ul style="list-style-type: none"> <li>• Medical model described by participants as the prevailing culture within MH services.</li> <li>• The above imposed significant limitations on the development and effectiveness of the lived experience roles, as well as themselves as individuals.</li> <li>• LEPs remained in a disempowered and discriminated sector of society by virtue of the status as MH service users</li> </ul>
Author(s), Year, Country of Publication & Title	Key Findings/Concepts
<p><b>Collins et al, 2016 (UK)</b></p> <p>'Very much evolving: a qualitative study of the views of psychiatrists about peer support workers'</p>	<ul style="list-style-type: none"> <li>• Respondents recognised the benefits of the PSW role in offering a different type of service to clients (one being the ability to reverse the low expectations SUs may have of themselves), however, felt that the role would not be necessary if professional staff were more open with their own lived experience.</li> <li>• Many referred to the personal benefits for users engaging in the PSW role (such as accessing a career)</li> <li>• Many pointed to a lack of clarity around the PSW role.</li> <li>• </li> </ul>
<p><b>Moth et al, 2016 (UK)</b></p> <p>'Realising Sedgwick's vision: theorising strategies of resistance to neoliberal mental health policy'</p>	<ul style="list-style-type: none"> <li>• Pointed to Sedgwick's requirement for transformative change to be the development of a politics that incorporated the demands not only of users/survivors of the MH system, but professionals and the wider public (he would term this 'Psychopolitics').</li> <li>• Outlined three strategic components for mental health activism in C21: CONTENT (push back on rhetoric that seeks to divide those who experience mental distress and those who do not, particularly when it comes to work and claiming benefits), FORM (transitional approach to movement goals, which makes practical, concrete demands for change now, underpinned by a new social logic), AGENCY (cross-sectional alliances to combat a 'divide and rule' social policy)</li> </ul>

<p><b>Rebeiro et al, 2016 (Canada)</b></p> <p>'Authentic peer support work: challenges and opportunities for an evolving occupation'</p>	<ul style="list-style-type: none"> <li>Although authentic peer support activities were found to be of value to others, but often not reflected within the daily work they undertook (more generic duties)</li> <li>The primary challenge to the PSW roles was being accepted and valued by others in the mainstream MH system (this only increased if the PSW had either a diploma or training available to others staff) – lived experience alone not enough.</li> </ul>
<p><b>Rose, 2016 (UK)</b></p> <p>'Experience, madness, theory and politics'</p>	<ul style="list-style-type: none"> <li>Makes the point that the 'mad' have perhaps been viewed as apolitical, even by those scholars writing about marginalisation – always seen as 'the other'</li> <li>Draws parallels between user/survivor groups and activism in terms of desire to share, validate and collectivise lived experience.</li> <li>Highlights the 'catch-22' that those with lived experience are in when they put themselves forward to call for change – seen as unrepresentative. Acknowledges most are white middle class who can behave appropriately, but states that this should not be a reason to ignore them.</li> </ul>
<p><b>Author(s), Year, Country of Publication &amp; Title</b></p> <p><b>Rose et al, 2016 (UK)</b></p> <p>'Service user led organisations in mental health today'</p>	<p><b>Key Findings/Concepts</b></p> <ul style="list-style-type: none"> <li>During the study one group ceased to operate – the one which refused to adopt the institutional rules and norms of the managerial discourse.</li> <li>The other four groups survived by negotiating their experiential knowledge through the establishment of positive working relationships with providers and managers to some a degree.</li> <li>ULOs described as being in "response mode" (P258) in constantly adapting to the turbulence existing within services.</li> </ul>
<p><b>Spandler et al, 2016 (UK)</b></p> <p>'Psychopolitics in the twenty first century'</p>	<ul style="list-style-type: none"> <li>The authors flag up 5 key areas in relation to C21 Psychopolitics: <ul style="list-style-type: none"> <li>Tension between developing and alternative politics to the present and defending current welfare services</li> <li>Utility of human rights orientation in MH activism.</li> <li>Role of families and carers in politics</li> <li>Development of a nuanced (socio-historical) materialist theory of mental distress.</li> <li>How class intersects with other forms of oppression (in MH)</li> </ul> </li> </ul>

<p><b>Voronka, 2016 (UK)</b></p> <p>‘The politics of people with lived experience’</p>	<ul style="list-style-type: none"> <li>• Suggests that attempting to unify people’s meaning making (from lived experience) to achieve political gains carries risks with it. The primary risk is identified as conflating the distinct ideological and conceptual explanatory models of mental distress to place all under the umbrella of ‘lived experience’</li> <li>• Argues that Disability and Mad studies have yet (in 2016) to engage in debate on the relative value of experiential claims.</li> <li>• Does acknowledge the neoliberal influences of mental health and social services, which is at odds with the social justices discourses of the original recovery movement.</li> </ul>
<p><b>Cosgrove &amp; Karter 2018 (USA)</b></p> <p>‘The poison in the cure: Neoliberalism and contemporary movements in mental health’</p>	<ul style="list-style-type: none"> <li>• Highlights how the use of modern technology (social media platforms) to predict depression and suicide epitomises the influence of the neoliberal agenda on the taxonomy of mental health</li> </ul>
<b>Author(s), Year, Country of Publication &amp; Title</b>	<b>Key Findings/Concepts</b>
<p><b>Beresford 2019 (UK)</b></p> <p>“Mad”, Mad studies and advancing inclusive resistance’</p>	<ul style="list-style-type: none"> <li>• MH survivor movement has always struggled to find a new language to describe mental distress that is not tied to the traditional biomedical model. Also have failed to unite around a counter philosophy.</li> <li>• Mad studies posited as the first survivor led movement, which attempted to create a robust theoretical and philosophical base. Allows for social understandings of mental health and how society and our personal circumstances makes people ‘mad’</li> </ul>
<p><b>Recovery in the Bin, Accessed 20/07/20 (RITB - <a href="http://www.recoveryinthebin.org">www.recoveryinthebin.org</a>)</b></p> <p>‘10 Key Principles of Recovery in the Bin’</p>	<ul style="list-style-type: none"> <li>• Outlines 10 principles which challenge the co-option of recovery by a neoliberal ideology, and calls for an alternative social model of mental distress, accompanied by a wider variance in treatment/support approaches. It also calls for professionals to protect services users from ‘harmful government policy’ in relation to mental health care.</li> </ul>



## **Appendix B: Research Protocol Submitted to University Ethics (ERGO) & NHS Research Ethics (NRES)**

(Text in red indicates the minor amendments on recommendations made by NRES)

**Study Title: Patients, Professionals and Power Dynamics: The Transition of the Service User to 'Expert by Experience' in UK Mental Health Service Improvement Activity**

**Researcher(s): Christopher Gale**

**Funder:**

**Sponsor (if known): University of Southampton**

### **Background**

This research will explore the experiences of mental health service users who have later become involved in the organisation and delivery of those services as 'experts by experience'. It will specifically look at service users' perceptions of the power dynamics within their relationships with clinical and managerial staff in these service improvement settings within a defined geographical area of the UK (the county of Hampshire).

### **Key research questions:**

- 1) What barriers have service users faced to effectively participate in the planning, delivery and recruitment activities within mental health provider organisations?
- 2) To what extent have service users been able to successfully overcome any barriers and if so, what approaches have they taken?
- 3) How have any potential barriers impacted on the recovery of service users?
- 4) To what degree do the concepts of power and empowerment concern mental health service users who have contributed to planning and recruitment activities?
- 5) To what extent do service users view themselves as part of a broader social movement, alongside other groups that have been historically marginalised or oppressed?
- 6) How do the narratives of service users participating in this project inform the future policy and practice of involving of experts by experience in the planning, delivery of and recruitment to mental health service providers in the UK?

### **Method**

This study will seek to explore these concepts of power and control, by adopting an oral history method of historiography; the process of conducting and recording interviews with people in order to elicit information from them about the past. 'The past' in the context of

this study relates to the aftermath of 1980s Thatcherite government policy around health care. The informants may not necessarily have been using services since the 1980s, but will have experienced its influences on modern care delivery, still felt in the present day.

Oral history does overlap with a number of other qualitative research approaches, particularly narrative, life history and bibliographic methods; seeking to capture the lived experiences of individuals and groups who may or may not have been previously denied a 'voice'. Like these other approaches it not only focuses on the content of the interview, but also the subjectivity, use of memory, narrative structure and the cultural context of the participant's 'performance' in the interview.

## Materials

The guided schedule for the Oral History recorded interviews can be found in the appendix. There is a longer version for the interviewer, but a more succinct one which will be sent to the participants prior to the interview taking place. The creation of two different versions was in response to feedback from a service user expert with whom I have consulted over this project.

## Participants

A theoretical sampling strategy will be utilised, whereby respondents are sought out who epitomise the focus of the project questions; active service users who are involved in service improvement activity within Hampshire. Using a "snowballing process", a small number of established service user contacts, with whom the researcher has an existing working relationship. Through their contacts in the area of service user and/or carer involvement other potential participants who meet the inclusion criteria will be identified. It is anticipated that this second wave of participants will then identify further potential interviewees.

No NHS organisations will be directly approached to identify potential participants, however, participants themselves are likely to have been or are currently users on NHS services.

### Inclusion Criteria:

- Historical and/or current user of adult mental health services or carer of a service user (**Age 18 upwards**).
- Currently not experiencing an acute phase of mental ill health/distress, residing in an inpatient setting and/or subject to a section of the Mental Health Act (2007), including Community Treatment Orders within the past 6 months.
- Accessed services within the county of Hampshire (includes unitary authorities of Southampton and Portsmouth).
- Has been actively involved in the planning and delivery of services and/or recruitment of staff members within mental health provider organisations in Hampshire.

### Exclusion Criteria:

- Has not historically and/or currently using adult mental health services or cared for a service user.
- **Under 18 years of age.**
- Currently experiencing an acute phase of mental ill health/distress, residing in an inpatient setting and/or subject to a section of the Mental Health Act (2007), including Community Treatment Orders within the past 6 months.
- Has accessed care outside of the county of Hampshire (includes unitary authorities of Southampton and Portsmouth) for a majority of their time in services.
- Has not been actively involved in the planning and delivery of services and/or recruitment of staff members within mental health provider organisations in Hampshire.

### Procedure

Action/Stage of Research Process	Number of times the action will be undertaken within the research process	Average time taken per action/stage	Anticipated timeframe (Week number)	Action/Stage initiated by:
Initial contact with participant and preliminary information giving about the research project - via telephone, email or letter depending on how the participant was identified (see Participants section above).	1-2	30 mins	Week 0	Christopher Gale PhD Student
Meeting to discuss the project in greater depth and answer any questions regarding the process.	1	60 mins	Week 2	Christopher Gale PhD Student Participant's home or community meeting place (such as GP surgery or wellbeing centre)
Subject to the completion of the consent form by the participant, recorded interview is undertaken.	1-2	90 mins	Week 3-7 (depending on time)	Christopher Gale PhD Student Participant's home or community meeting place (such as GP

			availability of the participant)	surgery or wellbeing centre)
Transcribing of audio recording of interview	1	Up to 4 weeks	Four weeks after completion of the interview (week 7-11)	Christopher Gale PhD Student
Participant to receive a copy of the audio interview recording and indicate any parts that they wish to be excluded when stored as a permanent record.	1	120 mins	Week 8-12 (Again depending on the previous two stages and availability of the participant)	Christopher Gale PhD Student

### Statistical analysis

Setting rigid numerical targets are cautioned against when undertaking oral history interviews, as rushing to achieve them can impact on the quality and depth of the data collected. Tentatively, given this warning and the very limited resources available for this doctoral project, my initial aim will be to recruit 8-10 participants. Should those interviews not be of sufficient depth or quality to produce identifiable themes within the analysis, further interviews would then be undertaken.

The analysis of the oral history interview data will, in the main, focus on the narrative, however, there is no single recommended approach. I will therefore, be adopting an approach taken by Alessandro Portelli (one of the key figures in oral history research), which would seem appropriate with participants whose accounts may involve individual and communal action.

Analysis will be carried out within the framework of three primary narrative modes; 'the institutional' (third person account of custom, rule, policy or practice), the 'communal' (account narrated in the first-person plural - 'we did this') and finally the 'personal' (first person singular account - 'I did this'). All three modes can be presented within one narrative account, but the use of them at different times can reveal a useful insight into how respondents represent themselves and their relationships with others. From this a broader thematic analysis can take place.

### Ethical issues

#### Risks or burdens to participants:

- Intrusion
- Risk of breach of confidentiality (naming of others service users, staff or service providers)

- Distress experienced by the participant at recalling potentially difficult life experiences.
- Belonging to a vulnerable population group.

**Potential benefits:**

- Participants are given the opportunity to recall experiences from their unique perspectives.
- Others may benefit from the outcomes (e.g. service user led organisations and statutory service providers).

**Steps to minimise risks of burdens:**

- The participant will be able to stop the interview at any point, for example if they become distressed, and have the option to continue at a later date.
- Each participant will be asked to identify a supportive relative, friend, professional or other who is available to talk through any distress caused by recalling experiences. A list of possible other sources of support is included in the Participant Information Sheet.
- Participant's names and those of people and organisations deliberately or inadvertently included in the interview recording will be edited out of the recording and transcripts.
- Every participant will be given an audio recording of their interview and asked if there is any other information that they wish to be removed prior to depositing in a permanent archive.

**Data protection and anonymity**

Data will be link anonymised and stored.

All research data (audio recordings) during the study will be captured on a hand-held digital recorder. The digital file containing each recording will be moved to a secure folder held within the University of Southampton's IT system. This folder has been created so that only I as the researcher have password protected access.

Email correspondence, which will contain names and possibly other contact details will be kept within a secure folder held in my personal university email account and accessed only when at a desktop computer on the university campus.

Paper consent forms with personal information included will be stored within a locked filing cabinet within the academic offices of the Faculty of Health Sciences building, University of Southampton. These offices are only accessible by staff smart card. Interview transcripts (which will not contain any identifiable personal data) will be stored in the same cabinet.

**Guided Schedule for Oral History Recorded Interviews (Interviewer & Participant versions)**

**Guided Schedule for Oral History Recorded Interviews (Interviewer):**

***Introduction:***

Explain again the context and purpose of the recorded interview; that there has been an increasing focus in policy and practice on service users and/or carers being actively involved in service improvement activities, with the view that this will improve the quality of and satisfaction with care provision. The aim of this project is to understand the perspectives of service users and carers on their contributions and the relationships with those in organisations they are working with.

***Biographical section:***

(Aim of this section is to settle the narrator, and ease him/her into recollection of the period under study)

Establish:

- Date and place of birth
- Family & friendship experiences when growing up & and who are significant to them now?
- Education from early years into adulthood
- Employment history

**1) Focusing on the narrator's experience of mental health services when in mental distress or when supporting a partner who was experiencing mental distress.**

- Provide prompts to explore through anecdote the areas relating to:
- How they came to be referred into mental health services and how long were they engaged with services?
- What interventions/support did they receive and how did they happen?
- What were their thoughts about the environment where the treatments took place?
- What aftercare did they receive?

**2) Focusing on the narrator's path into involvement in improving the organisation and delivery of services.**

- How did their first experience of being involved in forums/meetings or other activity related to service improvement come about and who initiated this idea?
- Did this initial experience open up opportunities to be involved in other arenas?
- Do they feel that they represent the voice of service users and/or carers in the service improvement environment?
- Have they received feedback as to how their involvement has led to service improvement (such as a change in policy or the appointment of a staff member)?
- How have they experienced relationships with clinicians and managers in the service improvement rather than a clinical setting?
- Has this changed if their mental health has deteriorated? How did it feel to return to any meetings/forums/committees if they had been absent for a period of time?

- Have they identified 'allies' in supporting them to have a meaningful voice in service improvement activities and if so, who are they and what have they done to support?
- What other barriers have they encountered in effective participation in service improvement?
- Do they still have a role in the service improvement setting? If they have, how do they see this developing in the future? If they haven't, what has prompted them to withdraw from this role?

**3) Closing the interview.**

- Are there any questions that the interviewer has failed to ask, which they believe would be useful to respond to?
- Are there any areas of the discussion that they would like to return to?

**Guided Schedule for Oral History Recorded Interviews (Participant):**

***Introduction:***

There has been an increasing focus in policy and practice on service users and/or carers being actively involved in service improvement activities, with the view that this will improve the quality of and satisfaction with care provision. The aim of the interviews being undertaken are to understand the perspectives of service users and carers on their contributions and the relationships with those in organisations they are working with.

**1) About you:**

- Date and place of birth
- Family & friendship experiences when growing up & and who are significant to you now?
- Education from early years into adulthood
- Any employment history

**2) A brief overview of how you or someone you know became involved in mental health services.**

Your experience of being referred mental health services when in mental distress or when supporting a partner who was experiencing mental distress. Discussing the interventions or support received.

**3) The main part of the interview: Your experience of involvement in improving the organisation and delivery of services.**

Thinking about how you initially became involved, the experience of being involved and how valued you have felt in your contributions.

**4) End of the interview.**

- Are there any questions that the interviewer has failed to ask, which you believe would be useful to respond to or any areas of the discussion that you would like to return to?



## **Appendix C: Participant Invitation Letter (Version 2) & Participant Information Sheet (Version 2)**

Health  
Sciences

UNIVERSITY OF  
**Southampton**

Date:

Dear XXXXXX

**Re: Research project on service user experience in mental health improvement activity**

I am writing to you as a student at the University of Southampton who is looking to undertake some research for my PhD. I have a keen interest in the experiences of people who have previously or are currently using mental health services, but also have at some time used their experience to contribute in the improvement of services. This may be through participation in forums, committees or boards, recruiting staff or being formally employed within a health care organisation.

XXXXX XXXXX has suggested that you have had experience in this area which could contribute to the research I am undertaking. **With this letter I have enclosed a participant information sheet, which gives further details as to what involvement in this project would entail and what to do next if you are interested. Reading this information does not commit you to participate.**

Yours Sincerely

Chris Gale

Doctoral Student

[chris.gale@soton.ac.uk](mailto:chris.gale@soton.ac.uk)

Tel: 023 80XX XXXX

**Participant Information Sheet (V2)**

**Study Title:** Service User Experience in Mental Health Improvement Activity

**Researcher:** Christopher Gale

**University Ethics number:** 9374

**Research Ethics Committee Number:** 14/SC/1063

I would like to invite you to take part in my doctoral research study with the University of Southampton. Before you decide I would like to outline why this research is being done and what it would involve for you. Please take time to read this information sheet and I am available to answer any questions you have.

**What is the research about?**

This study aims to fill a gap in current knowledge related to the important role that experts by experience (as service users or carers) play in the planning and delivery of mental health services in the Hampshire area. The study will take an oral history approach, which refers to the process of collecting people's experiences and stories with an audio recorder then transcribing them for analysis and the learning of future generations.

**Who is organising and funding the research?**

As the doctoral student I will be undertaking the research myself, supported by two supervisors. The research is based at the Faculty of Sciences within the University of Southampton and will be self-funded. My background is working with young people experiencing difficulties around their mental health and since joining the university in 2008 I have had the privilege of working closely with adults who have expertise by experience in mental health (as users and carers).

**Who has reviewed this study?**

This study has been reviewed by the by the University of Southampton's Research Governance Office. Additionally, all research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your interests. This study has been reviewed and given favourable opinion by the South-Central Oxford C NHS research Ethics Committee.

**Why have I been invited?**

I aim to interview up to twenty people in the Hampshire area who have accessed mental health services for treatment or support, but then gone on to take an active role in the running of that provider organisation. This may be in the form of sitting on focus groups, committees and boards, becoming involved in the recruitment of clinical or managerial staff or being directly employed in a peer support capacity. I think that you would match these criteria and that is why I am requesting your participation.

**Do I have to take part?**

It is up to you if you decide to join the study. I will describe the study and go through this information sheet with you. If you agree to take part you will be asked to sign a pre-interview consent form. But please note that you will still be free to withdraw at any time and do not have to give a reason if you choose to do so.

**What does taking part mean?**

If you agree to take part I will arrange an interview with you and will audio record the interview. The home setting is often where people feel most relaxed to talk about their experiences, but if you would prefer to have the interview somewhere else that feels more comfortable and convenient for you, this can be arranged. The interviews may last up to 90 minutes or longer depending how much you wish to talk about. However, this can be spread over more than one visit if you would prefer shorter sessions. I will have some guiding prompts for discussion within the interview and you will be sent a summary of these beforehand. However, as this is an oral history interview, you will be guiding me as to the important issues you have found from your experience.

After the interview I will transcribe the audio recording for my research analysis in its non-edited form. This will take up to four weeks. Once completed I will send you an audio copy of the recording to listen to and keep. At this point you have the option to edit out some parts of the recording that you would not wish to be heard by others when it is archived with University of Southampton. I am happy to meet with you to discuss and identify any parts for editing should you wish to do this. Please see the section below regarding confidentiality, which provides further information on the confidential storage of the audio recording.

### Should I bring anything with me to the interview?

Yes, if you have any materials which would help to explain your experiences, such as diaries, letters, meeting minutes, publications, policy documents, newspaper reports, photographs, websites or blogs. However, if you do not have access to materials, please do not worry – your recollections are the most valuable source!

### Are there any benefits in my taking part?

There will be no financial benefit to taking part, however, you will be adding to current knowledge around the experiences of experts by experience in mental health service settings and potentially influence the way in which people contribute in the future to such activity.

### Are there any risks involved?

It is hoped that sharing your story and contributing to future knowledge will be an interesting and valuable experience for you. However, recalling experiences that were negative can potentially be difficult. If this should happen during the interview, you are free to request that the interview is suspended for a short time and resumed or even postponed to another occasion. Also, within the pre-interview consent form you will be asked to identify a supported relative, friend, worker or other whom can offer support if you are left feeling upset after the interview has finished. The non-exhaustive list below includes the suggested names and contact details of individuals or organisations that may be helpful in this instance.

- The GP with whom you are registered.
- A mental health worker, such as a Peer Support Worker, Mental Health Nurse, Social Worker or Occupational Therapist, with whom you have a positive relationship.
- Sane – National mental health charity offering 1:1 support every day (6-11pm) - 0845 767 8000
- The Samaritans – 24 hours support helpline - 08457 90 90 90
- MIND – offers a range of support services – accessing <http://www.mind.org.uk/information-support/> will enable you to find out the support available in your local area.

**Will my participation be confidential?**

All information relating to this research will comply with the Data Protection Act and the University of Southampton's policy relating to the storage of confidential information. Practically with face to face interviews your name, address and contact details cannot remain anonymous to me as the researcher and my project supervisors. However, your details will be kept on my secure desktop computer within a locked office area. The interview audio recording and transcript will be coded, so only I can link them to your personal details, and will be stored within a secure file on the university's computer system (accessible only by me). Any information held in paper format will be locked within a filing cabinet, again in a locked office area.

After the research project has been completed fully anonymised copies of the audio recordings and transcripts of interviews will be stored in the University of Southampton Library's e-Prints repository and will be accessible to users worldwide.

**What happens if I change my mind?**

You have the right to withdraw from the research at any time prior to and during the interview.

**What happens if something goes wrong?**

In the unlikely case of concern or complaint, you can contact Barbara Halliday, Head of Research Governance at the University of Southampton (02380 595058, [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk)).

**Where can I get more information?**

If you have any more questions relating to the research project, please do not hesitate to contact me on 023 8059 7863 or [chris.gale@soton.ac.uk](mailto:chris.gale@soton.ac.uk)

## **Appendix D: : NRES Approval for the Study (August 2014)**

### ***Health Research Authority***

**NRES Committee South Central - Oxford C**  
Level 3, Block B Whitefriars Building  
Lewins Mead

Telephone: 01173 421383

19 August 2014

Mr. Christopher  
Gale Faculty of  
Health  
Sciences  
Building 67, University of  
Southampton Highfield,  
Southampton  
SO171BJ

Dear Mr. Gale

**Study title: Patients, Professionals and Power Dynamics: The Transition of the Service User to 'Expert by Experience' in UK Mental Health Service Improvement Activity**

**REC:** 14/SC/1063  
**IRAS:** 148303

Thank you for your letter responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair. We plan to publish your research summary wording for the above study on the HRA website,

together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Lauren Allen, nrescommittee.southcentral-oxfordc@nhs.net.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where an NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre, guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

### **Registration of Clinical Trials**

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs .net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### **Ethical review of research sites**

#### **NHS sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### **Approved Documents**

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Covering Letter]	1	07 June 2014
Covering letter on headed paper [Covering Letter- Response to Provisional Opinion]	2	13 August 2014
Letter from sponsor [Sponsorship confirmation from UoS]	1	09 May 2014
Letters of invitation to participant (Participant invite letter V1]	2	13 August 2014
Participant consent form [C Gale Pre-Interview Consent Form]	3	13 August 2014
Participant consent form [C Gale Pre-Recording Release Consent Form]	2	02 May 2014
Participant information sheet (PIS) [C Gale Participant Info Sheet]	2	13 August 2014
REC Application Form [REC_Form_18082014)		18 August 2014
Referee's report or other scientific critique report [C Gale University Peer Review Feedback]	1	06 January 2014
Research protocol or project proposal [C Gale Research Protocol]	2	13 August 2014
Summary CV for Chief Investigator (CI) (C Gale Short CV)	1	05 June 2014
Summary CV for supervisor (student research) [Dr D Carpenter Short CV]	1	29 April 2014

### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### **After ethical review**

#### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

The Health Research Authority is continually striving to provide a high-quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known, please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

#### **HRA Training**

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

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| 14/SC/1063      **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this  
project. Yours sincerely



**Professor David Scott Vice-Chair**

Email: nrescommittee.southcentral-oxfordc@nhs.net

*Enclosures:*                    "After ethical review – guidance  
for researchers "

*Copy to:*        *Mrs Barbara Halliday*







## Appendix E: Pre- Interview Consent Form (Version 2), Interview Schedule (Interviewer & Participant) & Post Interview Letter with Recording Release Consent Form

**Study title:** Service User Experience in Mental Health Improvement Activity

**Researcher name:** Christopher Gale

**University Ethics Reference:** 9374

**Research Ethics Committee Reference:** 14/SC/1063

*Please initial the boxes if you agree with the statement(s):*

I have read and understood the participant information sheet (13/08/14/version 3), have had the opportunity to ask questions

I agree to take part in this research project, consent to the use of audio recording and agree for my non-edited data to be used for the purpose of this study, with possible use of verbatim

I understand my participation is voluntary and I may withdraw at

I have identified a relative, friend, professional or other whom I can contact after the interview, should I feel upset in any way.

I understand that I will have the opportunity to listen to the recording of my interview (anonymised) and sign a recording release form prior to it being placed with others in the University of Southampton Library's e-Print online repository.

### ***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.....

Name of person taking consent (print name) .....

Signature of person taking consent.....

Date.....

## Guided Schedule for Recorded Interviews (Interviewer)

### **Introduction:**

Explain again the context and purpose of the recorded interview; that there has been an increasing focus in policy and practice on service users and/or carers being actively involved in service improvement activities, with the view that this will improve the quality of and satisfaction with care provision. The aim of this project is to understand the perspectives of service users and carers on their contributions and the relationships with those in organisations they are working with.

### **Biographical section:**

(Aim of this section is to settle the narrator, and ease him/her into recollection of the period under study)

Establish:

- Date and place of birth
- Family & friendship experiences when growing up & and who are significant to them now?
- Education from early years into adulthood
- Employment history

**1) Focusing on the narrator's experience of mental health services when in mental distress or when supporting a partner who was experiencing mental distress.**

- Provide prompts to explore through anecdote the areas relating to:
- How they came to be referred into mental health services and how long were they engaged with services?
- What interventions/support did they receive and how did they happen?
- What were their thoughts about the environment where the treatments took place?
- What aftercare did they receive?

**2) Focusing on the narrator's path into involvement in improving the organisation and delivery of services.**

- How did their first experience of being involved in forums/meetings or other activity related to service improvement come about and who initiated this idea?
- Did this initial experience open up opportunities to be involved in other arenas?
- Do they feel that they represent the voice of service users and/or carers in the service improvement environment?
- Have they received feedback as to how their involvement has led to service improvement (such as a change in policy or the appointment of a staff member)?
- How have they experienced relationships with clinicians and managers in the service improvement rather than a clinical setting?
- Has this changed if their mental health has deteriorated? How did it feel to return to any meetings/forums/committees if they had been absent for a period of time?
- Have they identified 'allies' in supporting them to have a meaningful voice in service improvement activities and if so, who are they and what have they done to support?
- What other barriers have they encountered in effective participation in service improvement?
- Do they still have a role in the service improvement setting? If they have, how do they see this developing in the future? If they haven't, what has prompted them to withdraw from this role?

**3) Closing the interview.**

- Are there any questions that the interviewer has failed to ask, which they believe would be useful to respond to?

Are there any areas of the discussion that they would like to return to?

**Guided Schedule for Recorded Interviews (Participant):*****Introduction:***

There has been an increasing focus in policy and practice on service users and/or carers being actively involved in service improvement activities, with the view that this will improve the quality of and satisfaction with care provision. The aim of the interviews being undertaken are to understand the perspectives of service users and carers on their contributions and the relationships with those in organisations they are working with.

**1) About you:**

- Date and place of birth
- Family & friendship experiences when growing up & and who are significant to you now?
- Education from early years into adulthood
- Any employment history

**2) A brief overview of how you or someone you know became involved in mental health services.**

Your experience of being referred mental health services when in mental distress or when supporting a partner who was experiencing mental distress. Discussing the interventions or support received.

**3) The main part of the interview: Your experience of involvement in improving the organisation and delivery of services.**

Thinking about how you initially became involved, the experience of being involved and how valued you have felt in your contributions.

**4) End of the interview.**

- Are there any questions that the interviewer has failed to ask, which you believe would be useful to respond to or any areas of the discussion that you would like to return to?

Date:

Dear XXXX

**Re: Research project on service user experience in mental health improvement activity**

Thank you again for participating in the research interview on XXXX

Please find enclosed a data stick containing the unedited version of the interview. Having listened to the recording, if you are happy to sign the enclosed recording release form, please could you do so and pop it in the stamped address envelope provided. Just to remind you that the copy available for public access will have all personal identifiable data removed.

I wanted also to reassure you that you won't be forgotten and that I am looking to transcribe the interview in the next couple of months, after which I will email a word document containing the full transcript.

Yours Sincerely

Chris Gale

Doctoral Student

[chris.gale@soton.ac.uk](mailto:chris.gale@soton.ac.uk)

Tel: 023 8059 7863

## Recording Release Consent Form (Version 2)

**Study title:** Service User Experience in Mental Health Improvement Activity

**Researcher name:** Christopher Gale

**Ethics reference:** 9374

Your recorded interview will be used in the completion of the above doctoral research project and stored with the University of Southampton Library's e-Prints online depository as a permanent reference resource for use in research, publication, education, lectures, broadcasting and the internet. The purpose of this Agreement is to ensure that your contribution is added to this small collection of oral history recordings in strict accordance with your wishes.

This agreement is made between **Christopher Gale, Faculty of Health Sciences, University of Southampton, Highfield, Southampton, SO17 1BJ** ("the interviewer") and you ("the participant", "I"):

**Your Name:** .....

**Your Address:** .....

In regard to the recorded interview/s which took place on:

**Declaration:** *I, the participant confirm that I consented to take part in the recording and hereby assign to Christopher Gale all copyright in my use in all and any media. I understand that this will not affect my moral right to be identified as the 'performer' in accordance with the Copyright, Design and Patents Act 1988. I understand that no payment is due to me for this assignment and consent.*

*If you do not wish to assign your copyright to Christopher Gale or you may wish to limit public access to your contribution in some way, please state the conditions here:*

.....  
.....

This Agreement will be governed by and construed in accordance with English Law and the jurisdiction of the English courts.

Both parties shall, by signing below, indicate acceptance of the agreement.

By the participant:

**Signed:** .....

Name in block capitals: .....

Date: .....

By the interviewer:

**Signed:** .....

Name in block capitals: .....

Date: .....



## Appendix F: Example of Initial Interview Noting, Reflexive Comments &amp; Annotation (Beth)

P1110914

(1)

- \* Terminology → connotations of labels (3 sisters, 2 brothers)
- \* Family life
  - Family, youngest of 7 by some years - siblings ranged from 8 - early 20s 'Atlantic college'
  - scholarship - escape (School in Wales for IB)
  - violence/psychological abuse
  - Dad died at 10
  - Always had message she ruined mother's life.
  - Didn't live with sisters, but v. close geographically - spent a lot of time there
  - Held family hope - v. bright (even though not feeling wanted)
    - top in "sink" school.
    - played sports for school + town
  - School.
    - didn't think about move to Wales until it happened

(2)

- homesick in first terms, but mum didn't ask her to come back (best thing she did).
- flourished in Wales - IB subjects + taught local children, out and about activities, met husband who was a cliff instructor.
- saw schoolmaster last year - said everyone wanted her in their class, as working class (rare)
- started labour family - working as soon as kid. Marched for miners + Barlays protests (80s)
- \* University
  - went to Reading - 'workman like' thing as had farm experience at school
  - always worked even though uni.
  - Navy wanted her + would sponsor during uni. But 'no role' for male partners. Wanted to be with ~~Mike~~ (Mike)
  - 1 year accountancy, but hates it.

(3)

17-19

→ moved to York to undertake teacher training. (Mike) came with, as finished degree. Did conservation  
Good year in York

→ first teaching job in Gloucester  
'fast-tracked' a running car kept by 23/24. Planned to be Head by mid 30s.

→ Had [redacted] - 'world collapsed'  
(son)

Assumed life would continue, but didn't, although still involved in school (son replaced as mat leave)

8 weeks mat leave. - sense of bereavement.

• No language to understand what was happening

• Decided to kill self instead of going into school, but [redacted] stopped her (not sure why). (Mike)

→ 1st episode but unwell

at exam time in school + college (Mike) [redacted] got her thru.

(19m)

(4)

"Really big moment for me". Went to G.P. who wanted her to see CPN. Didn't want to due to stigma + not being able to work in school.

" "

Got antidepressants.

(son)

• [redacted] still @ nursery. Wasn't looking after him at all. (Mike) for 10 yrs (son) juggled jobs, looking after her to [redacted]. Not certain if he came back + find her alive.

(Mike)

\* Didn't go back to work, [redacted] got promotion (1998) + went to Birmingham (fresh start). Found out that day that next sister up had terminal cancer. Said she couldn't stay.

Told

\* HV she was suicidal - attending therapy day hospital next day - best experience of care

(5)

- Sister died after 4 MO + felt she had to move back to ~~Gosport~~ (SOUTH COAST). Moved after 6 mo
- Psychoanalysis + Art therapy, relaxation / creative visualisation (SOUTH COAST)
- Met to ~~work~~ - "stop back" in services - 1:1 work with someone in Fareham.
- Unsure of referral between Solihull + CMHT.
- Started Psychology degree (OU) took exam at home in 2002.
- Put pen down + went to bed for 3 months
  - ↳ In between worked as advisor in school for challenging pupils,
  - Suicide attempt (2002) - went to GP who said 'you got yourself into the system then (2003)

(6)

- Went to ~~work~~ (NHS MH UNIT) + released after 8 weeks (too early), needed to come back, but no beds.
- " (PRIVATE MH UNIT) Went to ~~work~~ - had structured programme (like day hospital)
- Had CBT
- (Mike) caught her to stay (which she did for some months), as bad as ~~work~~ came up a week later. (NHS MH UNIT)
- Therapist there said she "wasn't a victim" (QUOTES)
- Had Care Co-ordinator from CMHT (July 2003), who said there is nothing out there for her
  - " Confused at time, but now thinks mother doesn't want her to sit in day services for rest of life.

(7)

- \* Couldn't work with her => went thru several until after Josca (lost worker) => looked holistically

(MIRE)

- had covers ass't - assess mentioned for G SUN

"give it a go", but no sense of agency

- \* TN (from SUN) came around, said that there was a lot she could do.

feels it was suggested as something for her to do. "could not string two words together". DISTRACTION

- \* TN felt she could do more of this than being "wheeled out + back into the cupboard"

- \* SUN model v. benevolent. TN "face of native", everyone followed in her wake.

(8)

(MM NHS TRUST)

- \* [REDACTED] wanted SU involvement - locality TN suggested clinical governance meeting (every 2 mo)

not interested in that sort of thing - "wheeled out", but what she could cope with. "Has a warm body"

→  
Moved onto LIT (Local Implementation Team) - more about day to day running. Reported back to sun & day groups - took feedback to LIT.

- \* Developed training programme for other SUs to feel confident + involved in groups such as LIT. Also helped with *Plant Pathogen* books, (resource)

(local)

- \* MIND searching organisation - joined committee (ran all non stat M4 service) 2006. Became Chair 2009 - 2011.

(LOCAL MH TRUST)  
 Joined ~~SLT~~ in 2010 (9)  
 described self as 'package' car  
 of experience + teaching background  
 " "  
 TN suggested applying for job  
 to replace LH in ~~SLT~~ (didn't think  
 she could do anything).  
 11  
 2010 "Went over to the dark side"  
 (got job)  
 wasn't true spirit of involvement  
 wanted a lot of her 'package' to go  
 away once in post  
 SV Involvement Co-ordinator  
 for Trust, based in ~~Salisbury~~  
 (TOWN ON SOUTH COAST)  
 => Job was to make her wanted  
 to empower SVS, BUT in ~~SLT~~  
 business.  
 (LOCAL MH TRUST)  
 had to train + motivate  
 people when ~~SLT~~ wanted them.

(10)  
 People would be brought in, do a  
 job, but left waiting for next time  
 they were called.  
 One of jobs was to challenge people.  
 SV should be at start of processes  
 such as recruitment, but wheeled in  
 for interview panels, but never  
 informed of outcome.  
 Not necessarily would she know  
 outcomes.  
 Did a lot of project management -  
 support service designs to become more  
 recovery orientated (part of national  
 project)  
 Developed Skills database for SVs,  
 so they were empowered to be  
 more than 'arm bodies'  
 Problem with SUN - TN would  
 have people come with her - people  
 never got a word in - SUN

(11)  
became 'broken' - SVs had not interested in task at hand, more of a day out.

Wanted people to be contribute in areas of interest, not be grateful to be asked.

- Often called 'them' in meetings when representing SVs.
- most proud of project work.
- Always hoped she represented SVs well

not allowing profs not to be benevolent & patronising. Do this in a diplomatic way

Had to work within a conservative organisation. Colleague in basing state v. anti-psychiatry + thought it should happen outside system. She felt change needed to happen within.

Proud of work around Care planning did new training for Care Coordinators

(12)  
Report she prepared - CPlanning 'not fit for purpose' - working with SVs in preparing this report.

C coordinator training - all kn, but no practical training

Built up a team of inspectors to look at wards (SVs + staff)  
✓ nurses.

Inspected all wards.

↳ 'concrete changes' to the ward.

Work "not all about nursing" - needed to give opps for this then focus on the task.

Role became destructive towards end - clash of personalities.  
Recovery team "not sufficiently focused" in trust.

↳ Recovery College

(13)

- Budgets tighter. All managers went on 360° training + changed their personalities.

→ outcome driven. Didn't want them to be SVs anymore - operate above their profs.

- Increasingly voice as SV rep slt down - constantly told to follow party line. National Bars - restrictions - told what to say.

(Fellow SV co-ordinator)

→ When left, [redacted] guy said, she was forced to had got voice back

- Things should be challenged assertively - why? questions

boss said was "above you pay grade." PhD above pay grade - decisions to come out.  
(Role has gone + structures in place. No local dialogue)

(LOCAL MH TRUST)

between [redacted] + local groups.

(14)

- Wellbeing centres - no opps to develop SV involvement. Told by boss not to do their job for them.

- Impl to put structures in place for institutionalised to have a voice

→ more her working outside trust.  
(trust bottom line - SVs to be used for trust business)

" "

She wanted them to have a voice in how their services were run, rather than trust business.

- Use CQC as example - limit was for her to make SVs were there for inspection visit.

- TN + 6 SVs turning up at meeting + being quiet - not what SV

15

involvement was about. Needed to be progression for SUs. Easy not to say anything. Got to be more than getting out the house.

- \* Likes being external + not being ~~challenged~~ constrained by job role + be able to challenge.
- \* Really aware of power imbalance.
- \* Involvement should be one aspect of recovery → cannot make a living from it.
- \* Has to work hard at being well - having therapy during involvement years. Understanding system helped in relationships with profs as a SU.
  - much more equitable.

HTT in 2011 + slips along way.

16

- \* Medication not being useful
  - ↓ Psychiatrist - "still alive don't you"
  - ↓ stopped being grateful when joined the trust.
- \* Talked about experience of lithium toxicity + almost dying. (2 yrs ago)
  - ↓ but put back on lithium again - toxicity again. Psychiatrist told her to go + research alternatives + come back and discuss options.

- \* Has times when doesn't want pills at all, but threat of sectioning over her. Had good care - coordinator ~~etc~~ - was assertive + works manager meds with prof support. BOT
- \* Psych left + CC moved to other ~~team~~ ~~and to another~~

17

- Allocated to 6 month rotation doctor, wanted her to go to full dose then manage ↴
  - response didn't want to be subject to medical model - discharged, as "nothing I can do for you".
- DBT v. good for her - told her it was okay to be angry or sad (emotions not allowed in childhood)
  - treated better as worked in trust.
- In 2 year psychodynamic group - treated with suspicion by other members, as worked in trust
  - balancing act between my + Trust work. (Private + public persona).

18

- Doing P4D => first time being honest (with supervisors) - telling them she was struggling.
- \* Could she have done this in trust?
  - different - wasn't allowed to be vulnerable in trust (influence of her boss - need to be in control)
  - lithium poisoning - support not from team, thru occupational health.
- LL => saw her team as luxury in atmosphere of job cuts to front line services. Allowed to exist & be creative in this situation.
  - Reflection of personal vulnerability? Trapped in trust.
- New lease of life since she left.

trust.

19

Where does that leave the activist in you?

↳ almost ~~involved~~ involved in recovery college with other trust. BUT each course run by prof + peer. Didn't account for her teaching experience

→ Helping to develop narrative groups in ~~groups~~ (SOUTH COAST Towns)

→ likes idea of being an agent of change externally.

Don't have to do things in a regimented fashion. Was on trust - will before 1996 - doesn't want that

↳ likes mixed portfolio.

→ PhD is activism at moment - hopefully make difference to how

people see selves.

20

Over last year - not hide with probs - okay to have them.

↳ majority of time art + design, but times when not functioning

Ph.D → feels proud she is doing something she wants to do - not given to her.

↳ design not to be mapped out, enjoy journey now.

→ wonders how much about involvement has been about her issues. Always aware of power imbalances

↳ profs in higher chains.

→ sitting drinking coffee not her life - okay for some to exist. even without MI world

have different outlooks

37

Told one she was 'with saving' -  
not sure what that means for the  
others!

has worked hard in therapy.  
+ 'put back'

109 mins

## Reflexive Comments: Beth

**1) I've known this narrator for a couple of years prior to the interview as a colleague within a service user reference group at work and she is my link to recruiting further participants**

**So, What?** – Her familiarity with my research and our working relationship could have influenced her response to my questions. Is she going to tell me the answers she thinks I would want? Would that be the case, even if I did not know her (as with some other participants), as the interviewer/interviewee dynamic creates this possibility? It will be useful to pick this up when talking about storytelling devices in the analysis and discussion chapters.

**2) After the interview, but prior to analysis, our relationship has shifted. She is now undertaking her own doctoral studies and has planned to recruit from the same group of contacts she passed on to me. We have inevitably talked about our respective projects and their focus, sometimes over lunch and therefore have formed a social relationship.**

**So, What?** – Will this social relationship impact on my analysis? Will I hold back on analytical comments which will be interpreted as making a judgement about her story (inevitable with the approach I'm using)? Will be important to focus on the pseudonym created when undertaking analysis to detach 'Beth' from the person I know.

**3) There were moments in the interview (listening back to the audio recording) where Beth's tone suggested looking for validation of what she had said (rising inflection at the end of sentences). Usually this was in relation to the treatment she has been on the receiving end of.**

**So, What?** – Is Beth conscious of my background as a mental health nurse and academic when framing her story? Beth had identified mental health professionals whom she almost regarded as 'allies', as opposed to those whom were regarded as oppressors – do I fit into the former category? I did not get the sense she was 'filtering' key information, but then how would I know if she had?

## Example Annotation of Interview Transcript (Beth)

P1: Well ... well first, first of all I suppose .... That, you know, I've done all this bloody work, I've been through, you know a nightmare really and she was, I was basically feeling I could, I could actually come home. And she was saying there is nothing out there to support you in that. And I think now, you know, when I look back, what she meant was she didn't want me to go to day services and sit and drink coffee for the rest of my life. But I don't think she quite knew what to do with me either, um, because she thought if I did, I did that, I'd be... living a no life. So... but that was her statement and I remember being really angry with it and saying to [redacted] you know... I used to swear quite a lot in those situations (Laughs)... and I came home and I said "I can't, I can't work with her" and so I actually went through quite a few care coordinators until I got one. And the manager of the [redacted] said "This is the last one, if he's no good we are going to have to look out of area". But it was with a guy called [redacted], whose now the chief social worker in [redacted] now, and he was really good and he was the first one that really, erm, looked holistically and, and he'd let me moan and then say "Right, you've had your moan, let's work now". So he was... but, but so, but erm, so... she said "There's nothing out there for you", and then Don had a carers assessment and the carers support worker said "Actually..." he must have mentioned to her, "There's something called SUN in [redacted]", which was the Service User Network. And I you know, I suppose prior to this you know. I'd never had... no interest in mental health. It wasn't my thing....erm.... So, so, you know, involvement, it's in a way because of what happened; it wasn't a life choice, erm and I was at the point I'll give anything a go. Quite... no sense of agency or anything in there and [redacted] came round (smiles). Came here, she was sitting where you are. And she said "There's lots that you can do". And so from that point started my involvement journey.

CG: How was it... so you've got this carer support worker suggesting SUN, and were they suggesting it in terms of sharing your experiences or was it as a kind of therapeutic avenue?

P1: I think it was something for me to do. That... I suppose even then that, that I could barely string two words together, that they could see in a sense that I needed to be doing something. And... So... I, it was initially it was more distraction, but I suppose there was a sense quite quickly that actually it could be more than just a distraction or I suppose [redacted] sort of... sort of sensed that, yeah I could do more than...., you know, it didn't need to just be wheeled out as a service user and moved back into the cupboard until the next time. So, but in itself, so, but it's been a very therap... journey for me erm.... yeah.

CG: So you said that the first... that was the beginning of your involvement journey. So, what did that involve, what did you kind of do from that point? You've got [redacted] who is saying she felt you could do...

P1: Yeah, I mean she came, she came and sat here and she said "actually..." ... she told be what SUN did and that there was a number of ways of doing something. And, you know, she, she had a group that erm... in a way, you know ... the model was very benevolent, which again I can see now, but at the time, yeah, basically [redacted] was a force of nature, you know, a huge presence and she, we all sort of followed in her wake. Erm, so, but you know, she had a group of people that she was working with in SUN and for some it was just helping out at a day group, but, but I think, erm, [redacted] [redacted] it was then wanted service user involvement on, erm, community meetings and [redacted] suggested I, erm, sit on the clinical governance one. I think because she, she felt that a lot of people wouldn't understand what they we talking about. Erm and so that was my starting point. I used to go to the clinical governance meeting once every couple of months.

CG: And this was for the whole trust is it or this part of it..?



## Appendix G: Extract of Interview Transcript (Beth) & Preliminary Analysis

This extract comes after Beth has described her early life

### Key:

████████ = Names of people and locations blanked to maintain anonymity.

XXXX = Rising inflection at end of a sentence (could be a narrative device to check my understanding of participant's point or seek agreement?)

(XXXX) = non-verbal behaviours

**Key Narrative Remarks (Black text)**

**Initial Exploratory Comments (Blue text)**

**Emerging Thematic Comments (Red text)**

**Emerging Themes (Green text)**

Unedited Interview Transcript (with the exception of the employing organisation, which has been changed to 'the Trust')	Key Narrative Remarks (Black), Initial Exploratory Comments (Blue), & Emerging Thematic Comments (Red)	Themes for Cross-Case Analysis over the Participant Data Set
<p><b>BETH:</b> Appl, well again it was [REDACTED] had said, had said erm ... this job had come up, this job was coming up... It was [REDACTED], [REDACTED] [REDACTED]'s job and erm she... the Trust were about to develop their peer support ... service and she'd been seconded to get this going and so there was a, it was a one-year job while she was on this project. And so, I went for it.</p>	<p>Job within local MH trust identified by SUN co-ordinator – patronage and permission given to P1 to pursue this as a potential opportunity.</p>	<p><b>PATRONAGE &amp; PERMISSION BESTOWED BY OTHERS</b></p>
<p>And bearing in mind, at the time, you know, I didn't think I could do anything, I was, you know, erm, I got the job and it ended up being .... you know [REDACTED] sort of moved but she never came back to that job.</p>	<p><i>'bearing in mind, at the time... I didn't think I could do anything'</i> – significant contrast here to the description over recent pages around her increasing SU involvement, application of skills from different lives and status this had afforded her in the 3<sup>rd</sup> sector organisation. Fragile self-esteem OR the activities here not viewed as worthwhile as those aspired to in former life?</p>	<p><b>FRAGILE SENSE OF SELF-ESTEEM GAINED THROUGH SU ACTIVITY?</b></p>
<p>And so, in my, my job became permanent. Erm, so, but, you know, so 2010 I went across to the dark side (<b>smiles</b>).</p>	<p><i>'went across to the dark side'</i> - 'Star Wars' reference – contrasting with the 'good side' (light side), which presumably is the status as service user and person engagement in 3<sup>rd</sup> sector involvement activities. NO shades of grey here – light vs dark / good vs evil / users vs services</p>	<p><b>STATUTORY SERVICES = THE DARK SIDE (ALIGNING WITH THIS OR A FOOT IN BOTH CAMPS?)</b></p>

And .... It, it was .... Reflecting on it now... It was... so beneficial in so many ways, but it was also, in terms of activism.... and the true spirit I think of involvement, it wasn't that at all in that they, you know,	Refers to 'activism' and 'the true spirit of involvement' – activism synonymised with true SU involvement here. Resisting dominant powers and pursuing an alternative agenda.	ACTIVISM = TRUE SU INVOLVEMENT?
they had recruited me on the base of that package, but soon as I was in post they wanted a lot of that package to go away.	Recruited on basis of 'package' she offered, but feels that once in post a lot of what she offered they did not want. Feeling duped by those with power/authority – seduced by the 'dark side' only to find out that it was based on falsehood. Untrustworthy dominant institutions.	SEDUCED AND EXPLOITED BY DARK SIDE
<b>CG:</b> So, what was the post title?		
<b>BETH:</b> The post title was a real mouthful. It was Service User Involvement Coordinator.		
<b>CG:</b> Right... and was this for the trust?		
<b>BETH:</b> The Trust, the whole trust.		
<b>CG:</b> That's huge, a huge area.		
<b>BETH:</b> Right, so I, yeah I used to go all over the trust. I was based in [REDACTED], erm, but yeah I went, I went all over, to people all over. Erm, I mean initially I think it, it, my job was to... In a, in a way it was all about portfolio – I was to make it how I wanted, but with the sense of being about empowering other service users to be involved. But, to be involved in Trust business. Which I really only got quite at the end when I really didn't like it at all, cause there was this feeling that my	Conflict between her view of empowering SUs and the trust wanting them to be used for trust related business. Again, that sense of feeling duped into something that wasn't all that it seemed. SUs seen as a 'commodity' for the trust – similarities can be drawn here with the 'wheeling' in and out of the community meetings as a passive service user. Reliance on power and patronage.	SUS A COMMODITY FOR THE TRUST (BEING DUPED)

job was to train, motivate these people to be there when we wanted them.		
<b>CG:</b> So was it that... you referred to a couple of times the wheeling in and wheeling out...		
<b>BETH:</b> Yeah it was that, yeah. And there was, there was, you know, a sense I was doing this work with individuals and would do this work, but there was nowhere for them to go... until we wanted them. So, if, if, if I was running a project and I needed people, a focus group or something, then there was a sense I've got these people out there waiting to be, erm, wheeled in, and I, I and I didn't really, I suppose I react quite badly to that ...erm... Because my view was that you can't expect them to be waiting ( <b>smirks</b> )...	Interesting referral to SUs 'waiting' and having 'nowhere to go' until required by the trust. Further description confirming the above. <b>Exploitation of SUs wanting to be involved and she as SU involvement co-ordinator, was being used as a tool to do this. Reliance on power and patronage + untrustworthy institutions.</b>  <i>'my view was you can't expect them to be waiting...' Keen to convey that she was not complicit in the trust's behaviour and attitude. An activist, working on the inside??</i>	<b>EXPLOITED AS A TOOL TO EXPLOIT OTHERS (SUS WISHING TO GET INVOLVED) – UNTRUSTWORTHY INSTITUTIONS</b>  <b>RESISTANCE &amp; ACTIVISM (FROM THE INSIDE)</b>
<b>CG:</b> No, for the call...		
<b>BETH:</b> For the call, you know people used to get quite pissed off when... and cause, you know, I'd been there three years and one of my jobs was to challenge people, and, and I worked really hard, sort of, cause, it would be, say you were being interviewed for a job next week and suddenly thought " <i>Oh bloody hell, we need a service user on that panel</i> ", and then they would, I would get these phone calls sort of saying " <i>Oh you know, we want, we want a one-legged lesbian service user who (Laughs), and we want them tomorrow.</i> "	'Oh, you know, we want, we want a one-legged lesbian service user who... and we want them tomorrow' – <b>uses comic turn to highlight the unreasonable nature of the trust's relationship with service users engaging in involvement activity (short notice and the specificity of the requirements). Another act of defiance?</b>	<b>SUS AT THE BEHEST OF THE TRUST – POWER TO EXPLOIT.</b>

And so, where do I magic these people up from?	Uses the phrase ' <i>where do I magic these up from?</i> ' Demands presented unreasonable on the service users, but also on her as co-ordinator. Suggestion of being asked to achieve the impossible.	<b>BURDEN OF REPSONSIBILITY TO APPEASE MASTERS.</b>
And, you know, my view was that actually they should be at the start of the process with the job spec and the... And not just wheeled out. I think people are particularly bad, you'd get people in to do different things and you'd never tell them that outcome. And that was the sense of being wheeled in and wheeled out, so people would be on interview panels and hey would never know who had been appointed or not. It was, you needed the warm body.	Service users only privy to the face to face interview part of the selection process, rather than from the shortlisting stage. Also suggests that service users would not be informed of the outcome (i.e. which interviewed candidate eventually secured the position). Tokenism alluded to once more (reference to being a warm body')	<b>TOKENISM OF SU INVOLVEMENT</b>
<b>CG:</b> Okay yeah, someone to be there.		
<b>BETH:</b> Yeah		
<b>CG:</b> Did you get to know the outcome as the person recruiting these people in to the...?		
<b>BETH:</b> Not necessarily, cause, as... I mean I, I think I very quickly outgrew my brief. In that, erm, I, I, both my, when I started the job I had very little confidence in my own, I think and... I thought I will never teach again and actually I was, I was using a lot of skills. So, I did a lot of project management? Erm and one of those was to erm, to make the Trust through all the service development, redesign, make Southern Health recovery orientated.	States that she ' <i>outgrew</i> ' (her) ' <i>brief</i> ', then goes on to discuss project management activities. Does this suggest that the role wasn't highly valued by trust management (low expectations) OR her level of skills/experience was too high? Restoration of lost identity?  Using project management skills – rekindling of her 'life' as a deputy-head teacher? Restoration again?	<b>FIGHTING AGAINST TOKENISM AND RECLAIMING OF FUTURE/EXPECTED SELF</b>

<p>We were part of a national project? Erm, to support the organisation change needed to make everything about recovery, erm, and so I was part of that project. Erm, and, oh ... I've lost my track.... Er...So, yeah, I think.... I suppose my job could have been split in two; I was there to work to support people to be involved and as part of that I put in place systems, so I, I developed a skills database for service users.</p>	<p>Part of a national project to introduce recovery concept to the organisation. Refers to 'we' when explaining this, not 'I' or 'the trust'. Despite talking about going over to the dark side, this suggests a sense of collegiately within the organisation. Sees self has a professional among a range of professionals working within the organisation?</p> <p>Loses track of her conversation at this point. Reflective of the confusion and conflict experienced when undertaking this role within the trust?</p> <p>Developed a trust database of service users willing to engage, framing this as a desire to empower people. However, such activity could be seen as facilitating the trust to be able to have what it wanted – services users ready at hand to be present for key activities? Unwitting collusion?</p>	<p><b>COLLEGIALITY WITHIN 'THE DARK SIDE' – SHIFTING ALLEGIANCES/ BALANCING IDENTITIES</b></p> <p><b>UNWITTING COLLUSION?</b></p>
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## Appendix H: Extract of Merged Thematic Analyses

### ACT 1: Life before Contact with Mental Health Services

#### 1) Power & Dominance

##### (i) The Shame of Abuse & Rejection

###### BETH:

Early abuse and trauma (P3)

Exploitation by dominant figures (P4)

Abandonment and rejection (P3) & Hoping for rescue that didn't come (P5)

###### MIKE:

Abandonment/lack of importance to parents (P4)

###### ELSA:

Blind faith – misplaced (p2)

Rejection & abandonment by mother (resented for being alive) (p2, 3)

Deliberate cruelty (p3)

Rejection by adult authority figures (mother & nuns) (p5)

Let down by authority figures (nuns in the catholic school) (p6)

Humiliation and shame at an early age (7) (p6)

Subject to ridicule (p6)

Inconsistent adult behaviour (p7)

Not the only one humiliated in the family (referring to brother) (p8)

Humiliation (p9)

False hope of affection brothers received from mother (p9)

Unprotected from abusive behaviours (p9)

Naïve to the ways of the world – vulnerable to exploitation? (p10)

Hoping for affection/approval from mother into mother's old age (p14)

Now knowing where she stands (false praise) (p14)

Humiliation by brothers – lowliness of status (p19)

Father = predator (p19)

Mother did not rescue her (p19)

Retreating to home (however humiliating/shaming that might be) P21

Abandoned at a time of real need (by aunt) (p21)

Being abandoned and left to 'get on with it' (p21)

Kindness and good nature taken advantage of (by husband) (p26)

Things no longer making sense – all that she knew was based on a lie (revelation of husband's affair) (p26)

Isolation in a time of crisis (p27)

Clear sense of right & wrong – the church hypocritical (p29)

Exploited by institutions (they cannot be trusted) (p29)

Good things (job) tainted by bullying (p30)

Not defended by others when being bullied (p30)

Naivety – core beliefs rocked to the core (p31)

Institutions against her (p34)

**ORLA:**

Abuse/trauma – not safe inside or outside the family home (P1)

**SIMON:**

Unreliable institutions (p3)

Family dynamics – lowly status/dominated & abused (p7)

**MAGGIE:**

Robbed of hopes & dreams (by college tutor) (p5)

Confidence/freedom undermined once more (this time by husband) (p17)

Patriarchal authority and fear of disloyalty (p18)

**GEOFF:**

Born into an abusive family (physically abused by both parents) (p1)

“one develops coping mechanisms in childhood that become really unhelpful in adulthood” (p1)

## 2) The Tragic Turn

### (i) Overwhelming Trauma

**BETH:**

Collapsing of world (P10)

Loss of future/expected self (as mother and within teaching career) (P10 & 11)

Fear and paralysis created by loss (P10)

Loss and grief across the generations (P11)

Tragedy sometimes too much for husband to rescue her from (P11)

Tragic turn of life events (P12)

**MIKE:**

Death of childhood friend – the need to inject trauma into the story? (P2)

**ELSA:**

Emphasising drama/danger of her fragile mental state (p24)

The tragic victim once more (p25)

Adding to the adversity (p33)

Distress and trauma in children (p28)

**ORLA:**

Desperation to escape (suicide attempt) (P2)

**MAGGIE:**

Tragedy in the story (p5)

Trauma of realising she had been abused as a child (p12)

Tragedy & dysfunctional family relationships (p12)

Unbearable emotional pain (p13)

Realisation of scale of trauma – overwhelming (p18)

Emphasis on tragedy in life (p21)

**RUTH:**

Tragedy & loss (p7)

Further tragedy & loss (p10)

Tragedy & loss (p12)

Ultimate tragedy loss- no hope for the future – emotional breaking point (p13)

**SIMON:**

Loss of physical health and potential to impact on future plans?? (p6)

Loss of drive (p8)

Traumatic experience of serious physical assault (p10-11)

**JESS:** Trauma and lack of containment provided around her? (p3)

**GEOFF:**

Memories before the age of 25 are “thin and patchy”

Two siblings – close with one, “the other chap” not so much. Doesn’t remember younger brother being an usher at his wedding at the age of 23 – “it’s like he’s appeared out of nowhere”

“I didn’t receive my diagnoses until my early 40s” – but clearly not mentally well through adulthood.

Marriage failed after 12 years, but no difficulties in terms of arguments, but wife cited emotional cruelty as ground for divorce. Geoff states he is not a cruel or angry person, but did not communicate on an emotional level.

### 3) Status & Identity

#### i) Lowly Status (Not being heard):

**BETH:**

Fragility of self-esteem (P5)

Powerlessness against external forces/influences (P5)

Power of external influences on mental well-being (P10)

**ELSA:**

Submits to perceived authority (p2)

‘Unfortunately, I survived’ (p3)

Not worthy enough to be referred to by name (p3)

Sealed fate (in terms of relationship with mother) (p3)

“Wait your turn” (p3)

Lowest of the low (p4)

Passive and powerless (p4)

No win situation (punished by both mother and nuns) (p5)

Told to be grateful (p6)

Missing out on patronage and privilege (p7)

‘Invites’ bullying (p7)

Mother dictates enjoyment of life (or not) – all powerful (p8)  
Authority figures – all powerful and have no option but to comply (p8)  
A ‘mouse’ – insignificant, but an irritant when noticed (p9)  
Demands to respect herself, but not respected by those around her (p10)  
Others needs/wishes before her own (p10)  
Knowing your place (p10 & 11)  
Being a mouse – disappearing from view (p11)  
Lack of concern about self (p11)  
Following the man’s lead (p13)  
Drawn back to home (& abusive treatment?) (p13)  
Returns to be a dogsbody once more (p15)  
Not coping with the harshness of daily life (p18)  
Self not worthy of defending, but can rescue others (p19)  
The dogsbody (p20)  
Volunteer role (helping in school) not seen as work (p20)  
Subservience to dominant male (husband) (p20)  
Own needs secondary to others’ – don’t cause a fuss (p22)  
Not being heard by others when communicating distress – invisible (p25)  
Reinforcement of martyr (Cinderella) character (p25)  
Self-blaming for inviting others to bully her (p31)  
Not being heard again (p31)  
Self-loathing – living out her worthlessness (p32)  
Self as a toxic being – anything she touches will be instilled with pain (p33)  
Not being listened to once more (p33)  
Isolation & not being heard (p35)  
Reinforcement of not being heard (p37)  
Rarity of being heard and acknowledged as a person (p39)

**ORLA:**

Subservience to dominant male (husband) (P1)  
Unhealthy dependence on husband – no separate identity (P1)  
Deference to higher authority (p9)

**SIMON:**

Powerless in decision making of family - lowly status/not heard? (p4)  
Again, the sense of powerlessness over what happens to him (p4)

**MAGGIE:**

Lack of personal agency in own life (p3)  
Defined role in life allocated by others (p4)  
Masculine strength/agency she could never possess (p15)

**(ii) Needing to Please / Accepting the Burden of Responsibility**

**BETH:**

Burden of responsibility (P4)

Enjoying praise and patronage (P7)

Proving sense of worth through praise bestowed by others (P8)

Drawn back to home and birth family, but life going backwards when drawn to home (P13 & 14)

**MIKE:**

Burden of being the 'perfect child' (no choice in this) (P2)

Holding back on overt criticism resentment towards parents – need to be the perfect child still? (P3)

Carrying the family hope (P3)

Leaves activity he enjoyed (conservation work) to return to engineering – lack of choice? (P5)

Need to please other people as a child, adult (& within the interview?) (P8)

Holding the hopes of others? (P9)

Pressure of structure and expectation (P10)

**ELSA:**

Blight of 'people pleasing' (p5)

Accepting the burden of blame and punishment (p5)

Trying to please (her mother) (p6)

Burden of taking blame and responsibility (p8)

Defending her abuser (mother) (p8)

Meeting expectations (to get married) (p10)

Advocating for abuser – trying to please? (p11)

Cultural expectation to be engaged/married? (p13)

Exploited for desire to please (p14)

Taking burden of blame/responsibility for daughter's self-harm (p15)

Accepting lowly status, but still trying to win approval (of mother) (p16)

Needing to please/make everything all right (p16)

Accepting of blame for other's behaviour (p27)

Enduring hardship to please others (p27)

Putting children before own needs (p28)

Will sacrifice relationship with son to save him (martyr?) (p36)

Not taking any of the credit (p36)

**ORLA:**

Burden of hope and expectation (academic) (P1)

**MAGGIE:**

Burden of expectation of community (p4)

Must submit to patriarchal authority (p13)

Anger at others turned in on self (p14)

**JESS:**

Needing to please? (p2)

Again, this sense of needing to get it right (p4)

**GEOFF:**

Followed father's footsteps and worked in a shipyard – not him, but “what was expected of me” – Was part of the new comprehensive system and streamed to undertake CSEs rather than O levels – feels this deprived him of the opportunity to go to university (which he eventually did much later) (p2)

**(iii) Fitting In:**

**BETH:**

Importance of enduring relationships (P6)

Strength of union with husband (to be) (P8)

**MIKE:**

Feeling isolated & on the outside of things – didn't quite fit (P2)

Differing values from family – an outsider? (P4)

Working in a field that “never felt quite right” (P4)

Not fitting in & being unsettled (P10)

**ELSA:**

Envy of those with a 'normal' life (bin men) (p4)

Didn't fit in the family (p7)

Moved around a lot (p14)

Didn't fit in (p14)

'Always new' when they moved to a new location (p14)

'I felt like the odd one out' (p18)

Needing to feel like she belonged (p20)

**ORLA:**

Outsider in own family (P1)

“a square peg in a round hole” at work – not fitting in (P1)

**RUTH:**

Struggling to fit in (p4)

Greater sense of belonging (p4)

Sense of purpose/direction (p6)

Wanting to fit in? (p10)

**SIMON:**

Where did he fit in? (p2)

**4) Survival**

**(i) The Practicalities of Surviving:**

**BETH:**

Survivor in the story (P1)

Dissociation from early trauma (P3)  
Dismissive of undergraduate university education (P8)  
Survival (P11)  
Hope of a fresh start (P12)  
Life on a knife edge (P12)  
The need for a 'fresh start' (P3)  
Emotional detachment from birth family (P4)  
Reiterating the experience of a fresh start when moving to college (P4)  
Unrealistic expectations (rose-tinted) held by wife of birth family (P6)  
Disorientation/lack of clarity in life (P6)  
Unstable home and work life (P6)  
Adapting to loss of former life and new expectations of life (P7)  
Cycle of loss and restoration when wife was mentally distressed (P7)  
Looking for quick and easy solutions to own mental distress – pragmatic (P8)  
Importance of travelling – escapism (P8)  
Struggling through to a point (P9)  
Pragmatics of getting through life (finance, etc.) (P11)

**ELSA:**

Small positive amidst the misery (p5)  
Clear sense of right and wrong (p8)  
Survival behaviours (please mother & stop father looking at her) (p19)  
Soldiering on (p22)  
Shift to being the provider/breadwinner (p28)  
Working hard to survive (applied for 300 jobs) (p28)  
Importance on personal integrity (source of pride?) (p29)  
Importance of loyalty (p30)  
Existing/surviving (p32)  
Surviving – need to eat to live (p37)

**ORLA:**

Burying strong emotions (resentment/anger) (P2)  
Avoiding the issue (through alcohol use) (P2)

**RUTH:**

Survival (p8)  
Survival or avoidance of appearing weak? (p9)  
Survival (p11)

**JESS:**

Need to be in control (p5)

**SIMON:**

Sense of drive/ambition for future (p6)

Moving on from adversity (p8)

Compromise (p9)

Survival again (p10)

**MAGGIE:**

Surviving oppressive life through creative arts (p4)

**GEOFF:**

Ran pubs/restaurants with his wife for a few years – “breaking the mould” At time of relationship breakdown he became a sales rep for a local frozen meat company (p2)

Became a workaholic in frozen meat company and was elevated to general manager position – oversaw staff of 50 and the company turnover was £8-9 million (p2)

**(ii) Avoidance of Shame/Appearing Weak:**

**BETH:**

Incongruence around presentation of family – symbolic of dysfunction? (P5)

**MIKE:**

Insight into ‘Britishness’ of self and repressed childhood (P2)

**ELSA:**

Private vs public: weakness vs perceived strength and authority (p2)

Keeping shameful things secret (p10)

Never reveal pain (p11)

Keeping shameful things secret (p11)

Avoiding the shame of making a relationship mistake (marrying second husband quickly) (p13)

Importance of avoiding shame (p22)

Could not face shame of marriage failure with children (p25)

Shame of appearing weak in front of others (p32)

Children in care (not mentioned in the initial interview) (p34)

**MAGGIE:**

Mitigating dysfunctional family members (p14)

Importance of maintaining a façade (p16)

**RUTH:**

Avoidance of shame/appearing weak – don’t show emotion (p2)

Avoidance of shame/appearing weak (p3)

Avoidance of shame/weakness? (p11)

**JESS:**

Hiding true self from the world? (p4)

**(iii) Resistance and Activism:**

**BETH:**

Activism and pride in working class roots (P7)

Resisting/changing the ‘family script’ (P10)

ELSA:

Taking small opportunities to resist/rebel (p4)  
Irreverent humour as an act of rebellion/resistance (p6)  
Momentary rebellion (p11)  
Free to pursue studying when her husband left (p12)  
Blaming the other (God) (p15)  
Small acts of rebellion as an adult (P16)  
Despite life experienced – outraged at the cruelty people are capable of (p30)  
Small acts of resistance (p31)  
Freedom to have a say and be heard (p13)  
Proving worth (p16)  
Resistance/fighting back (p16)

**(iv) Rescuing or Being Rescued:**

BETH:

Giving hope to the disadvantaged/disenfranchised (P6)  
Being rescued (P2)  
Importance of husband's role (P3)  
Husband as the rescuer/hero (P6)  
Strength of bond with husband, but as an equal or rescuer/rescue? (P8)  
Husband's sacrificial actions making her feel valued and supported (P9)  
Husband's continuing sacrifice for her (P9)  
Husband as rescuer (once more) (P10)  
Husband usually got her through (P11)  
Husband rescuing her and son (P11)

MIKE:

Rescuing wife from possible death (through suicide) (P5)  
Caring role for the long haul – sacrificing 'normal life' (P5)  
Caring not a duty, but a promise as part of marriage relationship (P7)

ELSA:

Children are 'grounded' (p36)  
Finally heard and given hope (p38)

MAGGIE:

Rescuing others to survive herself (p13)

RUTH:

Being rescued/the beneficiary (p11)

## Appendix I: Summary of Dissemination Strategy

