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Examining a social network approach to self-management support in people with Chronic Obstructive Pulmonary Disease.

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by

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Thesis for the degree of Doctor of Philosophy

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Abstract

Faculty of Environmental and Life Sciences
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Examining a social network approach to self-management support in people with Chronic Obstructive Pulmonary Disease.

By
Ms. Lindsay Welch

Self-management support [SMS] is fundamental in the management of Chronic Obstructive Pulmonary Disease [COPD]. However, personal engagement and effectiveness of SMS is currently suboptimal. SMS for COPD based on action planning alone, is limited, and confounded by multiple complex, frightening symptoms that are challenging to negotiate alone. Suggesting the need for a more elaborate approach to SMS in COPD. In other long-term conditions, SMS has been influenced positively by promoting access to connections and resources through social networks. Therefore, a social network approach, promoting peer relationships has the potential to offer enhanced support, improve SMS personal capability and increase social capital in people with COPD.

Explored here is the implementation and evaluation of a social network approach to SMS in a community-based COPD population. Three interlinked studies with mixed methods were employed. A qualitative meta-synthesis; to capture the personal enactment of SMS in COPD. An empirical pilot study evaluated the implementation of Generating Engagement in Network Involvement (GENIE), social network tool. A further nested feasibility study, guided theory concepts to explore the acceptability of GENIE in community NHS services.

The qualitative meta-synthesis of COPD SMS practices suggests that this is a complicated social phenomenon; comprised of personally valued practices, activities and experiences. People with COPD negotiate complex health situations across multiple social platforms. The GENIE intervention was acceptable to clinicians and people with COPD. Findings suggest that the intervention may have a protective effect against decline in diet quality and activity in people with COPD. People using the GENIE tool-maintained health status and clinical symptoms, increased quality of life, decreased anxiety and reduced costs in NHS service utilisation.

Enactment of SMS in COPD is influenced by personal experience and a fear of dependence. SMS in COPD requires readdressing to embrace social network approaches as part of the COPD care pathway.

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Research Thesis: Declaration of Authorship

Print name:	Lindsay Welch

Title of thesis:	**Examining a social network approach to Self-Management Support in people with Chronic Obstructive Pulmonary Disease.**

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 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. Parts of this work have been published as:

Bloom, I.* Welch, L.* Vassilev, I. Rogers, A. Jameson, K. Cooper, C. Robinson, S. Baird, J. **Findings from an exploration of a social network intervention to promote diet quality in older adults with COPD: a feasibility study.** Pilot and Feasibility studies (BMC). Accepted Jan 2020. **Ilse Bloom and Lindsay Welch (joint first authorship).* Open Access Feb 2020.

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Abbreviations

Agenda for Change (AFC)

British Lung Foundation (BLF)

Chronic Obstructive Pulmonary Disease [COPD]

Client Service Receipt Inventory (CSRI)

COPD Assessment Tool (CAT)

Ethics Research Governance Online (ERGO)

EuroQoL instrument (EQ5D)

Generalised Anxiety Disorder (GAD-7)

Generating Engagement in Network Support (GENIE)

Global Initiative for Chronic Obstructive Lung Disease (GOLD)

Health Research Authority (HRA)

National Institute of Clinical Excellence (NICE)

Patient Health Questionnaire (PHQ-9)

Personal Social Services Research Unit (PSSRU)

Pulmonary Rehabilitation (PR)

Self-Management Support [SMS]

Chapter 1 Introduction to the thesis

1.1 Structure and justification of the thesis

The thesis will explore a potential new avenue for self-management support in COPD. The decision to investigate self-management support in COPD was conceived in clinical practice during a 10-year period of providing care, treatment and support to people with COPD and long-term respiratory conditions. My clinical work has spanned research delivery (research nursing), urgent COPD care, community COPD nursing care and pulmonary rehabilitation. Through this clinical interface I have experienced the many facets of the health service and I have witnessed the challenges of navigating health services for people and families with respiratory disease. The original proposal for this thesis was to investigate help-seeking behaviour in COPD. Life limiting long term illnesses can have periods of worsening symptoms that may or may not require the interventions of health care professionals. However, I noted a clinical disparity in those people who sought support for worsening symptoms. People with COPD did not necessarily seek-help due to the severity of the symptoms. Often people with milder symptom sought help more frequently, and conversely those with more severe symptoms did not seek help. This, I felt, warranted exploration. At the time I was part of a longitudinal study collating diary symptom data on a cohort of people with COPD. This prompted the development of thinking in this sphere, and a protocol was drafted; EXPERTS 1—experiences of long-term life-limiting conditions among patients and carers: protocol for a qualitative meta-synthesis and conceptual modelling study (May et al, 2015). Unfortunately, due to issues with the ownership of the diary data; the help-seeking investigation could not be continued.

The concept of how and when people with COPD access care still resonated in my daily clinical practice. Many people with COPD accessed care too frequently and other people did not access health professional support and instead struggled with disabling respiratory symptoms at home. In contemporary clinical practice the emphasis of care is often placed upon the ability of people with COPD to react and self-treat their own symptoms in order to avoid medical attention or admission to hospital. Reactive self-care was prioritised, in preference to encouraging people with COPD to develop strategies to adapt to complex disease symptoms and to learn to live with continually fluctuating disease. For health care professionals the main purpose of patient self-management is the understanding and taking action upon deteriorating clinical symptoms, in terms of compliance with clinical treatment (Sadler et al, 2014).

However, from the perspective of a person living with COPD and learning to adapt to, cope and manage their long-term condition, especially one as complex as COPD, this requires daily negotiation and coordination of activity and medicines regimes. Furthermore, additional health behaviours are required to continue to live well with a long-term condition; these include smoking cessation, change in diet and adhering to regular exercise. These behaviours are currently supported by community programmes such as pulmonary rehabilitation (Bolton et al, 2013) (Johnston and Grimmer-Somers, 2010). The expectation by health professionals is that people with COPD will change and sustain these behaviours, to maintain their own health, while negotiating and adapting to new and frightening symptoms. However, such expectations are perhaps unrealistic as the evidence suggests that continuation of the health behaviours decreases over time (Donesky et al., 2011).

This evidence, and unrealistic expectations of personal disease management in people with COPD led me to explore the theme of self-management support. As a health care professional, in clinical practice, the dearth of funded, cost effective, realistic and well evidenced solutions for proactive self-management support (Pinnock et al, 2017) in COPD is an issue.

Pulmonary rehabilitation is deemed as a SMS and exercise intervention, which does provide a link to community based SMS programmes and has been proven successful in COPD management (Bolton et al, 2013). It contains a balance of tailored exercise instruction, and respiratory self-care education, delivered over twelve face to face sessions. Those enrolled on the programme have reported a reduction in hospital admissions and state confidence in symptom management (Bolton et al, 2013, Bourbeau, 2009).

However, after leaving the programme, many people cannot maintain the positive behaviour changes, and discontinue regular exercise (Lewis and Cramp, 2010).Furthermore, I witnessed the apprehension of people completing the programme, and leaving the people they had met who had supported them on their disease journey. It was apparent that people with COPD struggled to employ new health strategies into their daily lives without the constant support of others. These experiences in clinical practice have provided the catalyst to understand and develop novel solutions for SMS in order to improve clinical services and the personal experiences for people living with COPD. Moreover, to critically investigate the contemporary evidence to understand what could be added to treatment regimens and current care pathways to improve COPD care. Therefore, this investigation is designed to explore novel and cost-effective solutions for people with COPD to continue SMS after pulmonary rehabilitation, thus providing a step from statutory services into self-led care.

This thesis aims to explore the overarching question; ‘’ Can people with COPD Self-manage’’? Questioning whether self-management and current self-management concepts are feasible and effective in COPD.

This thesis is presented in a 3-paper format. The 3-paper format was selected to more efficiently disseminate research findings at the pace of clinical development and to directly inform and change clinical practice. The thesis aims to identify, describe and evaluate the potential of a social network approach to SMS in COPD. The thesis will describe the background of SMS in COPD and the current issues facing effective disease management in COPD care, these will be addressed in chapters 1 and 2. In order to define existing SMS approaches and intervention in SMS in COPD chapter 3 describes the findings from a scoping review of the literature. The review identifies some of the more successful components of SMS interventions; namely social network support. Chapter 4 explores contemporary social network theories, to provide a basis of how social network theory is applicable in chronic disease management, and how a specific intervention; Generating Engagement in Network Involvement (GENIE) could have the potential to promote socially directed self-management support in people with COPD. Chapter 5 employs a targeted literature review and subsequent qualitative meta-synthesis to explain how people with COPD engage with and interpret SMS interventions in COPD. This chapter is an independent piece that reviewed a targeted selection of literature to describe the theories of SMS enactment in people with COPD. In doing so this enabled the development of a conceptual model to illustrate the complexities of COPD, and how these create a dichotomy in personal decision making. Chapter 6 is the description of the development of the methods required to test, and evaluate the GENIE tool, a social network intervention in people with COPD. Chapter 7 then describes the main findings from the pilot study, in terms of social network diversification, patient benefit and cost effectiveness of the intervention, are described in chapter 7. Further to the pilot study, the feasibility outcomes of a nutrition and health behavioural change, are discussed in a sub-study; chapter 8. The maintenance of a prudent diet, exercise and smoking cessation are all associated with improved outcomes in COPD (Shaheen et al, 2010). Therefore, the sub-study investigated to impact of a social intervention on diet and exercise outcomes and describes the findings of a process evaluation; to understand the practicability and any adaptions that may be required to develop a social invention to use at full scale. Chapter 9 is the discussion chapter, through this chapter the findings of chapters 5, 7, and 8 are re-analysed to draw a conclusion to the argument. Furthermore, this discussion chapter deliberates the limitations and ethical issues in the design and delivery of the empirical study. The thesis concludes with recommendations for clinical practice and potential areas for future investigation.

1.2 Personal and professional development

The journey through a research training pathway is complex and diverse. It both complements and necessitates distance from the clinical practice. Balancing the academic activities and priorities with the dissemination of clinical best practice is a challenge. As often new evidence and clinical practices are introduced that maybe in conflict. In order to deliver the empirical section of this thesis, and to ensure the intervention was relevant to the field of practice, community networks were developed with local providers and existing social groups. Much of this networking was external within voluntary organisations. Further networking was required internally within the NHS organisation (Solent NHS Trust), to facilitate the implementation of the empirical study. In the conceptual phase of the study in order to engage the local community NHS Trust, I set up a self-management group to share best practice and current research evidence within the organisation. In this way I was also able to present the progress and any preliminary findings from the study directly to clinical teams and interested community practitioners. These personal and professional connections supported the development of clinical implementation strategies and enabled resources to be added to the GENIE tool, and the empirical study design.

Research training was an integral part of my personal development; in October 2016 and April 2017 I was able to attend a CLARHC funded introduction to statistics and regression analysis. I also completed the NIHR primary care and community GCP training; to enable a broader understanding of ethical and study administration issues in a community research environment.

I have been fortunate to be able to present my work both nationally and within Solent NHS Trust and the University of Southampton. Early presentation of results has enabled critical feedback, which is instrumental in enhancing the quality and depth of the published findings. In the early stages of the conceptualisation of the study I was able to present my research ideas at the RCN international conference, this was an international audience and I obtained valuable critical feedback. I was then able to appraise and adapt my work for presentation within the School of Medicine and Health Sciences conference at the University of Southampton.

Throughout this research I have built upon existing personal and professional networks and developed new collaborators. These activities contributed to the conceptualisation and quality of the studies.

It is my intention to submit an abstract to conference for the qualitative meta-synthesis and seek publication post thesis submission.

Chapter 2 Background

2.1 Chronic Obstructive Pulmonary Disease– Living with Long term illness

Chronic Obstructive Pulmonary Disease is a life limiting progressive illness punctuated by acute episodes or flare ups of respiratory symptoms, termed exacerbations (Wedzicha and Seemungal, 2007). COPD is categorised according to severity of airflow limitation, breathlessness score, and symptom severity; such as cough, mucus colour and viscosity (GOLD., 2018). The limitations in airflow, fluctuations in respiratory symptoms and associated pulmonary infections cause functional deterioration in terms of activity, muscle wastage, and associated cardio vascular issues (Mannino, 2002) (Bhatt and Dransfield, 2013). Furthermore, decrease of appetite along with reduction of activity and muscle loss can compound these symptoms (Ferreira et al., 2000).

Worsening of cough, breathlessness and mucus hypersecretion can be classified as an exacerbation (Anthonisen et al, 1987) (Wedzicha and Donaldson, 2003). Exacerbation frequency can be increased with severity and underlying infection or multi-morbid disease. During exacerbations the increase in respiratory symptoms can be frightening, debilitating and life threatening, warranting health care support and possible hospitalisation (Donaldson et al, 2013). However, some exacerbations can be safely self-treated, and medicines self-administered, at home in the community. This enables potential areas to target self-management support through education, or action plans, to encourage reactive self-management strategies (Pinnock et al, 2016). However, COPD is not only life threatening, it is also a life limiting, long term condition with an illness trajectory which is challenging to predict (Pinnock et al., 2011). Therefore, there is a need to understand how to promote SMS across the illness trajectory, rather than just being responsive to deteriorating symptoms.

The high symptom burden including the mobility limitations and fear of acute episodes of breathlessness often leads to decreased social interaction and isolation (Abrams et al, 2011). Once diagnosed with COPD breathlessness is a frightening symptom to manage without assistance, but management support interventions in tertiary care with pulmonary rehabilitation programmes and therapies. Many therapies are medication-based (inhaled and oral). The quantity of medicines increases and the regime of taking medicines become more complex as the COPD worsens. This adds extra practical work to disease management at a time when sufferers are experiencing an increase in symptoms and are less active due to increased breathlessness and associated limitations in their mobility. The increasing treatment work in the management of long term conditions creates a treatment burden (May et al, 2014, Gallacher et al, 2013). Treatment burden can be described as the self-care practices that people with a long term conditions must perform to mobilise health resources, adhere to medicinal regimes and to meet the demands of health care providers and systems (Gallacher et al., 2013). People living with COPD have multiple treatment options and regimes, some of these include; increasing amounts of inhaled therapy, up to three to four separate inhalers a day in some cases, regular oral medication, emergency oral medication, possible oxygen therapy and the negotiation of regular visits to both primary and secondary care providers. If these visits are overlaid with breathlessness symptoms and a complex medical regime the whole nature of the health care interaction becomes challenging, or a burden. The increasing burden of treatment could be a potential barrier to successful SMS in COPD and needs to be considered in the development of any novel SMS strategies.

Throughout the COPD disease trajectory, the nature of disabling physical symptoms for people with COPD increase. These are compounded by complex comorbidity, psychological distress, malnutrition and social isolation. These additional pathologies have been recently referred to as the COPD comorbidome (Almagro et al., 2012). These complex overlying conditions make symptom isolation and action planning challenging for both health professionals and patients.

2.2 COPD – Prevalence and societal impact

The prevalence of COPD continues to rise both locally in Southampton and nationally in the UK. Overall, the prevalence of COPD in the UK population is estimated at 10% of adults aged over 40. A higher prevalence was reported in subgroups of males, smokers and urban residents (Halbert et al., 2006). In 2006 the expectation was that the prevalence of COPD would continue to rise due to concurrent tobacco use and an aging population (Halbert et al., 2006). While the prevalence went up by less than what was expected, COPD in the UK still increased by 9% between 2008 and 2012. It is estimated that 1.2 million people are living in the UK with diagnosed COPD (Foundation, 2012). COPD is the second most common lung disease in the UK (Foundation, 2012), and is responsible for 26.1 % of UK respiratory related deaths.

Recent literature has also recognised the contribution of COPD to the global disease burden. This is noted in terms of mortality and years of life lost (Lozano et al., 2012) and the contribution of COPD to the global burden of non-communicable disease. In 2015, 3.2 million people globally died from COPD, an increase of 11.6% from 1990 (Lozano et al., 2012). Furthermore, COPD contributed to 51,803 (49,898 to 53,611) years of life lost globally and 12,047 (10,207 to 13,725) years lived with a disability. The data was skewed to the low-middle social demographic index (SDI quintile), who proportionally reported 17,444 (16,260 to 18,652) years of life lost from COPD (Lozano et al., 2012). Years of life lost indicate the socio-economic impact the disease has on individuals, families and society. Therefore, COPD is an increasing local and global problem, with rising disease prevalence. This coupled with the individual challenges of the disease, including the personal negotiation of daily complex symptoms, makes a case for the investigation of a workable solution to promote proactive self-management support in this population.

As COPD prevalence and the related social burden grow, this in turn has a multifactorial impact on society, families, and health systems. This is further exacerbated by deprivation (McAllister et al, 2013), poor housing, continued tobacco use and low literacy levels often prevalent in COPD (Donaldson and Wedzicha, 2013) (Andreas et al., 2009). These social factors further add to the complexity of health care access, the understanding of increasingly complex health care services and affordability of travel. These social and economic concerns are further clinically complicated by the overlaying of ageing, and early onset frailty. As an example, previous research has suggested that frailty is exacerbated by malnutrition and muscle loss in the later stages of COPD (Wust and Degens, 2007). Together this leads to further immobility, loss of finance and work, depression and social isolation. Moreover, lower literacy levels, depression (Wells, 2016) and poor confidence mean that people have a low self-efficacy. Low self-efficacy refers to the concept of having low confidence in one’s own abilities to control, or change ones behaviour or environment (Bandura, 1997). People with COPD, who have these attributes may then struggle to engage with existing SMS strategies, due to lack of confidence in their ability to be effective.

Health systems have difficulty with managing acute care for COPD (exacerbations of COPD), with over 140,000 hospital admissions and over a million bed days each year across the UK (Donaldson and Wedzicha, 2013). Furthermore, presentation to primary care and the long-term disease management in primary care is a growing issue. In order to try and address the extent of the healthcare use by COPD patients, NHS policy has generated a drive by healthcare professionals and researchers to develop initiatives to encourage patients to support themselves with their own disease, or long-term condition.

However, the successful components of a self-management solution in COPD have not yet been fully identified and any intervention needs to be clinically safe, and promote daily self-care activities alongside crisis negotiation, when symptoms decline.

The prevalence and challenges of COPD SMS supports the direction of this thesis and the decision to develop research questions formed around reframing the conventional methods of self-management support.

SMS in COPD is clearly a suitable line of enquiry to investigate, due to the challenges in delivery self-management in the disease. Yet there is a lack of consistent and clinically significant positive effects of self-management education on quality of life and health related quality of life (Taylor et al., 2014). The challenges of implementing successful self-management programmes in COPD have been discussed in the literature. Many of these challenges relate to the clinical population and disease burden in COPD patients, rather than the policies, or intentions behind the self-management intervention.

These are some of the key barriers and challenges specific to COPD that undermine traditional approaches to SMS interventions and support. The evidence base in the literature regularly calls for cost effective and successful solutions to the management of SMS in the COPD population. Therefore, in order to meet the issues and challenges of SMS in people with COPD a novel approach is required.

2.3 Self-management Paradigms in COPD management

Self-management is a term used to include all the actions taken by people to recognise, treat and manage their own health. They may do this independently or in partnership with the healthcare system (Trappenburg et al., 2011). Supportive self-management (Pinnock et al, 2016) has been an area of focus within the NHS, in the last five years and remains so in the next five. SMS is viewed as a key solution within stretched health services to support in the management of long-term conditions. The NHS five year forward view and NHS long term plan by NHS England (Fund, 2014) are keen to encourage the concept of people protecting their own health, and choosing treatments for their long-term conditions. The rhetoric of this plan remains closely aligned with enabling patient, family and carer choice through a shift towards personalised care. Furthermore, the NHS is currently committed to increasing its activity within social prescribing, through funding and supporting alternative social solutions to disease management. This health care climate actively promotes the ethos of self-management in health care; therefore, it is strategically the right time to investigate, evaluate and make recommendations for policy makers and clinical leaders in terms of how SMS might be successfully implemented in COPD.

Many self-management interventions have been evaluated using randomised controlled trials (RCTs) and are currently being promoted as an effective strategy for improving quality of life and reducing unnecessary health utilisation in individuals suffering from a range of long-term health conditions. These are often condition focused, and tailored around self-monitoring and coaching for behavioural change, these take the form of decision aids, shared decision-making, care planning and action plans (Kaptein et al., 2014). Although these tools exist to support clinical consultations, raising the issue of SMS in a primary care consultation can be difficult for both health professionals and people with COPD (Blakeman et al, 2009). Clinicians and people with long-term conditions felt uncomfortable talking about the relative success of their personal SMS strategies and therefore there was a reluctant to discuss SMS in clinical consultations (Blakeman et al, 2009). Therefore, COPD, as an long term condition is still a clinical challenge, with multifactorial issues impacting patients and clinicians abilities to find workable valued solutions for SMS (Bentsen et al., 2012).

Self-management interventions have proved successful in reducing burden of disease and improving quality of life (Andenæs et al., 2014), furthermore early identification and action of deteriorating respiratory symptoms can improve recovery times post exacerbation of COPD (Wilkinson et al., 2004). Therefore successful self-management interventions, or support can be beneficial and potentially reduce the risk of hospitalisation with early treatment and positive health behaviours (Gudmundsson et al, 2005). SMS and education can reduce unnecessary health care contacts when delivered and targeted appropriately (Taylor et al., 2014). To date the effectiveness of SMS for COPD based for example on action planning alone has been limited (for example changing utilization patterns) and suggests the need for a more elaborate approach to SMS in clinical settings to manage living with COPD along the illness trajectory (Walters et al., 2010). Being able to effectively self-manage enables a more stable control of symptoms, and therefore more control in daily life.

Despite the positive recognition that self-management in COPD can have positive results in terms of reduction in hospitalisation, earlier recovery and reduction in health care contacts; clinical trials in COPD self-management interventions have yielded mixed results (Bourbeau, 2003) with regards to success in terms of implementation and clinical evaluation. The clinical perspective of SMS strategies is beginning to change; based on studies that dramatically moved the clinical paradigm of SMS thinking. Notably a randomised controlled trial to evaluate a comprehensive care management programme, focused around improving people’s ability to self-monitor and self-manage for people with COPD, was stopped prematurely, due to an unanticipated excess in mortality in the intervention group (Fan et al, 2012) (Nici et al., 2014).

Currently action planning and admission avoidance interventions are designed to support people with COPD when they have a ‘flare up’, or exacerbation of their existing respiratory symptoms, rely broadly on psychological principles of self-efficacy and behaviour change. This requires personal responsibility and confidence in disease management to take the most appropriate clinical action. Furthermore, people with COPD need to be engaged in the recognition of their overall condition and symptom(s), further possessing the correct knowledge to understand how and why any particular action would improve symptoms.

These clinical decisions can be challenging to make without support and understanding of the disease trajectory. When one is breathless and unwell and further compounded by physical limitations, emotional distress and social isolation (Schroedl et al., 2014). This often prompts people with COPD to call for support and assistance, as their condition is frightening and disabling.

Action planning alone does not address the concurrent, debilitating long-term COPD symptoms that impact on all daily activities (Almagro et al., 2012). Moreover, the very nature of a long-term condition can have on-going multifactorial issues that make self-management challenging.

Therefore, considering the mixed evidence of action planning alone, and limited success and indeed safety in the COPD population, then clearly a move to an alternative focus on SMS interventions is required. Considering shifting the paradigm towards social approaches and support networks is an emerging school of thought (Nici et al., 2014). This incorporates seeking emotional and decision making support from family friends and others as part of one's illness management (Jonsdottir et al, 2013) . This is termed collective efficacy. Collective efficacy is a shared perception and capacity to successfully perform through shared effort, beliefs and influences (Vassilev et al, 2019). It could be inclusion of a spouse or involves more members of a social group in illness management. These principles broaden the scope of illness management away from the single responsibility of the person with the illness. However, such collective engagement can only be effective if one is able to navigate and negotiate their social world, and services accessing the right support at the right time.

Therefore, potential barriers or challenges to self-management within long term conditions, namely COPD can be placed in 5 categories:

- **Physical:** physical disability, such as reduced strength or fatigue.
- **Psychological:** depression, emotional distress.
- **Cognitive:** patient's knowledge about their condition. Poor health literacy-ability to apply new knowledge. Ability to learn and utilise new skills.
- **Economic:** Socioeconomic position, or deprivation – resource poor - often needed to support optimum self-management.
- **Social and Cultural:** social networks and cultural practices can either support or hinder self-management behaviours (Vassilev et al., 2013)

It has been suggested in previous studies that these barriers above can be overcome by educational programmes and improved SMS delivery methods. Often however socio-cultural and socio-economic issues still prevail. Therefore, the NHS economic and political climate and direct COPD patient need, suggests an alternative SMS theoretical perspective could be explored, examined and applied self-management support to understand how to focus new thinking on future SMS models in long-term conditions, and COPD.

2.4 Socially supportive self-management

As explored above, self-management faces many challenges in COPD including timely health care consultations when symptoms are progressing. These decision-making processes, as in other conditions may be influenced positively by promoting access to connections and resources through social networks, to offer both day to day support and support in times of a crisis. Evidence suggests that social interaction acts positively in terms of influencing wellbeing and living successfully with a LTC (Reeves et al., 2014). Isolation has a negative impact on health in general and those with a long-term condition. It leads to low mood and an increasing inability to engage with self-care and self-management, and has physiological effects on health (Holt-Lunstad and Smith, 2016) . Recent research which explores the nature of consultations with people with COPD suggests that opportunities for engagement with SMS (Pinnock et al, 2016) are often missed (Chatwin et al., 2014). Moreover, social network connections might be a promising avenue for bringing into focus SMS options that have not previously been explored in professional patient encounters. The latter have been shown to have utility for the mobilisation of resources for self-management and for social involvement likely, to have an impact on self-management and health related outcomes.

However, to date the concept of socially supportive self-management in COPD has a limited evidence base in terms of how this might be implemented successfully in practice settings. Furthermore, in the clinical setting, social factors such as social networks and engagement with community-based institutions, are not usually included in the design of interventions to promote improved health strategies, such as healthy eating among older people, or reduction in tobacco use (Zhou et al, 2018). There is also a lack of research on the impact of community engagement activities on health-related behaviours (Jones et al, 2013). Thus, little is known about how interventions aimed at supporting social networks and engagement with community activities might impact on the promotion of healthy behaviours in later life.

2.5 Aims and Objectives

In order to address the clinical problem, this thesis will aim to explore the self-management context, effectiveness, acceptability and implementation of a social network approach to self-management support in a primary care-based COPD population. An existing social network intervention will be adapted for people with COPD and evaluated in a primary care context. The social network intervention selected for investigation is referred to as the GENIE (Generating Engagement in Network Involvement) tool. The GENIE tool maps exiting social networks, allows for user-centred preference, conducts a needs assessment and facilitates engagement with local support resources (Kennedy et al., 2016). The GENIE tool is described in full in the methods section, chapter 6, the underpinning theory of the GENIE intervention will be described in Chapter 4. In order to operationalise this aim, key questions and avenues for exploration will be identified.

Overall, the objectives are:

- To explore; through a scoping review, current self-management interventions and understand their relative successes in people with COPD
- To understand the clinical and psycho-social complexities of self-managing COPD
- To provide rationale and evidence for empirical enquiry centred on a social networked approach to SMS

Research question (s):

1. What are the challenges with current SMS in COPD and how do they differ from other long-term conditions?

This question is addressed in the background and literature review. The literature is presented as a scoping review, the aim here is to provide an overview of the evidence and to understand the current political and cultural context of SMS in COPD. The broad view of the literature will enable an understanding of contemporary self-management interventions and a critical appraisal of their relative success in terms of SMS.

Namely the aim here is to understand the context of SMS interventions and draw out the specific complexities of SMS in COPD. This evidence should underpin the social theory approach to SMS and inform the adaptation, development and delivery of a SMS intervention with people who have COPD.

2. Would a social network approach be a feasible and a workable option to deliver SMS support in COPD within NHS services?
3. How does a social network approach to SMS benefit people with COPD in terms of behaviour change, health status, quality of life?

These two research questions are addressed in the main empirical pilot study and in the feasibility sub- study. The social network adaptation, implementation and evaluation plan are addressed through the main methods section of the thesis. The feasibility and workability of a SMS intervention in COPD is addressed by a process evaluation. The process evaluation forms part of a nutritional and behavioural change sub-study, which seeks to understand the mechanisms of behaviour change and promotion of positive health behaviours in people with COPD. The data for this study was collected through an implementation diary and videos made by people with COPD who used the intervention. In order to evaluate the clinical benefits and the broader benefits to health services of an SMS social intervention then clinical quantitative outcomes measures were used alongside health utilisation outcomes and written up in the paper entitled ‘’Findings from a randomised trial of a social network self-management intervention in COPD’’. The findings from both empirical studies, together, further inform research question 5, and are brought together in the discussion with the qualitative meta-synthesis.

4. How do people with COPD view current SMS support for their condition? What elements do they value, and which elements are challenging?

This research question will be addressed through the qualitative meta-synthesis. The main aim here is to understand the view of SMS through the lens of a person with COPD, enabling re-interpretation of existing research to develop new understanding of how and why people with COPD engage and enact self-management in their daily lives. This is a fundamental part of the thesis, as the personal approach and understanding of the social benefits of SMS support, needs to be approached from the perspective of the person with COPD. The meta-synthesis with the empirical studies together will answer research question 5.

5. How does a social network approach to SMS meet the perceived needs of people with COPD?

This final question will be addressed in the discussion. This question will consider the studies in chapters 4 and 5 and draw on the data form the meta-synthesis to provide an overarching summary of the work and how, why and when SMS could benefit people with COPD. Further to discuss any emerging new theories or approached for SMS in COPD and make recommendations for clinical practice, and further avenues for investigation.

Chapter 3 Literature review

Summary – This chapter details the organisation, delivery and findings from the scoping review. The scoping review provides the context of the nature of the problem, and channels this into four areas. The scoping review addressed research question one; '' what are the challenges with current SMS in COPD and how do they differ from other long-term conditions? ''. The scoping review is broad approach to reviewing the literature and aims to provide a comprehensive background to the argument for exploring social network in SMS.

3.1 Introduction and context

Self-management support is now an integral part of care pathways for a comprehensive range of long-term conditions, such as asthma, irritable bowel syndrome and COPD. However, it is increasingly recognised that a pre-condition for the successful deployment of SMS is an understanding of the condition and the context in order to design any novel successful intervention (Kennedy et al., 2016). Therefore, this literature review will answer research question 1,

'' *What are the challenges with current self-management in COPD compared to other long-term conditions?''*

The aim of this review is to broaden the understanding of the current SMS intervention and mechanisms in COPD and identify any barriers with existing interventions or programmes.

3.2 Method

Evidence based practice draws conclusions from literature to inform clinical decision-making. Therefore, in order to obtain the right type of evidence the correct review process requires a selection strategy. As this is a scoping review the PICO tool was selected to provide a framework to the searching process (Cooke et al., 2012). The PICO tool provides a structured framework for addressing a research question. It is an acronym designed to address the population or the problem, the intervention, the comparison and the outcome. In this way the search terms can be structured to ensure a systematic search of the literature. **(Table 1)**

A scoping review was selected as this type of review aims to identify the nature and extent of the research evidence; it provides a broad view of the literature and informs researchers and/or policymakers as to whether a full systematic review is required. It is like a systematic review in its processes but lacks the rigour and quality appraisal of a systematic review (Grant and Booth 2009).

However, because of its breadth, in terms of understanding the broader SMS challenges and their context with reference to COPD it represents an appropriate initial approach to a review of the literature. Through the scoping review the research question "*what are the challenges with current self-management in COPD compared to other long-term conditions? How can they be addressed?*''

Table 1. PICO framework for the Scoping review

Pico Framework	**Literature review**
Population	People with COPD
Intervention	Self-management or self-care interventions
Context	Elements of success or challenges of SMS interventions
Outcomes	Themes or targets of current SMS interventions with their relative merits and challenges described

3.3 Search strategy

The initial search was conducted in March 2016 and repeated in October 2016. A final search and review of the literature was conducted in May 2019. The search strategy used library search software, and included the databases; EBSCO HOST including PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE and the Cochrane reviews library. These databases were purposefully selected to gather all SMS interventions in COPD and specifically to report the clinical outcomes (hence the social sciences indices were not selected during this search). **(Table 2).**

Table 2. Search criteria

Data Bases	PsycINFO
	Cumulative Index to Nursing and Allied Health Literature (CINAHL)
	MEDLINE
	Cochrane reviews library
	Hand searching, and reference list searching
	Google Scholar and recommendations from practice teams and fellow researchers.
MESH Terms	1- ’’COPD’’ and ’’emphysema’’ and ’’exacerbations’’.
	2- ’’Chronic Obstructive Pulmonary Disease’’ and related synonyms included ’’COPD’’ and ’’Emphysema ’’ and including ’’Self-management’’.
	3- ’’social networks’’ and ’’social prescribing’’

The first round of searching in 2016 incorporated the MESH terms, ’’COPD’’ and ’’emphysema’’ and ’’exacerbations’’. This search enables a broader baseline to draft a background and research questions. The phrase ‘exacerbations’ was an addition at this stage. It was included as to focus the search; as more SMS interventions are targeted at people with COPD who frequently exacerbate. Furthermore, many SMS interventions are designed to reduce COPD exacerbations frequency or contact with health care providers, so it was envisaged that the search would highlight more COPD SMS interventions. However, this avenue was too narrow and did not yield studies that considered a whole system, or broader interventional approach to SMS.

Therefore, further searches were performed in 2016 within particular social science journals, PLOS One and Implementation Science, using the search terms ’’social networks’’ and ’’social prescribing’’ particularly focused on a line of enquiry and intervention development (Kennedy et al., 2016, Rogers, 2014). In order to maintain a contemporary evidence base by including up to date and newly published studies, the 2016 search was repeated, in May 2019 and yielded several newer papers that had been published in 2017/18. This time the MESH terms aimed specifically to encompass all the previous searches and could be re-run as an update. The MESH terms ''Chronic Obstructive Pulmonary Disease'' and related synonyms included ''COPD'' and ''Emphysema '' and including ''Self-management''. In total 13, more studies including refreshed meta-synthesis and consensus statements. (Table 3)

3.3.1 Selection criteria

Selected papers included both quantitative and qualitative studies focused on SMS. Meta-synthesis and Cochrane reviews were identified for inclusion, as these were already collated reviews of SMS evidence, which had been quality appraised. Grey literature was included and literature that was recommended or signposted by experts, (added in the flow chart as 'additional papers'). Political and clinical updates were also included.

Care was taken to ensure that the studies selected were concerned principally with SMS and evaluation of SMS interventions in COPD and associated long-term conditions. The inclusion of relevant associated conditions would enable a potential comparison across other conditions (Table 3).

Table 3. Inclusion and exclusion criteria

Inclusion criteria	Rationale
Qualitative and quantitative Self-Management Support interventional studies	The aim is to understand to breadth of the literature on previous interventions, success and outcomes.
Include COPD studies	To provide specificity of the long-term condition and the nature of the types on interventional studies
Include meta-synthesis, analysis and Cochrane reviews	Previous review enables a comparison of successful interventions from previously appraised work
Meets the critical appraisal quality	Studies selected from reputable journals
Exclusion	Rationale

Tele-health / telephone coaching	Not a broad enough SMS intervention – although included if in a broader meta- analysis
Non-English Language	Unable to interpret or integrate
Not disease specific	Not specific to the investigational population
Pulmonary rehabilitation	Interventional specificity
Pharmaceutical studies	Not relevant to SMS support
Non-malignant palliation	Specific management and support required
Clinical coaching alone – not as part of a broader intervention	Too broad
Tobacco dependency studies	Not tailored to SMS support
Oxygen therapy and dyspnoea reduction programmes	To narrow a context within the field of COPD
Hospital @ home evaluation programmes and nurse led engagement programmes	Evaluation of the nurses' input, not the SMS intervention

3.3.2 Quality Appraisal

Although a scoping review does not specifically quality appraise each study, the review intended that all work was published in a scientific journal, or health service publication with references evidence. Furthermore, the review targeted existing quality appraised syntheses of SMS interventions, and published reviews and consensus statements. In this way, each publication has been peer reviewed, and therefore externally quality appraised in order to be of a high-quality standard.

A significant piece of literature in the scoping reviews was an NIHR programme of evidence syntheses on the topic of self-management (Taylor et al., 2014). The reviews all adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Moher et al, 2009b) guidelines and checklist. The PRISMA guidance ensures parity in evidence synthesis and itself is an evidenced based minimum set of items for reporting in systematic reviews and meta-analyses. These flow charts and adherence to guidelines represent assurances for the quality of Taylor's review methods. Each review was also disease specific, so could draw on the specificity of the issues and barriers to self-management in the COPD population. There was a limited body of literature reporting qualitative findings for COPD. Only papers were suitable for meta-synthesis, as per the Revised Assessment of Multiple Systematic Reviews (R-AMSTAR); this tool was adapted from the AMSTER instrument, aims to quantify the quality if the systematic reviews. This tool assessed the papers and provided a numerical score, high quality above 30, and low quality below 30 (Taylor et al., 2014). These dealt with the negative emotions in COPD associated with living with COPD and symptoms of breathlessness highlighting the positive role played by a in psychosocial support approach in learning to accept the condition and how alternative forms of activity and social support might improve the experience of living with COPD.

3.4 Scoping review findings

3.4.1 Review process

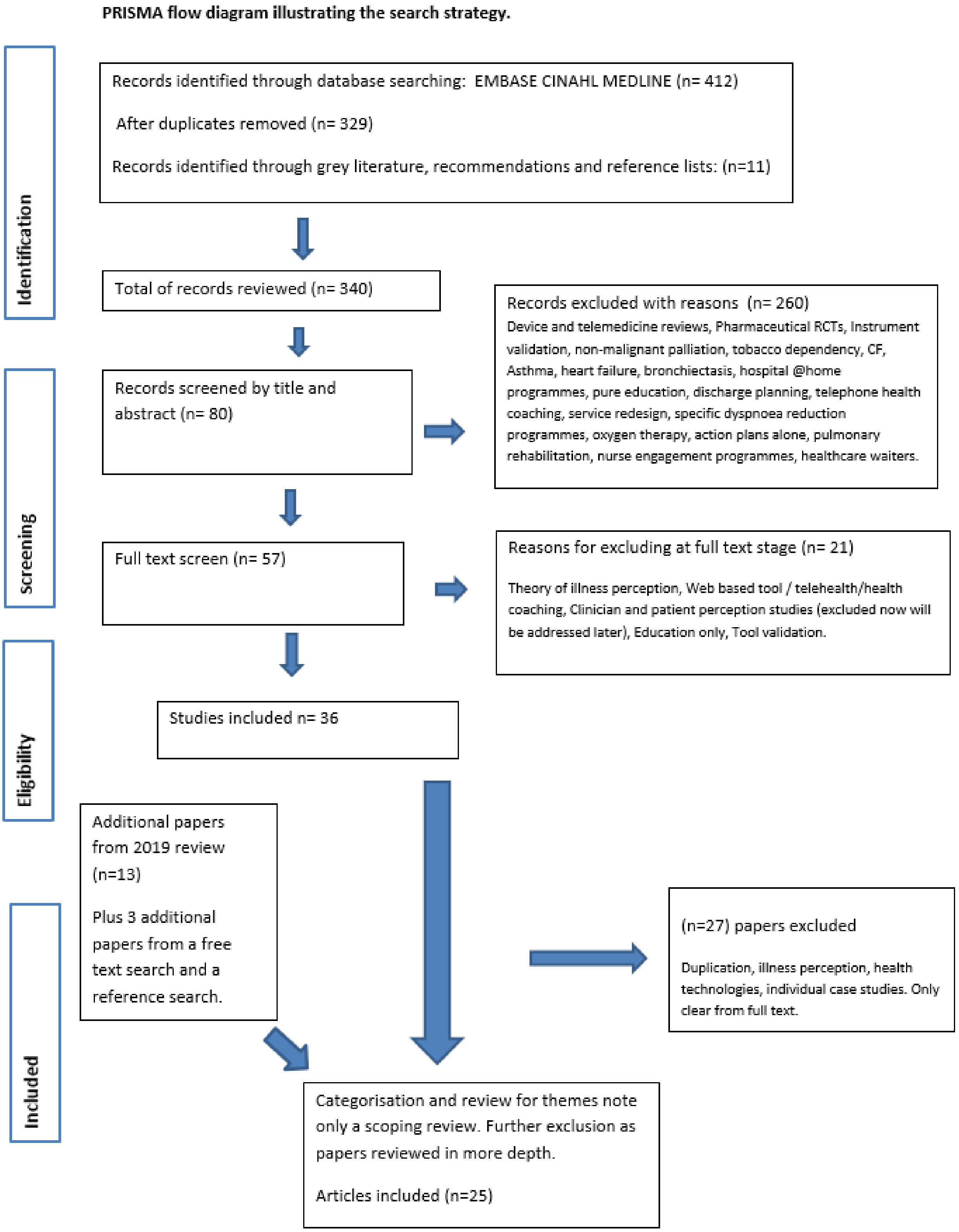
A total of 36 studies were eligible for review **(Appendix A).** The studies were read and categorised, then read again, in order to group the studies into the type of review and the main outcomes. As this is a scoping review the studies were not quality appraised, although peer reviewed studies were selected, during the abstract review. In this was the scoping review is able to offer the potential size and nature of the problem, SMS support in COPD, but lacks the rigour and depth of a systematic review (Grant and Booth, 2009).

During abstract review, a further 27 studies were excluded, but 15 more added from references reviews, and free searching of grey literature using Google Scholar. 25 papers were included in the final scoping review. In order to address the research question, the papers were grouped into sections, based on the review type and/or reported outcome:

1. *Consensus statements and expert opinions in COPD self-management*
2. *Learning from failure*
3. *Health economic and cost evaluations*
4. *Interventional SMS studies, systematic review and meta-synthesis.*

The process began with literature familiarisation, reading, categorisation, and then re-reading to draw out the themes to address the research questions **(Appendix A).**

Figure 1. PRISMA flow diagram illustrating the search strategy.



3.4.2 Interventional SMS studies, systematic reviews and meta-analysis

In terms of the evidence collected in the review, 2 of the 15 interventional SMS studies reported positive outcomes in terms self-management (Sedeno et al, 2009), evidence in these studies demonstrated a reduction in hospital admission and improvement in quality of life (Taylor et al., 2014). However, a similar study reported no impact of SMS on the time to readmission to an acute hospital with a COPD exacerbation. The same study noted that a sub-population did reduce readmission risk where study participants reported living with others (Bucknall et al., 2012).

However, one consistent component that delivered a favourable effect included interventions with peer contact (Jonkman et al., 2016). Studies focused on mental wellbeing, delivering peer support and self-management advice, also reported positive results in quality of life and knowledge attainment. This recent shift in paradigm to focus on the emotional burden of illness and to address mental health as well as physical COPD symptoms, yielded positive results in quality of life scores and through qualitative feedback (Joglekar et al, 2018, Jolly et al., 2018) (Vassilev et al, 2014) (Sewell et al, 2018). The qualitative reviews reported the importance of supporting patients to adjust to the physical and psychological symptoms of the disease and the need for tailored therapies.

Overall, the optimal combination of components in an intervention are yet to be identified to be able to successfully replicate an intervention. The unfeasibility of pooling studies due to the heterogeneity of the models, timelines, populations and outcome measures, makes making clear recommendations of any intervention challenging (Effing et al, 2007).

Studies in this group reported also that many patients in the studies had action plans, but did not act appropriately and use the action plans in times of crisis (Jolly et al., 2018). Higher symptom burden was directly associated with poorer scores in self-management ability, measured using the HeiQ tool. In turn, socio-demographics have little impact on the ability to self-manage, but increased disease burden does make self-management more challenging. This highlights the need to intervene with SMS at an early stage in the COPD disease trajectory, with a tailored peer support approach (Bringsvor et al, 2018).

3.4.3 Learning from failure

Further learning can be gained from published ‘failures’; or SMS interventions that detailed the reasons that they didn’t work as initially expected or had suboptimal results. Bucknall 2012 discussed the findings of a SMS RCT in a COPD population in Scotland. They measured readmission rates and found no impact of a SMS intervention. However notably a sub-group of younger participants that were living with others, did see a reduction. Kennedy 2013 delivered a large-scale primary care randomised controlled trial, again with a self-management intervention; the intervention aimed to develop the self-management skills of existing health professionals in primary care. The programme developed a whole systems approach to consultations and offered training and resources to primary care employees. The intervention is well described and has a sound theory and was well powered, and attempts were made to gain a large sample size, enough to make statistically significant inferences at the conclusion of the study. The study groups were equal in terms of demographics. The primary care staff although trained in the intervention, and attendance at the training was good, the staff did not embed the intervention into their clinical practice and therefore no clinically significant differences were made in terms of any of the primary of secondary outcomes. Although this is a negative result, from a large-scale study, it is a good study to draw learning from, in terms of design and delivery of and intervention. The message through this paper is that of self-management support being very multi-faceted, and not just the responsibility or the issue of patient uptake and patient engagement. The attitudes, values and beliefs of the caregiver or health professional are part of the system and require thought and possible intervention. Alternatively, perhaps SMS could be provided in another way, not solely relying on the direction of the health professionals; in this way making the SMS intervention a truly patient owned intervention.

This alternative direction for SMS delivery has affinities with SMS focused on engagement with personal communities. The ability of communities and families to re-shape roles and expectations to develop a collective efficacy; a shared goal or vision to increase the capacity to perform tasks (Vassilev et al, 2019, Rogers et al, 2014) (Jolly et al., 2018). This theory explains and contextualises the studies in which peer support has proved the successful component of an SMS intervention.

3.4.4 Consensus statements and expert opinions in COPD Self-Management

The scoping review is not based solely on peer reviewed studies, and therefore the search included statements from expert in the field of COPD management and self-management. The papers included in this section address the current barriers to COPD SMS and suggest future avenues for exploration (Bourbeau et al, 2015). Complications and barriers to SMS include compliance, literacy and understanding of the participants, clinical time and resources. Overall SMS is deemed worthy of pursuit if the right interventional ingredients can be found, which can then improve emotional health and quality of life, reduce health care interactions and be cost effective. The analysis of failures directs opinion to the notion that participants fail to act or intervene when their own symptoms are deteriorating, despite having knowledge (Bourbeau et al., 2015). Therefore, a paradigm shift would require a multi-faceted, peer approach to SMS (Bourbeau et al., 2015, Nici et al., 2014). SMS interventions would be better placed targeting emotional health, with elements designed to promote collective efficacy and self-efficacy, to be personalised and be concerned with behaviour change and skills acquisition (Nici et al., 2014). Consensus opinion suggested goal setting, as part of any potential SMS intervention to support the management of COPD symptom reduction and functional improvement. Further aims of any SMS intervention should be to increase emotional wellbeing, social wellbeing and quality of life (Simpson and Jones, 2013). In addition, it suggested the development of alliances with health care professionals, family, friends and the community (Nici and ZuWallack, 2015). Therefore, social infrastructure in SMS positively influences SM behaviours. Interventions are required to evaluate the nature and type of social support that is required in COPD (Lenferink et al., 2018).

3.4.5 Health economic evaluations of SMS interventions.

Taylor 2012 conducted a pilot randomised controlled trial in primary care for moderate to severe COPD patients. The study aimed to evaluate the feasibility, effectiveness and cost effectiveness of a taught, volunteer led, self-management intervention in COPD. The intervention was cost effective and led to improvement of self-reported quality of life. The cost effectiveness used an Incremental Cost Effectiveness Ration (ICER) at £11,710 of the Quality Adjusted Life Year (QALY) gained over 6 months. In order to understand the probability of cost effectives than a (Cost Effectiveness acceptability curve (CEAC) was constructed. If society were willing to pay £20,000 per additional QALY gained then the SMS, intervention (named BELLA) would have a 75 % probability of being cost effective (Taylor et al., 2012). The benefits in health-related quality of life and cost effectiveness probability have potential if the study was delivered over a longer period, with a larger number of participants.

However, this was a small pilot study and the intervention had little impact on disease and symptom scores. Taylor reported that only 1 quarter of the patients approached from primary care that were suitable for the study were interested in participating and then a further 35 % of those offered self-management courses, never attended. This attrition rate is high in this patient group, and therefore an interesting reportable finding, as it appears high and supports the anecdotal and clinical evidence around the challenges with engagement in traditional self-management interventions.

There is currently a dearth of literature pertaining to clinical and cost effectiveness of SMS interventions, this literature review only identified 2 studies. Health economic evaluations are valuable for clinical policy makers and commissioners to select appropriate SMS interventions in a balanced way, including cost, patient benefit, acceptability and ease of deployment in services. Although potentially more time consuming, people with COPD require intense personalised face to face support to implement SMS as they value psychological and social support (Baker and Fatoye, 2017) , which can prove more costly due to intensive clinical time.

3.5 Discussion of the literature review

SMS still warrants investigation as promising outcomes have been made in terms of emotional health, quality of life and resource utilisation in COPD. However, the heterogeneity in the studies make individual components of each intervention, the design of the study and the outcomes measures challenging to compare. The SMS ‘learning from failures’ section has provided valuable insight into some of the specific challenges and barriers in the implementation of SMS support in long-term conditions at primary care level (Kennedy et al, 2013). Furthermore, Taylor reported that only 1 quarter of the patients approached from primary care that were suitable for the study were actually interested in participating and then a further 35 % of those offered self-management courses, never attended (Taylor et al., 2014). A greater depth in our understanding regarding, why these studies, or interventions did not work and perhaps how the paradigm of SMS interventions could broaden to include engagement with network members in the context of people's everyday lives, emotional and practical support, and focus on quality of life and what people value. There is evidence that SMS interventions improve quality of life. The main components of successful interventions include peer contact (Jonkman et al., 2016), social support, and asset based community development (Jolly et al., 2018). These components enhance emotional wellbeing, engagement of networks or members of personal communities and utilisation of social assets to support day to today living. Therefore, the development of new SMS interventions that aim to build personal resources, activate and extend networks, increase access to social and community assets, and enhance emotional health and well-being would align with the evidence. The creation of social assets and networks extends to online communities. These online communities can be led by peer ' super-users' , who support others with day to day advice on healthy living and treatment management decisions through online peer networks (Joglekar et al., 2018).

The specific challenges of SMS in COPD as identified through the scoping review are:

1- How to elicit any economic benefits of an intervention? This requires consistent measurement with each intervention, so a wider evidence based is formed addressing the relative, or comparable economic value of each intervention.
2- How to tailor the approach of the intervention, to be more person centred? In order integrate of skills and knowledge of COPD disease management into the daily lives of people with COPD, then we first must understand how people prefer to interact with SMS and how people with COPD incorporate this into their daily lives (Bourbeau et al., 2015, Nici et al., 2014).
3- How can we effectively establish alliances with health care professionals and family, friends and community, to deliver effective social support and peer networks positively impact on SMS behaviours? Could a single intervention be developed or tailored to meet this need in people with COPD, a candidate intervention that could

be tailored and tested within this population could be the GENIE, social networking tool (Kennedy et al., 2016).

4- *How and what* we are delivering - challenges in the previous heterogeneity of interventions, meaning that the individual components of interventions cannot be directly compared (Effing et al, 2007) (Taylor et al., 2014, Jonkman et al., 2016).

5- *When* should we deliver SMS support? The fact the COPD symptoms are on a declining trajectory and challenges in disease prognostication, requires different approaches in different parts of the disease trajectory (Bringsvor et al, 2018).

6- Targeting, and effectively measuring emotional health and quality of life in COPD SMS support (Simpson and Jones, 2013, Effing et al., 2014, Effing et al., 2016).

The literature further suggests that in order to measure the effectiveness of such an intervention then the clinical, economic social and emotional outcomes need to be considered to understand the success of the intervention.

Therefore, this thesis will now move towards the development and reporting of the GENIE SMS intervention and methods for assessing its effectiveness of the GENIE intervention in the community COPD population. In order to do this the social network theories or approaches that could be employed to provide SMS will be discussed in chapter 4. The methods for adaptation and implementation of the GENIE tool for people with COPD are detailed in the methods, chapter 6. This included the primary design and objectives for the empirical study. The findings from the overarching pilot study are reported in chapter 7. A further nested feasibility study to understand the possibility of the GENIE tool to influence health behaviours in relation to improving health and diet in COPD are reported in chapter 7 (Hoffman et al, 2014).

Chapter 4 A social network approach to SMS

Summary – This chapter discusses the social theories and approaches that have been used in the development of the GENIE tool. The aim here is to discuss several social network theories or approaches that could be employed to provide SMS in people with COPD. Therefore, linking the theory of social networking, to COPD, and how social networks and a peer SMS could be beneficial in people with COPD. This chapter adds the theory and a rationale for the selection and the development of the GENIE tool for use in COPD.

4.1 Rationale for a Social network approach to COPD Self-management

This thesis is exploring social theory and its role in the development of a social network intervention in SMS for people with COPD. The literature review (Chapter 3) identified gaps in current SMS strategies. This included the lack of SMS interventions targeting social and emotional wellbeing, engaging family members, friends, community groups, and peers (Simpson and Jones, 2013, Effing et al., 2014, Effing et al., 2016). All of these were reported to have the potential to have a benefit on SMS. Therefore, this chapter will explore the theories that could help to address this knowledge gap; identify the theory base that informed the development of the GENIE intervention and link these theories to an application of an SMS intervention for people with COPD. For clarity, the chapter will be organised into the following sections:
Social roles and personal connections, developing the GENIE intervention and speculating how GENIE could work in people with COPD.

4.1.1 Social roles and personal connections

Current theories of self-management tend to either focus on the ability of individuals to manage a single clinical condition or to maintain a sense of normality in their everyday life. Success is defined in relation to happiness in one’s life and the ability to fulfil ‘normal’ social roles, such as being a mother, being employed, fulfilling familial expectations (Halding et al., 2010). Social roles are shaped by societal structures, cultures and expectations, and personal values and opinions of oneself. These are important as they are linked to people’s social identity which provides people with a sense of affiliation, a group belonging, and a place in the world. These affiliations promote acceptability and reflect back the social affirmation that contextualises the broader sense of self (Brown, 2000).

This broader sense of self –shaped by valued familial and societal roles suggests that social interaction, group affirmation, sense of belonging and may have a positive impact on the wellbeing for those people living with a long term condition (LTC), such as COPD (Reeves et al., 2014). In addition, there is evidence that isolation has a negative impact on health in general and those with a long term condition in particular, it leads to low mood and an increasing inability to engage with self-care, and has negative physiological effects on health (Cacioppo and Hawkley, 2003). Self-care includes more than achieving one's basic personal care needs, such as washing and dressing. Self-care refers to the wider context of personal and social wellbeing, and the maintenance of physical function (Sadler et al, 2014). This includes maintaining positive health behaviours, such as diet and exercise. Furthermore, self-care behaviours, can also be health protective. Better diet quality, broadly indicating greater adherence to dietary recommendations, has been associated with better lung health and maintenance of health and lung function (Reedy et al., 2014, Milte and McNaughton, 2016), as well as reduction in disease risk and frailty. Therefore, optimising personal wellbeing, through interactions, could in turn promote self-management or self-care (Sadler et al, 2014).

In consideration of the importance of a valued and active social world, to improve personal identity, wellbeing, mood and diet choice, then the significance of maintaining a social, outward facing self retains its importance in long term conditions management.

In terms of addressing SMS, this occurs both personally and with support of health professionals, to guide and advise on self-management in a clinical context. Therefore, the style and nature of the SMS interactions with health professional can also influence engagement with SMS support (Franklin et al, 2019). Interactions that are 'flexible' and reduce the emphasis on compliance and lifestyle recommendations have been found to elicit improved interactions, and indeed ownership (Franklin et al, 2019). Therefore, a more collaborative approach to self-care arrangements, which is led or directed by the person with the condition is preferable in terms of engagement and outcomes.

Collaboration can be considered both in terms of collaboration with health care professionals to promote SMS engagement, but also in terms of family and relational associations. Empirical evidence suggests that socially productive activities, which maintain and enhance value in society can promote wellbeing (McMunn et al, 2009). The concept of personal value can be extended to 'reciprocity'-- being valued for your activities and being both the recipient and the giver. Reciprocal societal relationships are associated with enhanced wellbeing in later life (McMunn et al, 2009). If giving and sharing promote value in society, then this societal value in turn can contribute to a broader sense of personal social identity. Broadening the whole concept of self-management to encompass everyday activities and day to day tasks, rather than the specificities of COPD related illness – enables a wider possibility of care interventions to support this patient group. When considering process of implementation of any intervention, one must consider that each intervention has steps, or sections that work together, creating a complex intervention. Programme theories explain how an intervention (a project, a programme, a policy, a strategy) is understood to contribute to a chain of results that produce the intended or actual impacts (Rogers et al, 2008). It works on the premise that interventions are complicated (several interwoven components) or complex (causal strands that need to work together) (Rogers et al, 2008). Programme theory here can be used as a theory to explain, how and why sections or parts of an intervention work together to deliver a whole intervention. Therefore is applicable to development of the GENIE intervention (Rogers et al, 2008), and specifically discussed through the process evaluation in chapter 8.

4.1.2 Developing the GENIE intervention

In order to draw on the relevant theory a broader re-conceptualisation of both the interpersonal relationships and illness relevant practices are required. Original work by Pescosolidio (1991) (Pescosolido, 1991) began to consider the interplay between illness and social networks, through a Network Episode Model (NEM). The NEM was designed to illustrate and understand the interplay of personal networks, in the context of help seeking during episodes of ill health. The model mapped the effect of the structure, content and function of network ties, and acknowledged the fluctuations of networks during times of emotional need and decision making. This work allowed the visualisation of the broader sets of social influences in the management of health conditions. These links or networks extend beyond an individual's capability to manage alone, drawing instead on wider groups of people and groups.

The work by Pescosolidio and the need in incorporate and value those ’small world’ encounters and macro social interactions in a social network model was further supported by Crossley 2010 (Crossley, 2010).

This complex negotiation of illness work and reliance on spouse is evidenced and discussed in Vassilev and Rogers’ work 2014 (Rogers et al, 2014). However, their analysis also identified a contribution to illness work by other network members. It seemed that the ability to negotiate and mobilise relationships that appear to be less important (such as neighbours, hobby groups, acquaintances) could have a positive impact on the overall amount of work done within a network. These network members were described as *‘weak ties’* and were found to be relevant in help-seeking behaviour, diversifications of information and mobilisation of new resources. These weak ties in practice could take the form of health relevant support groups, clubs, transport and other non-health relevant social groups. This enables the development of personal communities as a system of relationships, not dyadic relations, and that alternative network members can be called upon to support with long term condition management and in crisis situations (Vassilev et al, 2019).

The GENIE intervention builds on the concept of social connections and negotiations with broader network members. **GENIE** – Generating Engagement in Network Involvement, was first devised and reported by (Kennedy et al., 2016). The GENIE intervention aims to broaden network support and diversify existing networks. The intervention is based around network mapping, user-centred preference elicitation and needs assessment. The process although on-line was facilitated and could be performed on paper. The development of the GENIE tool allowed for the possibility for an intervention to reconstruct self-management differently and move away from the more psychological model of behavioural change. The GENIE concept further aligns to the social complexity work in relational modelling in older age (Antonucci et al, 2014). The concept of a convoy model. The convoy model describes social relationships as adaptable and variable in function, structure and quality; fluctuates during one’s life course (Antonucci et al, 2014) Furthermore, the convoy model described personal relationships as close, closer and closest. This model introduced this principle of mapping network members using the concentric circles approach (Antonucci et al, 2014). This concentric circle approach was then adapted and formed the initial mapping phase of the GENIE social networking tool.

The GENIE tool has been previously studied in diabetes patients and findings described the process of disruption of poor networks and reconstruction of positive networks; that where both welcomed by participants and facilitated health behaviour change (Reidy et al, 2020).

4.1.3 Speculating how the GENIE social networking tool might work in people with COPD

The GENIE social networking tool could support people with COPD in negotiating engagement with their existing network members and the development of new connections. People with COPD become increasing disabled as their disease progresses, leading to decreased mobility and subsequent isolation (Tomaka et al., 2006). Therefore, the support that people with COPD may require in a crisis may not be available through their informal network and so health service use and hospital admission may be greater compared to people with other long-term conditions in a crisis.

Enabling network diversification and reciprocal support can increase moral and societal worth, and by undertaking group SMS activity, can enable an interactional capacity and personal value in the here and now (Brooks et al, 2015). These are relevant in COPD and in mobilising people with COPD into voluntary sector support structures, and away from statutory NHS groups, which also incurs a clinical cost. Therefore, bridging the social network loss in the COPD population, and building weak ties could be beneficial in terms of enhanced social network support, for negotiating and improving both illness and emotional work.

In addition to this, the use of a flexible collaborative approach to goal setting conversations (Franklin et al, 2019), utilising the concentric circles to map relationships could have the potential to bridge the COPD social decline cycle, and therefore also investigate self-management from a social network angle. However, in order to be effective, any potential evaluation of the GENIE tool in COPD population required consideration around the most appropriate place in the existing COPD care pathway. During an acute exacerbation of COPD, the priorities remain within the realms of clinical safety and reduction of immediate harm, therefore this ruled out the acute part of the care pathway. However, placing the GENIE intervention as people leave pulmonary rehabilitation could potentially be successful. As the GENIE social networking tool, when applied to COPD patients, has the potential to both reduce illness work with negotiating and navigating exits from existing health care provision; such as Pulmonary Rehabilitation.

Further to this developing social ties and increasing activity within the COPD population, could potentially support NHS services and directly benefit people with COPD. This leads to the chapter 6, the development of the methods to develop the GENIE tool to be used in people with COPD. The methods chapter will describe the adaptions to the GENIE tool, the implementation plan, and the methods of evaluation.

The next chapter, chapter 5, is a further in-depth review of the literature, in the form of a meta-synthesis. The meta-synthesis findings link in later in the discussion; as the detailed meta-synthesis of SMS enactment, supports the interpretation of the empirical findings.

Chapter 5 Findings and recommendations from a Qualitative Meta-synthesis (QMS) of Self-management enactment and engagement in COPD

Summary – Chapter 5 is drafted in paper format. It describes the methods and findings from a qualitative meta-synthesis in SMS enactment in people with COPD. This paper adds to the conceptual theory of using a social approach to develop support networks to underpin SMS support. This qualitative meta-synthesis is an independent paper, that enables an in-depth review of a targeted area of the literature.

5.1 Background and rationale

Self-Management support (Pinnock et al, 2016) interventions are currently being promoted in the management of long term conditions, including Chronic Obstructive Pulmonary Disease (Celli et al, 2015), by the government and the National Health Service (NHS). The Health Foundation and NHS England both suggest that SMS options are a viable future solution to reduce unnecessary health care contacts and improve the lives of those living with long term illness (Wood et al, 2018). Self-management interventions have proved successful in reducing burden of disease and improving quality of life in long term conditions (Andenæs et al., 2014). Furthermore early identification and decisive action to intervene in the deterioration of respiratory symptoms can improve recovery times post exacerbation of COPD (Wilkinson et al., 2004). Therefore successful self-management interventions, or clinical intervention in terms of early treatment and positive health behaviours can be beneficial and potentially reduce the risk of hospitalisation (Gudmundsson et al, 2005).

However, SMS has not always been wholly successful in COPD care due to the challenges the disease presents. COPD is characterised by persistent breathlessness and sputum production which impact on daily activities such as mobilising, eating and socialising. COPD symptoms are further compounded by complex co-morbidities, such as nutritional deficits, muscle wasting, fatigue, depression and anxiety (Almagro et al., 2012). Cardio-vascular complaints can also co-exist in some people due to excessive past tobacco use (Mannino, 2002).

People with COPD also experience flare ups, or exacerbations of existing COPD symptoms, in which they are required to make decisions around care and treatment while experiencing frightening symptoms of breathlessness (Wilkinson et al., 2004). Therefore, the emphasis at present is mainly on the person with COPD being able to change behaviours, respond to a symptom or deterioration of symptoms, and to action planning. This requires a sense of self responsibility and confidence in disease management to take the most appropriate clinical action. This also requires psychological engagement with the overall condition and / or symptom(s) and the correct knowledge education to understand how and why any particular action would improve or decrease negative symptoms. These mechanisms of improving health are centred on the promotion of self-efficacy (Wigal et al, 1991). The concept of self-efficacy requires people to be self-efficacious, and harbour beliefs that they have the ability and capacity to bring about clinical change. Clinical care decisions can be challenging and complex and require a depth of understanding of the disease process and trajectory. Making decisions alone, when one is breathless and unwell is further compounded by physical limitations, emotional distress and social isolation (Schroedl et al., 2014), leaving people with COPD feeling the need to call for support and assistance, as their condition is frightening and disabling. Furthermore making an incorrect decision alone, or not seeking help, can compromise clinical care (Fan et al, 2012).

Self-management enactment is reliant on a broader set of people than just oneself and one’s health care professional. Those people living with long-term conditions spend very little time engaged with health care professionals in comparison to the amount of time they are expected to spend on activities they need to keep themselves well. Activities that are required to maintain wellness (or absences of illness) have been defined as illness work (Vassilev et al, 2013) which adds to other daily work tasks such as everyday work and emotional work. Illness work extends to the extra activities created by the management of a long-term condition. These include medicines management, emotional support, negotiated from others, complex decision making and practical support in terms of attending appointments and travelling. These activities are additional to daily work and tasks, which include; everyday work, housekeeping, diet and exercise and emotional work, comfort of others, wellbeing and companionship.

The ways, then, that self-management work is woven into daily lives and routines is complex and may differ with age and background. At present, it is not well understood how people with COPD choose to engage with SMS; what they choose to engage with and how they enact SMS; how they weave the necessary extra care components into their daily lives; if they have the scope and ability to adopt and enact SMS practices in their daily activities in a time of crisis.

In order to be successful in living with and managing a chronic condition such as COPD several defining attributes have been conceptualised that are required to enable successful self-management, these are: *acceptance, coping, integration, adjustment and self-management* (Ambrosio et al, 2015). It was posited by Ambrosio that only after acceptance of the long-term condition, can one begin to cope and adjust. Self-management is then, aligned with integration and adjustment, part of the steps to achieving positive living with a long-term condition.

Therefore, in order to successfully support SMS in people with COPD, one must first understand how people embed and enact SMS into their day to day lives, and how these personal perspectives align with acceptance, coping and integration of COPD into a person's daily life. The previous literature review in chapter 3, was designed as a broad scoping review to identify gaps in the literature and channel the scope of the thesis. Chapter 3 identified the need to broaden SMS support to include psycho-social aspects of SMS and highlighted the avenue of social or peer networks support for SMS as a promising avenue for investigation. However, chapter 3 did not identify an explanation as to 'why', or 'how' SMS is assimilated into people with COPD's daily lives.

Therefore, the main aim here is to understand the view of SMS through the lens of a person with COPD, enabling re-interpretation of existing research to develop new understanding of how and why people with COPD engage and enact self-management in their daily lives. In order to do this a meta-synthesis and third order interpretation will be undertaken. This is further supported through the findings of a systematic review by Russell (Russell et al., 2018). Russell explored the barriers and challenges of self-management in COPD, through the views of both patients and healthcare professionals in a systematic review. This was a systematic review, which was not synthesised. The review amalgamated and grouped the findings of the synthesis. It concluded that developing SMS in COPD is a protracted process, with overlaying emotional and psychological issues that complicate the process. Issues include the ‘all consuming’ physical symptoms of the condition and the feeling of being a burden to those that support you (Russell et al., 2018). However how, and why people who are successful with SMS in COPD enact and tailor changes in their everyday lives, was not discussed.

Therefore, in order to understand how and when people develop SMS strategies, the meta-synthesis purposefully selected research studies that focused on living with COPD and how people adopted new SMS strategies into their daily lives. Qualitative studies were selected, as they allow for open questioning and offer an insight into the personal experiences and perspectives of people with COPD and their families (Disler et al., 2014).

This paper will describe the aims, process and findings of a qualitative meta-synthesis in order to ascertain the enactment and engagement of people with COPD with self-management support (Pinnock et al, 2016). By framing this work through a meta-synthesis of the qualitative research it will enable us to understand and explain existing behaviours through an in-depth analysis of the enactment of SMS and understanding engagement from the viewpoint of a person with COPD.

5.2 Aims of the synthesis

This meta-synthesis aims to;

- Understand and conceptualise patient engagement and enactment of self-management support in COPD.
- Explore personal challenges in SMS enactment and develop common themes across the qualitative studies.

As this is a meta-synthesis this will include a literature review, and a re-interpretation of the synthesised findings from the papers included in the search. The aim of using a meta-synthesis in this case is to not only study the challenges to engagement with SMS but also to provide additional contributions, such as identification of patterns or contexts to deepen the understanding of how, when and why people choose to engage with SMS.

When using meta-synthesis to explore SMS interventions our understanding is broadened by recognising connections between activities and outcomes (Erwin et al, 2011). In order to maintain a reproducible structure to the meta-synthesis the methodology is based upon a worked example of meta-ethnography (Franklin et al., 2018, Britten et al, 2002b).

Meta-synthesis enables a systematic approach to the synthesis of qualitative research. However, the process of meta-synthesis is less well defined in the literature, and although it seeks to reinterpret original qualitative findings, it does adopt a more dialectical stance to the data, only including those qualitative studies with a similar design. As this area of investigation is a nuanced field, it was necessary to open the synthesis to all study designs, within scope. Therefore, the meta-ethnographical approach was selected to be used within the meta-synthesis as it is open to all qualitative study designs, if they are on the same topic. The notion of employing meta-ethnography within a meta-synthesis is not novel. This method has been used in social sciences and policy formation (Siau and Long, 2006). This translations of the studies, using meta-ethnography combines the translations of the studies, together with the researchers understanding of the phenomenon under investigation (Noblit and Hare, 1988).

It further offers a robust, frame worked process, with options of the synthesis methods. These include reciprocal translation, reputational synthesis or line of argument synthesis (Saini and Shlonsky, 2012). The aim here is to translate the studies into each other to establish new meaning. In order to do this a line or argument synthesis was selected to develop comparative relationships within the data. The seven steps of meta-ethnography have been well described in the literature and provide a clear guide to the synthesis (Noblit, 1988).

Noblit and Hares’ seven steps of meta-synthesis includes;

1. Getting Started
2. Deciding what is relevant to the initial interest
3. Reading the studies
4. Determining how they are related
5. Translating the studies into each other
6. Synthesising the translations
7. Expressing the Synthesis

In order to develop the research question and develop a search strategy several frameworks were considered. Qualitative evidence synthesis suggests using the SPICE or SPIDER tool. The SPIDER tool did not lend itself to the SMS interventional work in the same way as the PICO tool. The SPICE and the SPIDER (Setting, Perspective, Intervention, Comparison and Evaluation) tool define the research question by use of a comparator or intervention. This synthesis is open to understand how and why people enact SMS in COPD. The PICO tools enabled a more concise framework to address the research question, deliver an effective search strategy, whilst considering the potential outcomes.

The framework selected to support the structure of the systematic review was the PICO (population or problem interest, context, outcomes) tool for qualitative reviews (Cooke et al., 2012). PICO helps with the creation of a searchable question. In this study the PICO framework was operationalised in the following way:

Population or Problem: - People with COPD

Interest: – Enabling and enacting SMS (broadly defined, not specifically technology)

Context: -living with long term illness / community care

Outcomes: – higher order themes or concepts that influence patient enactment and engagement in SMS in COPD. (Cooke et al., 2012)

5.3 Literature review

Search terms

The search strategy used library search software and included the databases; EBSCO Host including; Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, Scopus (Social science and technology focus) and the Cochrane reviews library. The social science orientated data base was included to try and capture a greater breadth of literature, in terms of SMS interventions. Web of Science was not used as a nuanced COPD qualitative studies were required, and therefore the Scopus was deemed a suitable social sciences search, as COPD was a necessary search term.

The MESH terms used were mirrored from the scoping literature search originally conducted in chapter 2. The terms had been developed specifically to encompass all the previous searches, and therefore had been tested with the appropriateness of the yield. In addition to these terms; qualitative studies were added.

The MESH terms ‘’Chronic Obstructive Pulmonary Disease’’ and related synonyms included ‘’COPD’’ OR ‘’Emphysema ‘’ AND ‘’Self-management’’. Then a secondary search ‘’ ‘’Chronic Obstructive Pulmonary Disease’’ and related synonyms included ‘’COPD’’ OR

‘’Emphysema ‘’ AND ‘’Self-management’’’’ AND ‘’qualitative studies’’. The second search was included to build specificity into the yield, in order to ensure the ‘context’ element of the PICO tool was appropriately addressed. The context and population required the search to clearly address the views and perspectives of the people with COPD and those who care for them. Therefore, the search was narrowed the qualitative papers only. The dates ranged from 2010 -current, and English language only were included in the initial search round.

The systematic review of the literature was performed in July 2019. The search strategy (above) yielded 85 initial papers, and search 2 yielded 17 papers, 102 in total. After the initial search, the papers were tabulated together and any duplicates were removed, then hand reviewed to scope the relevance and appropriateness for synthesis (Noblit and Hare, 1988, Britten et al, 2002). This review of the literature was an initial appraisal of title and abstract against the inclusion and exclusion criteria (below). In order to ensure the literature remained specific to the research question the following paper were excluded; Not disease specific (asthma, reflux, cystic fibrosis, cancer care, palliation), and not focused on SMS enactment in COPD for example to following were excluded; pulmonary rehabilitation, instrument validation, clinical coaching, hospital care experiences, discharge planning, discharge experience, mindfulness, oxygen therapy, psychoeducation, evaluation of physical activity alone, breathlessness symptoms and evaluations of research participation. After these papers were excluded four extra hand selected studies were introduced by researcher (AR). In total 96 papers were excluded from the original 102 yielded in the initial search strategy.

The searches provided 6 papers for review plus the extra 4. The 4 hand selected papers also included at the abstract review stage; when read in full were then excluded as the focus was on oxygen therapy, not specifically SMS enactment, so only drawing on the engagement of oxygen use, rather than broader concepts that could be applied across self-management. Therefore 6 papers were eligible and subject to a joint quality and scope review by 2 researchers (LW and AR). The selection process is presented using a PRISMA flow diagram (Moher et al, 2009a) to identify which papers were rejected or included, at what stage, and the rationale for rejection.

Finally, five papers were purposefully selected to gain a depth of understanding into how people with COPD understand and engage with the principles of SMS in order to successfully enact SMS. This synthesis is valuable to policy makers and clinicians, to inform them of how people with COPD translate education and SMS tools into their daily lives, few studies have specifically translation in terms of enactment in this population. **Appendix B** details the data extraction, tabulates the description of the studies and illustrates the synthesis.

Literature review flow diagram and study inclusion exclusion rationale.

PRISMA Preferred reporting of meta-analysis (Moher 2009)

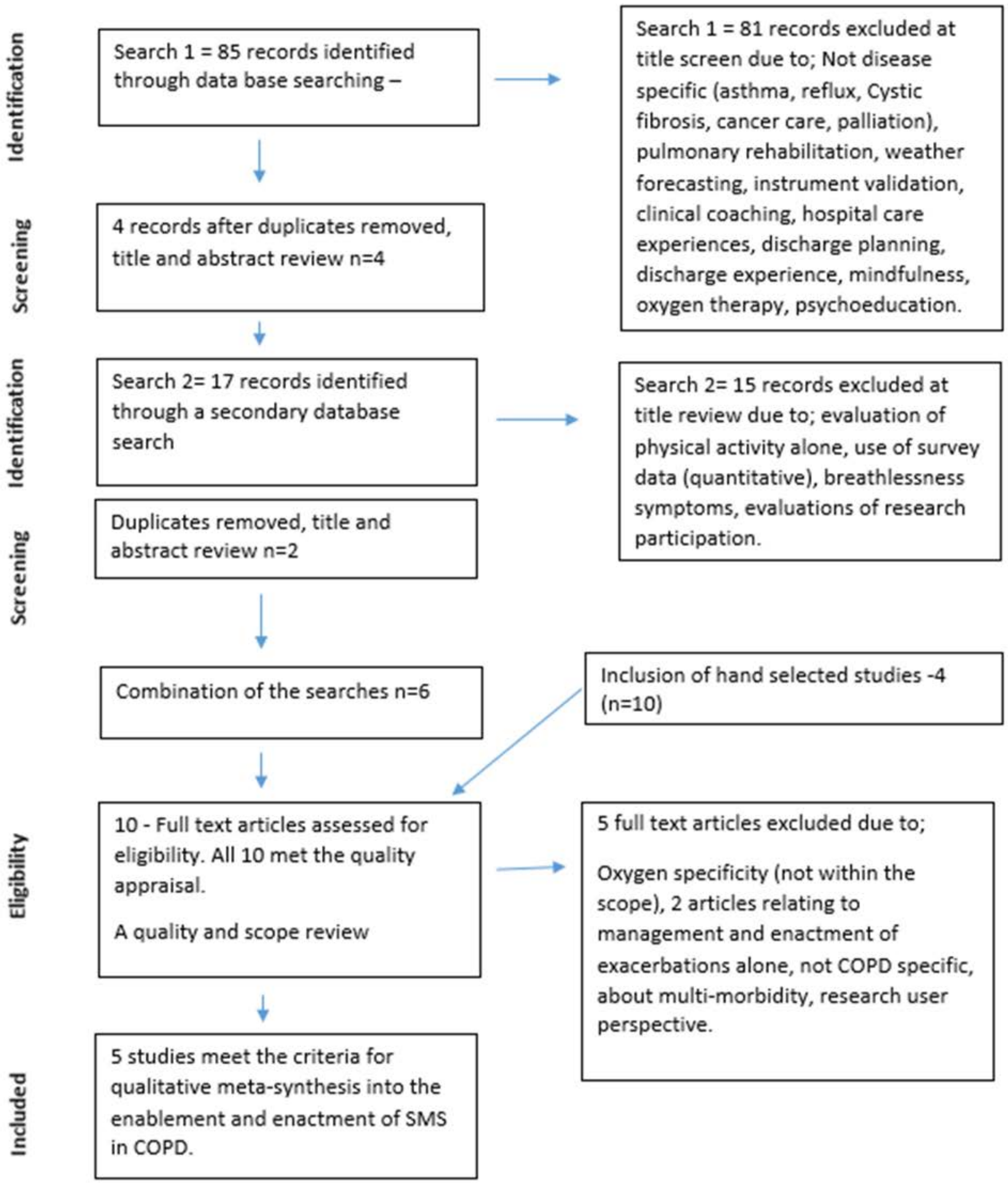


Figure 2. Prisma Flow Diagram

Table 4. Inclusion and exclusion criteria

Inclusion criteria	Rationale
Qualitative studies including patient and carer perspectives	The aim is to integrate and re-interpret qualitative findings
Include COPD and SMS studies	To provide specificity of the long-term condition and the nature of the types on interventional studies
Meets quality criteria (Blaxter 1996, 2013)	Guidelines for quality appraisal to ensure the selected studies methods and analysis were rigorous.
Exclusion	Rationale
Tele-health / telephone coaching	Not a broad SMS intervention
Existing meta-synthesis or aggregative works	QMS is required to reinterpret findings from original papers
Non-English Language	Unable to interpret or integrate
Not disease specific	Not specific to the investigational population
Pulmonary rehabilitation	Interventional specificity
Weather forecasting	Not relevant
Instrument validation	Not relevant
Clinical coaching	Evaluations of a specific intervention
Hospital care experiences	Specific not relatable experience
Discharge planning	Specific not relatable experience
Discharge experience	Specific not relatable experience
Mindfulness	Evaluations of a specific intervention
Oxygen therapy	To narrow a context within the field of COPD
Psychoeducation	Evaluations of a specific intervention
Evaluation of physical activity alone	Evaluations of a specific intervention
Use of survey data (quantitative)	Not qualitative
Breathlessness symptoms	Specific COPD symptom, not about SMS enactment
Evaluations of research participation.	Not relevant

5.4 Quality and scope of the literature.

There is an increased need to both amalgamate and reinterpret qualitative literature, particularly in health care. This process is multifaceted and cannot simply be processed in the same way quantitative literature, and therefore the quality appraisal process requires an alternate framework. Several frameworks have been developed to ensure the search, selection and quality appraisal process remain robust. The PICO tool is one such tool that was selected to support the development of the search strategy, synthesis methods and outcomes analysis for this synthesis.

Two quality appraisal tools were considered to support the quality appraisal of the final six papers. The Critical Appraisal Skills Programme (CASP) 2018 checklist was first considered. The CASP was originally designed as an educational tool and benefits from a methodical way of objectively assessing the quality of qualitative literature. The tool is an aid (so not scored) but enables a systematic approach to be assessing the quality of literature. However, the tool was educationally orientated and did not offer the depth required to review in detail the quality of a smaller number of sociological qualitative studies.

Therefore a second tool was considered and used; ''Criteria for the Evaluation of qualitative research papers'' (Blaxter, 2013). This quality appraisal tool was selected as it was developed within a group setting at a conference with the explicit purpose of demonstrating that the qualitative methods in the research have both rigour and sophistication. Blaxter's criteria offer a detailed framework that addresses each component of the research and the data, in order to deliver a rigorous quality review. Blaxter broke the quality appraisal process into 20 distinct questions with 4 categories;

Methods used: are these appropriate, clear, subject sensitive is data collection appropriate and is the method of record keeping specified.

Analysis: is the analysis an accepted procedure, how was it performed, is it systematic what are the new themes, concepts and categories

Presentation: Is the research clearly contextualised, is the data presented systematically, what are the distinctions between data and its interpretation, is the epistemological position of the author stated and are the results credible and appropriate

Ethical: are all ethical issues adequately addressed.

Adapted from Blaxter reissue 2013, conference 1996.

The quality appraisal process included an initial search and review by researcher (LW) and a review by researcher (AR), to ensure the selection and appraisal process was robust. Papers were reviewed individually and then together using the principles of Blaxter's guidelines. The papers were only included in the synthesis after agreement about quality from both researchers (AR) (LW).

5.5 Analytical framework and synthesis method

The aim of this meta-synthesis is to understand and conceptualise patient engagement and enactment of self-management support (Pinnock et al, 2016) in COPD and explore and develop new concepts and themes of the challenges of SMS participation based on these findings.

Meta-synthesis:	Ontological positioning:	Inclusion:	Framework analysis:	Indexing:	Output:
Integrative and interpretive	Interpretivist	All qualitative studies included. Pre-defined research question.	Codes clustered around new ideas	Re-application of the codes	New themes or concepts

Table 5. Analytical framework

In order to approach effective qualitative analysis, the ontological position needs to be pre-determined. Meta-synthesis is concerned with both integrating and interpreting qualitative data, by extracting concepts, comparing, contrasting and importantly translating. In order to view knowledge as meaning making then the stance of subjectivism, or interpretivist is required (Saini, 2012). Therefore, the studies were initially read. Then re-read more critically. In this case an interpretative stance was applied prior to reading. During the critical reading concepts where identified. At this stage these were broad ideas or themes that were apparent in each paper.

In this case a meta-ethnographical, line of argument, approach to synthesis was applied, adopting an interpretivist perspective to the data synthesis in order to form new meanings.

A framework analysis was employed to the meta-ethnography (Gale et al., 2013), chiefly to provide a robust structure, which could balance both comparative and contrasting data, with new interpretations. The framework provided a reproducible extraction method that enabled a new structure for the data so that the data could be reduced to effectively to answer the research question. Through this analysis it is envisaged that not only a greater understanding of patient's perspective of SMS in COPD be achieved, but that this will be reconstructed into new concepts. These should open avenues for further hypotheses and investigation. This method can be described as a stepped process, in which the framework analysis is a guide. 1) *Synthesis preparation*, 2) *Synthesis*: making theories comparable by breaking down the aspects into core components, and noting elements and convergence of divergence, 3) *Synthesis refinement* (Pound and Campbell, 2015). Synthesis refinement is the key to evolving the theory into further theoretical insights or deeper meaning. Furthermore, this can offer a novel interpretation, or third order interpretation (Britten et al, 2002a). It is therefore through the third order interpretation that the understanding of SMS enactment can be understood. Third order interpretations are the output of the synthesis. These are new concepts of theories that are directly derived from the collation and interpretation of second order constructs.

In order to demonstrate this process a table and grid layout where used to collate and analysis the data. In this way creating a visual method to break down to concepts or theories from the papers and then synthesis the theories across the papers (Britten et al, 2002). The first three rows of the grid **(Appendix B)** contextualise the synthesis, by comparing the study setting and the study design. The following four grid rows represent the concepts shared across the 5 papers. The penultimate row summarises the second order interpretations, which were developed by the original authors. The final row then begins to reinterpret these concepts into third order themes. The extraction grid is a working document but sharing this with the research enables the reader to visualise the studies being translating into each other.

Once the studies were translated into each other, the translation of the data required synthesis. Describing this process is challenging, so the synthesis was captured in a grid format. Again, this was a working document and re-visited and re-worked as the studies were re-read. The synthesis across the papers grid is also included to explicitly demonstrate the synthesis process (Pound and Campbell, 2015). Furthermore, this process demonstrates that the studies were not refutable, even if one study did not directly translate, it either did not include the concept, or was delivering a reciprocal argument, **(Table 6)** illustrates the line of argument synthesis.

5.6 Findings

Each author, there were 5 in total, Slevin et al, 2019, Sheridan et al, 2011, Apps et al, 2014, Fotokian et al, 2017 and Franklin et al, 2018 (Slevin et al., 2019, Sheridan et al., 2011, Apps et al., 2014, Fotokian et al., 2017, Franklin et al., 2018), reported the enactment of SMS through differing approaches, including; digital health technology (DHT) for symptom capture, experiences of enacting SMS for people from diverse cultural backgrounds, personal perceptions of COPD and managing symptoms of dyspnoea, problem solving with older people with COPD and understand how people maintain a normal life with disease. The data is presented in framework analysis tables, or extraction grids **(Appendix B)** and concept maps **(Table 6)** and described below.

Slevin's 2019 work was to understand person with COPD's perceptions of the benefits of DHT and how they believed it could support them with their own COPD management. The study focussed on the person with COPD perceptions of disease management and treatment using DHT. Slevin used a convenience sample of 30 people who regularly attended COPD clinic, notably these people all had no other life limiting conditions. Data was collected using in depth questionnaires and semi-structured interviews, with open ended questions.

Slevin found that respondents believed that DHT monitoring would support their decision making around when and how to access healthcare resources and that DHT enabled people to foster a sense of self efficacy, in turn increasing their confidence to manage tasks associated with their disease.

''…….I know that (DHT monitoring) have eased the worry I had about every little change I was feeling. I'm sure plenty do panic at the slightest sign of being breathless.'' (Patient 132: cited in Slevin et al,2019.)

People also reported feeling more empowered to collaborate in consultations around their own care, using the DHT as a prompt.

Sheridan's study reported the experiences of people with COPD in diverse populations in Australia. The study was pragmatically sampled to include people who had had 2 or more admissions due to COPD in the last 12 months and then grouped by ethnicity. In depth exploratory interviews were conducted in the home, using an interview topic guide in the native or preferred language of the person with COPD. In terms of experiences of illness; people reported struggling to live with debilitating symptoms of breathlessness and fatigue. This was further complicated through diagnostic uncertainty and an uncertain disease trajectory. People felt helpless and reported just 'letting go' and going with symptoms, rather than trying to manage or take control of them.

''Well it's just something I've got to put up with''

(European Women, cited in Sheridan et al, 2011)

Self-blame was reported in the people of European origin coupled with guilt and shame of having COPD. People of Pacific Island origin reported contrasting views in terms of helplessness.

''I look after my health very well and I pray to God to give life and strength.''

(Samoan women, cited in Sheridan et al, 2011)

Their faith in God, the church and family were the most valued activities and enabled them to retain a place in society and a sense of self-worth.

Apps 2014 (Apps et al., 2014), investigated people with COPD's experiences of dyspnoea, perceptions of COPD and their understanding self-management strategies. Apps used semi-structured interviews and interviewed an opportunistic sample of 15 people, who were already involved in another self-management study. Apps reported conflicts in self-management enactment, in terms of using adaptive measures to cope with symptoms, rather than SMS taught by healthcare professionals. People with COPD struggling to adapt, not just to the disease but to new symptoms. Furthermore, diagnostic uncertainty and the uncertainty of disease progression exacerbated these conflicts.

''*Because I don't look as though I am ill, the upsetting thing is that people don't believe you, they think you're putting it on, sometimes even friends and family.''* (P01 cited in Apps 2014).

People with COPD found issues with the redistribution of everyday tasks, as these supported coping with the illness, but in turn reduced their social role and household positioning.

Fotokian and Shahbouloghi 2017 (Fotokian et al., 2017), aimed to understand how people act and respond to problems they encounter in SMS. They purposely sampled people with COPD over 60 and their families and health care professionals (HCP). The families and HCP were all interviewed and grounded theory was used to interpret the research. Fotokian and Shahbouloghi found that the elders felt they were in 'battle with the disease'. They were constantly striving to keep abreast of life, they preferred to do this through information seeking from their peers and other non-professionals. These were the dominant influences on their SMS strategies. However, in seeking peer information in preference to HCP support the clinically correct information was not the most valued by the elders with COPD.

''My friends say that I should not suddenly quit smoking, or it will be problematic.'' (Participant 2, a 71-year-old man, cited in Fotokian and Shahbouloghi 2017).

They chose the information that supported their personal values and reduced dependencies on others.

Franklin aimed to deepen the understanding of self-management by reviewing the experiences of people with COPD and what they consider to be a 'normal' life. Franklin conducted a qualitative thematic synthesis of 14 studies. Franklin reported that people knew they had a responsibility to self-manage but found it too difficult to put into practice.

''I am the only person that knows my body. The issue is I don't want to take them [medication]…..maybe then I will give myself, Saturday, Sunday, Monday off…….'' (Participant quote cited in Franklin et al, 2018).

People found health care professional's expectations were too high and people with COPD struggled with uncertain diagnosis and disease progression. People with COPD would prefer to be able to balance illness work with their existing habits but find 'making the right choices' hard as it requires discipline. People valued being listened to and their own values being acknowledged.

These five papers described above were then synthesised together to develop a broad set of themes that was applicable to all papers. In order to promote transparency of the synthesis and analytical process; the CONSORT (2010) diagram, framework analysis tables, or extraction grids **(Appendix B)** and concept maps **(Table 6)** have been presented alongside the new interpretation of the data (Gale et al., 2013). The discussion of the findings presents a description of the new concepts through a line of argument drawn from the data. The interpretations have been presented in groups concepts that cluster across the selected papers, with the second order interpretations (SOI) , then the third order interpretations (TOI) or new hypothesis, again that are formed from the papers.

5.6.1 The Second order interpretations and the development of concepts.

Concepts are the broad themes that are translatable across each paper. The main aim of the second order interpretations has been to ensure the ideas and concepts are shared across the studies without altering the structure or the authors meaning of the original concept. In order to identify these themes, the papers were read, then re-read individually and as a group. Extraction grids where used to order the concepts, nature and type of the papers and to ensure they can be interpreted into each other. The extraction grid was maintained as a working document through the analysis and supported the synthesis by displaying the concepts in a logical order. The extraction grid included the sample used for each paper, the nature of the data collection and the overarching purpose of the study. The author and title of the study were listed to enable the data to be grouped logically. The extraction grid was developed over many iterations and shared with the second researcher (AR) throughout the analysis to ensure the iterations and concepts were supported by two researchers.

The concepts developed were contained within each paper and could be successfully translated back into the individual author's narrative **(See Table 6),** but also was broadly applicable across the papers. In total four overarching concepts were identified:

Self-management accountability, responsibility and blame; participation in healthcare interaction where SMS is relevant; interpreting symptoms and diagnostic uncertainty in COPD; and the importance of psychosocial needs of people with COPD in SMS. These concepts are described below.

Table 6. Qualitative meta-synthesis - Synthesis across the papers

Synthesis across the papers, including concepts, second order interpretations and third order interpretations		
Overarching Concepts	Second Order Interpretations	Third Order interpretations (TOI)
SMS Accountability, responsibility and blame. In people with COPD attribute blame to themselves (Self-blame) as the condition is usually smoking related. People understand they have responsibility and try to enact SMS but the failure to enact SMS successfully can lead to repetitive failures due to increasing self-blame. People felt that the expectations of them to manage alone were too high and support was not appropriately tailored to their individual needs.	In terms of SMS - Who fails when SMS fails? Does the HCP fail or does the people with COPD shoulder the responsibility and blame for this? How do we define failure? Potential for layers of failure. Intercultural differences in European population's stigmatisation of the disease increases guilt and shame. Reassurance and independence with DHT as an SMS support. Invisibility of disability in COPD, requiring negotiations and transfer of family and social 'work'.	**Fear or avoidance** of the **inevitability of dependency;** therefore, necessitating wider care networks, friends and family
Participating in health care interactions where SMS is relevant. People with COPD were more willing to engage in consultations when they viewed the HCP was also investing time. Quick or rushed interactions were viewed as a disinvestment. Being personally valued as an individual was preferable. (Franklin et al, 2018 quote). DHT can further maximise shared decision making in consultations.	Through DHT for SMS – levels of power are more even and evidence of symptoms can be opening discussed. Existing care models favour HCP or institutional control in consultations. **Relational capacity** (J Bridges), influenced by time, value and shared evidence of symptoms. Patients value trusting clinical relationships and engagement will grow if the relationships are valued.	**Macro (politico economic**) level of care institutions driving clinical outcomes; therefore, there is often less room for tailored SMS for individual patients.
Interpreting symptoms and diagnostic uncertainty in COPD. The constant struggle with breathlessness is a defining issue of COPD. The **validation of the fluctuation** and worsening of symptoms through HCP discussion or DHT encourages positive help seeking and successful feedback from self-initiated SMS.	Struggling with breathlessness, adaption to activity reduction, pacing and change behaviours. Influenced by personal success. Preparing to do battle with disease and anticipating unpleasant symptoms. **Peer information seeking** is often sought and valued; however, this may not always be clinically correct. **Knowing** – a knowing that is derived from experiential constructs that can positively and negatively influence care participation and initiation of self-care.	SMS **personal successes and adaptive self-care behaviours** can positively inform SMS choices. Negative **experiences** of SMS can reduce self-efficacy; **experiential failures** – affecting feeling powerlessness. Increasing dependency.
Psychosocial needs people with COPD. People with COPD preferred to discuss their disease in terms of psychosocial issues, and personal narratives. People with COPD place importance on increasing HCP confidence in initiating personal and difficult psycho-social conversations.	Faith, church and family links can support emotional needs. Close family and positive social structures can support the redistribution of work. However, people with COPD value social support but seek to reduce dependencies when they can.	

Self-management accountability, responsibility and blame

COPD is a debilitating life-limiting condition, which is causality linked to tobacco use and occupational activity involving dust inhalation. The progression of COPD and mobility limitations causes by increasing breathlessness creates the need to redistribute everyday work, heavy work and family responsibility (Apps et al., 2014). However, people reported a wish to balance illness work with existing habits, people reported understanding they needed to make the 'right' choices in terms of lifestyle and self-care. However, the inability to be have the discipline to do this created an underlying feeling of self-blame and guilt (Franklin et al, 2018).

'I know I have to take the responsibility; it's harmful to me if I don't. This is what the nurse said.' (P19 cited in Franklin et al, 2018).

This attribution of self- blame is reiterated in terms of guilt and shame, particularly in European cultures as the condition is usually smoking related (Sheridan et al., 2011). Europeans' self-blame was uncommon in Pacific Island participants. These people were more fatalistic, valuing the church and family. This attitude enabled them to 'go with the symptoms' and accept support from the people around them. However, dependency on others in these cultures does not hold the same stigma or dependency and blame in European culture (Sheridan et al., 2011).

Self-care behaviours are often self-initiated as people understand they have responsibility and try to enact SMS. These enactments are based on personal and peer experiences; experiential constructs fostered by a sense of knowing (Fotokian et al., 2017). The knowing, is built on a personal disease skill set, learnt through experience (personal and peer experience) and induction.

'When I spoke with my friends and relatives and told them that I had this problem, they taught me a lot and have increased my knowledge.'' (Participant 1 cited in Fotokian, 2017).

Self-management therefore is developed through an independent initiation of self-care behaviours through experience with no formal support (Apps et al., 2014). Often this was not considered SMS, more sets of personal behaviours that enabled people to successfully redesign and manage their day to day tasks. However, it is acknowledged that this method often lacked health professional input. Knowing – a knowing that is derived from experiential constructs that can positively and negatively influence care participation and initiation of self-care.

However, the failure to enact SMS successfully can lead to repetitive failures and in turn increase self-blame. People felt that the expectations of them to manage alone were too high and support was not appropriately tailored to their individual needs, causing personal conflicts in adaptive versus taught SMS (Apps et al., 2014). The balance of accountability can be fostered through increasing self-efficacy. DHT has the potential to meet in the experiential SMS and health professional directed SMS space. DHT can offer disease specific information and advice around specific symptoms, reassuring people and influencing their enactment of SMS (Slevin et al., 2019).

Participation in health care interaction where SMS is relevant

In terms of participating in their own care people with COPD were more willing to engage in consultations when they viewed the HCP was also investing time and with a trusted HCP (Sheridan et al, 2011) (Fotokian et al., 2017). Quick or rushed interactions were viewed as a disinvestment and therefore people were less willing to invest in their own care needs. In order to motivate participation in care, people cited that being personally valued as an individual was preferable and enhanced participation, and indeed the ethos of a shared care agenda (Franklin et al, 2018).

''The GP would tell me straightaway ''This is not on, my friend'' I like this GP a lot as I have the opinion that I can talk opening to him about my problems….that would not happen if I did not trust the doctor.'' (P100 cited in Franklin et al, 2018)

However people with COPD continued to report having no recollection of SMS strategies and little understanding of symptom recognition, even when this had been addressed from the perspective of the HCP (Sheridan et al, 2011). Care participation was viewed as challenging across all papers, requiring trusted relationships with HCP, in order to successfully incorporate care participation into disease management. Patients value trusting clinical relationships and engagement will grow if the relationships are valued.

In contrast DHT was reported to have the potential, in the view of participants, to optimise consultation experiences. It was considered by participants to be empowering in facilitating conversations and validating the reporting of complex symptoms. This was due to the ability to have a clear record of symptoms that could be shared, real time, with the health professional, and therefore was not just a verbal report of retrospective symptoms, which participants often found difficult to recall.

DHT can further maximise shared decision making in consultations. The potential of DHT for SMS is within the levelling of the balance of power in consultations and providing clear documentary evidence of symptoms, enabling open discussion (Slevin et al., 2019).

Currently existing care models favour HCP or institutional control in consultations, so consultations are rarely patient led. DHT could promote a shift in institutional control in favour of the person living with the long-term condition, and potentially maximise the consultation experience in favour of a personal agenda, leading to true participation in care.

Wider experiences of families and communities' further shapes experiences and expectations of health care. Preconceived ideas and values can reflect in the interactions. Cognitive impairment, communication difficulties, perceived power imbalances between care provider and patients care impact both on the pre expectations of an encounter, and in turn the level of participation (Bridges et al, 2019).

Interpreting symptoms and diagnostic uncertainty in COPD

The constant struggle with breathlessness is a defining issue of COPD. Struggling with breathlessness, fatigue requires adaption to activity reduction, pacing and change behaviours (Apps et al., 2014). In order to be successful at managing COPD a person must adapt their life to incorporate the complex symptoms of breathlessness, fatigue and mucus hypersecretion alongside knowing how to manage exacerbations and exercise regimes. This can be supported through the validation of the fluctuation and worsening of symptoms through HCP discussion or DHT.

''Imagine after my diagnosis I'd be given a device to help me see the differences in a good day of breathing against a bad day of breathing? I know that would have eased the worry I had about every little change I was feeling. I'm sure plenty do panic at the slightest sign of being breathless.'' (Patient 132, cited in Slevin et al, 2019).

These can encourage positive help seeking and successful feedback from self-initiated SMS. However there are conflicts in the adaptive SMS self-tailored interventions and those taught by HCP (Apps et al, 2014). Peer information seeking is often sought and valued in order to stay abreast of symptoms, however, this may not always be clinically correct (Fotokian et al, 2017).

Furthermore people with COPD reported recognising their responsibility to look after themselves, but found the SMS intervention too difficult to put into practice and the expectation of the clinicians was too high (Franklin et al, 2018). The challenges with symptom interpretation were further complicated through continued diagnostic uncertainty and uncertainty of disease progression (Franklin et al., 2018, Sheridan et al., 2011, Apps et al., 2014).

The importance of psychosocial needs of people with COPD in SMS

People with COPD preferred to discuss their disease in terms of psychosocial issues, and personal narratives. People with COPD place importance on increasing HCP confidence in initiating personal and difficult psycho-social conversations (Franklin et al, 2018) (Fotokian et al., 2017). Close family and positive social structures can support the redistribution of personal and social work. This is viewed externally as a positive mechanism to support the person with the condition. However the reassignment of emotional and family tasks can lead to social displacement, reducing the social role, and that person’s position in the family or wider society, (i.e. employment loss) (Apps et al., 2014). The church and a faith we viewed as having a positive role in the lives of pacific island groups COPD sufferers: these were reported to support emotional needs and family needs, and were hugely valued (Sheridan et al., 2011). This was contradicted in the Western communities, but all papers noted that people with COPD value social support but seek to reduce dependencies when they can.

5.7 Third order interpretations

Third order interpretations are the results of the reinterpretation and translation of all the previously described second order interpretations. The second order interpretations were derived directly from the synthesis of each of the selected papers being synthesised into one another, using line of argument synthesis. This section can also be termed as *synthesis refinement* (Pound and Campbell, 2015), and is concerned with understanding causal processes and development of new theory from the existing theories. The second order synthesis developed four concepts that arise from the combination of the 5 papers. These are:

Interpreting symptoms and diagnostic uncertainty in COPD

Self-management accountability, responsibility and self-blame

Participating in health care interactions where SMS is relevant

Psycho-social needs as a priority in self-management interactions

These concepts suggest that enactment and engagement in COPD SMS support is influenced through a mixture of positive health care interactions and interventions and yet enactment is challenged through self-blame and uncertainly of the disease and diagnosis. People who were confident in their knowledge and interpretations of their disease felt more able to engage with SMS activity, that those who had not yet understand the trajectory or the fluctuating nature of the symptoms.

Experiential knowledge has formed from working through episodes of illness. Illness experience is formed through personal exposure, having the disease and experiencing the symptoms, and being part of the experiences in others both close experiences, but also those of their peers (Apps et al., 2014, Slevin et al., 2019, Sheridan et al., 2011, Fotokian et al., 2017).

Valued practices are concerned with the practices that people value in their lives, their rituals and activities. In this analysis, these also extend to health care professionals and society, and the value of people in society beyond illness (Franklin et al., 2018) (Fotokian et al., 2017).

People with COPD juggle the looming inevitability of dependence, whilst managing the disease and working to retain independence. By seeking, gaining and using experiential knowledge in disease management people can maintain the balance between dependence and independence.

In these experiences with disease, day to day management (i.e. did giving up smoking help) or in acute fluctuations of disease (i.e. I used my inhaled therapy early then usual and I didn’t get as unwell) enable a process of self-appraisal of disease phenomena. This appraisal draws from narratives or experiences of what has personally worked well in the past. Importantly ‘’working well’’ is what has enabled independence, not necessarily what is deemed to be clinically correct disease management. Therefore, if one’s experience of smoking cessation is that they have increased disease progression and increased hospitalisation, then this experiential knowledge informs people that smoking cessation will decrease their independence and in turn reduce access to valued activities. Therefore, people with COPD may dismiss smoking cessation as a viable SMS option, due to their experiential knowledge, not health professional advice.

These interpretative accounts lead to a broader overarching concept that influences both positive and negative engagement along a continuum. The fear, or avoidance of the inevitability of dependency.

This continuum can explain SMS enactment through the driver of dependency on others. Furthermore, SMS personal successes and adaptive self-care behaviours can positively inform SMS choices and conversely negative experiences of SMS can reduce self-efficacy; experiential failures – affecting feeling powerlessness. Increasing dependency. The conceptual model below displays the independence experience continuum. Each person with COPD is either a novice to SMS, or has experience, based and personal knowing and experience of the disease. People move both between novice and experience and their own SMS enactment, whilst simultaneously striving to remain as independent as they can for a long as they can. Figure 3, QMS conceptual model of SMS engagement in COPD, is displayed below. In chapter 9, the discussion, this model is further developed, drawing from the empirical findings.

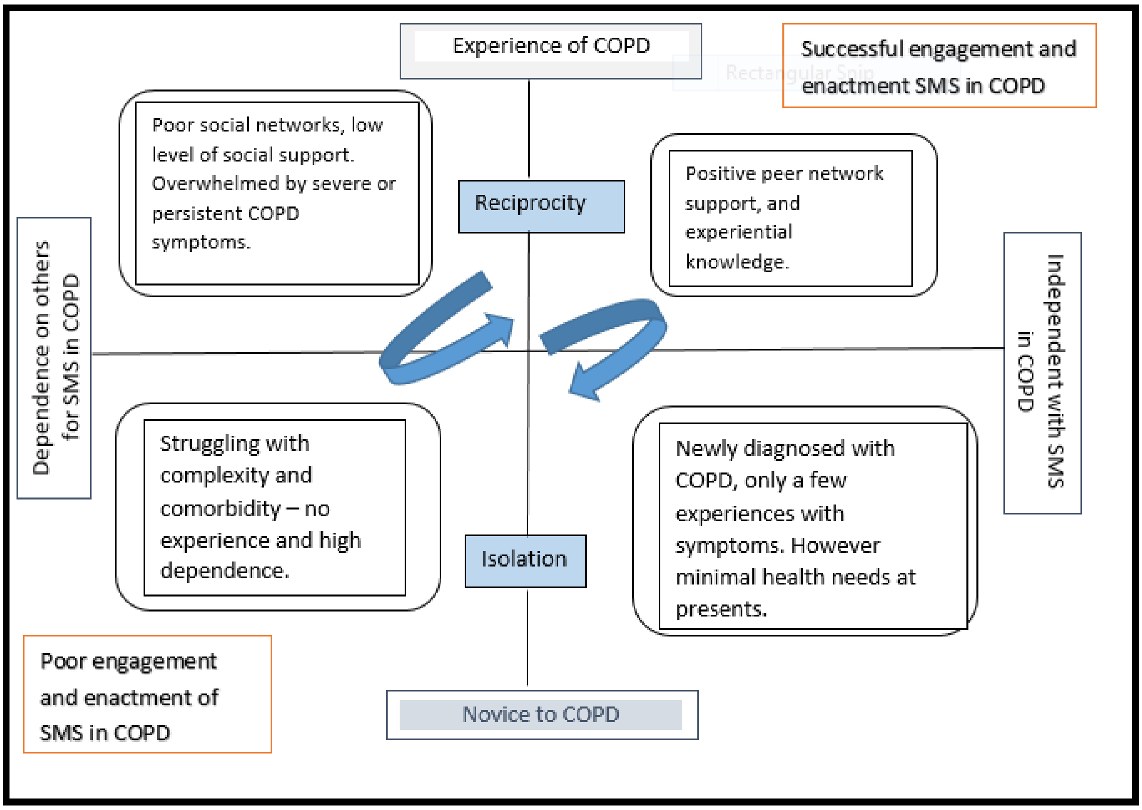


Figure 3. A conceptual model of self-management enactment and engagement in COPD.

The continuum can be influenced positively through peer support structures and positive social networks, negatively when alone and a novice in COPD SM. Furthermore, poor experiences and layers of failure and complexity can lead to dependency and fear of engagement and enactment in SMS activity.

Macro (politico economic) level of care institutions driving clinical outcomes. A further third order interpretation relates to the wider socio-political direction of care. In order to maximise care efficiency and deliver on commissioned service outcomes; the personalised care agenda is lost. Time, or temporal capacity, is perceived as reduced in health care interaction with people with COPD, across health care settings. The perception reduces meaningful interaction, opening questioning and tailored personal support. Communities and families can also shape expectation of health care interactions (Bridges et al, 2019). As disease progresses and self-care needs change in COPD the requirement to check in to re-align SMS support or re-negotiating social network structures can be lost due to the broader construction of the health care system.

5.8 Discussion

Main findings

This meta-synthesis was based on the re-interpretation of synthesised findings for qualitative papers identified through literature searching. The literature search specifically aimed to identify papers that sought to understand how and why people with COPD engage in SMS and the personal challenges they face in incorporating SMS skills into their lives.

This literature review and synthesis expands on the scoping literature review in chapter 3. The sequence of the meta-synthesis allows the findings here to be combined with the findings from the empirical investigation as part of the discussion. In this way supporting the interpretations of the findings and developing a clear avenue for further research. The objective of this qualitative meta-synthesis was to appreciate SMS from a lived experience perspective and identify targets for future SMS intervention. The findings from the synthesis allude that SMS in COPD is a more complicated social phenomenon that initially conceptualised. People with COPD are required to understand and negotiate complex health situations across a range of social platforms. These include day to day social work based negotiations (Vassilev et al, 2014), health care interactions (Franklin et al., 2018), social negotiations concerned with symptom interpretation (Apps et al., 2014) and the experiences and negotiations they have with wider society, including acceptance of the disease and its limitations, by themselves and others (Sheridan et al., 2011). Therefore, engaging with COPD SMS requires multiple skills of negotiation organisation and social stability, to achieve successful SMS.

COPD has a complex and uncertain pathology and trajectory meaning that the pursuit for clinical and social stability is challenging. The longer people live with COPD, the more opportunity there is to enhance skills and knowledge for SMS, but these enhanced skills are often against a backdrop of failing health, and the constant strive for independence. The study broadens the enactment of COPD SMS, beyond taught HCP interactions into a more complex personal interplay with personal and peer acquired knowledge and fear of dependence.

Through developing an understanding of personally valued practices, or activities and developing personally tailored health care encounters one can improve engagement with SMS in people with COPD. However, primary care practitioners often prioritise education, and giving information to people with COPD, over more psycho-social approaches to care (Ogunbayo et al, 2017). Therefore, this becomes a barrier to engagement as time invested in consultations and personal support is more valued by the person with COPD.

Living with a long-term condition is a tiring journey, which is often travelled alone, with only minimal interactions and advice from HCP, which may even be contradictory. Knowing that a technique, intervention of medicine works based on one’s own experience or that of their peers provides confidence in enacting a new treatment or intervention.

Enhancing or broadening social and peer network support to support decision making and promoting independence with complex disease symptoms, could show promise in people with COPD.

Interpretation of the findings in relation to previous work

These findings are supported by the work of (Ambrosio et al, 2015) and her conceptual model of the process of living with chronic illness. The model suggests that successful SMS enactment can only occur once acceptance and coping with the long-term condition have been personally addressed. In terms of further enactment integration of new rituals and living patterns must then be applied prior to final adjustment and being able to live positively with a long-term illness. The model supports the findings of this meta-synthesis and can over lay the specific COPD issues of dependency and fear, which are heighted in COPD due to persistent and fluctuating breathlessness and fatigue.

Engaging in self-management activities is positively correlated with the length of time living with the condition. This review further considered a sub-theme of a ‘trial and error’ approach to adaptive behaviours. This supports the third order interpretation of experiential learning to develop a personal sense of knowing. The sense of knowing is developed over time and with disease experience (Fotokian et al., 2017). The knowing developed from the experiential constructs can however both positively and negatively influence participation in SMS. The knowing relies on peer information, and a wish to reduce dependence (Fotokian et al., 2017, Franklin et al., 2018).

A narrative synthesis of lay and health professional understandings of SMS found that in terms of personal support with COPD, and the time spend with the clinician, can be interpreted by lay-people as positive input into SMS activities (Sadler et al, 2014b). This supports the findings of health professionals taking the time to listen and understand personal narratives and valued practices. Furthermore, the SMS enactment is tailored to individual lived experiences, and the wider value of that person for society, and the value of their social role (Sadler et al, 2014, Fotokian et al., 2017, Franklin et al, 2018).

The personal value of social roles, and one's position in society, is related to peer acceptance. Sharing ideas and information within peer networks is part of developing a social role, and as position in a social group. The exchanges and use of peer knowledge are to maintain independence, in relation to similar others. This independence operates along a dependence and independence continuum and enables us to further our understanding of how people with COPD engage with SMS. Engagement of SMS is driven through peer relationships, support and education. People with COPD use SMS to maintain their dependence. Therefore, this can be via peer reciprocity, or maintaining personal symptom control. However, independence through symptom control can often only be achieved with lived disease experience and understanding of symptom fluctuation.

Implications for future research policy and practice

This third order themes are supported in the qualitative literature in COPD SMS, however further work could test the conceptual model in a clinical setting. Obtaining the views of expert patient with COPD and clinical experts. In this way developing a framework to improve the clinical understanding of the processes people with COPD adopt in order to engage and enact self-management activity to maintain their own health and wellbeing.

In terms of health care professionals and the delivery of SMS in clinical practice; attention should be paid to the valued activities and developing a personal and trusted relationship, wherever possible. Clinicians should further consider integrating peer support groups and services into existing tertiary health care systems to build a purposefully selected peer infrastructure to enable supportive, and positive peer engagement. As peer influences on health care decision making are clearly the dominant driver is successful SMS enactment.

5.8.1 Strengths and limitations

This meta-synthesis has its strengths in the methodology and duplications of analysis by second researcher. This triangulation of theory supports the data extraction and formulation of new theory. The methods are drawn from several sources (Noblit and Hare, 1988, Britten et al, 2002, Pound and Campbell, 2015), and compared against other similar meta-synthesis (Allen et al, 2016) to ensure robust methodology. However, a synthesis is limited by the inclusion of the SMS papers, although this was a robust search and selection criteria, it is limited by not including other similar synthesis into SMS in COPD. A larger synthesis would have taken longer to synthesis and therefore would be less contemporary when published.

5.9 Conclusion

This research provides insights into how and why people engage, or indeed struggle to engage with the principles and practices of self-management. Furthermore, if engaged, how people enact, or weave SMS activities into their daily lives. People with COPD wish for an understanding of their personally valued activities and a more psycho-social approach to SMS engagement. Enactment of SMS in COPD is influenced by a fear of dependence and a knowing, based on peer inferences, and peer connections. Therefore, SMS in COPD requires readdressing to embrace peer support as a fundamental part of the COPD care pathway.

Chapter 6 Methods

Summary – This chapter steps away from theory to the design of the empirical investigation. The GENIE intervention fulfils the gap identified in the literature to introduce and evaluate a SMS intervention to people with COPD that is aimed at supported the psycho-social needs of this population. The methods describe the methodological development of both the pilot study and the nested feasibility sub-study in nutrition and behaviour change.

6.1 Exploration and adaptation of Genie in COPD

The methods section here relates to the design and delivery of the primary empirical study. It aimed to test a social self-management tool in the COPD population in community care, in order to understand its acceptability, workability and potential cost effectiveness. Furthermore, in a sub-study the aim was to explore the validity of nutritional outcome measures for assessing a social tool. Secondly to understand the feasibility of a social intervention to support self-management.

The empirical work therefore aims to address 3 research questions;

''Would a social network approach be a feasible and workable option to deliver SMS support in COPD?

Would this work within existing NHS services?

How does a social network approach to SMS support benefit people with COPD, in terms of behaviour change, health status, quality of life? ''

In order to do this the study was designed to deliver three main objectives;

- To use social network mapping techniques and preference elicitation to engage COPD patients in reflecting on their support preferences and needs, help them access further resources and knowledge.
- To evaluate the utility of the social network intervention, GENIE, in the COPD patient population in primary care.
- To understand the potential cost benefit to both to patients (individual cost) and to the health service (NHS costs) with a view to up-scaling.

6.2 Study design

The study objectives were designed to use evaluation methods to effectively evaluate the GENIE tool in clinical practice within the existing COPD service. The scoping review in chapter 2 highlighted areas to target specific outcomes measures for any novel intervention in SMS, these included; evaluation of the economic benefits of an intervention, understanding how to tailor any intervention to be used in different populations, and effectively measuring emotional health and quality of life in COPD SMS support (Simpson and Jones, 2013, Effing et al., 2014, Effing et al., 2016). The outcomes and methods were primarily quantitative to ensure a reliable comparative set of measures, using validated instruments, pre and post intervention. Qualitative outcomes were considered here; however, the qualitative design element was not approved by the NHS ethics committee, this is discussed on pages, 80, 81 and 82.

Therefore, the outcome measures were designed to evaluate the economic benefits, clinical benefits in the COPD populations and ensuring the inclusion of wellbeing and quality of life measures. The clinical outcomes measures were selected as these are clinically used to routinely evaluate COPD care and symptom burden. These included the COPD assessment tool (CAT) Generalised Anxiety Score (GAD-7) (Hardy et al., 2014) and the community depression score (PHQ-9). Decisions regarding the methodology; quantitative, qualitative or a mixed method, were considered at length. Previous GENIE studies have included mixed methods, with substantive qualitative outcomes (Walker et al, 2018, Kennedy et al., 2016). The main outcomes measure was to be quantitative to capture clinical outcomes, symptom burden and cost effectiveness. The pilot study aimed to capture a qualitative component; this would have been through semi-structured interviews with study participants. The aim was then to thematically analyse (Braun and Clarke, 2006) the narratives to understand the uptake and value of social activities. Unfortunately, the qualitative arm of the study did not receive ethical approval, this is discussed in section 6.6 and the issues and implications of this ethical decision are in the discussion, chapter 9. The clinical feasibility of the study will also be evaluated through a feasibility trial, using field notes or diary method to understand the feasibility of introducing a socially supportive self-management intervention in the COPD population.

6.2.1 Primary objectives and outcome measure

The primary outcomes are to compare and evaluate the health care utilisation, quality of life and symptom burden in COPD patients using GENIE alongside usual care after leaving the COPD service with those offered only a current practice discharge plan.

In order to measure the areas of enquiry; clinical effectiveness, cost effectiveness and behavioural change, validated instruments were selected to inform each area. Baseline data was designed to include education and job status, as well as age, sex and COPD severity. The clinical outcomes included standard COPD validated questionnaires, already familiar to patients, as they were used routinely in practice. Disease impact in patient with COPD was evaluated by COPD Assessment Tool (CAT, GSK) along with screening tools for anxiety (GAD-7) and depression (PHQ-9) (Spitzer et al, 2006) (Schomerus et al., 2009).

The economic evaluation tool is a measure of resource use; a healthcare utilisation questionnaire adapted from Client Service Receipt Inventory (CSRI) (Beecham et al, 1999a) (Beecham et al, 1999b) (Mayer et al, 2017) this questionnaire enabled the investigation of the GENIE tool’s abilities to redirect healthcare use away from formal health care to voluntary sector resources. It further enabled the evaluation of relevant costs incurred by patients within the healthcare sector under NHS and patient’s perspective (out-of-pocket expenses).

The validated EuroQoL instrument EQ5D was administered to describe people’s quality of life (QoL) in terms of mobility, self-care, usual activities, pain/discomfort and anxiety/depression (Nolan et al, 2016). Along with QoL we collected also health status information with Visual Analogue Scale (VAS) (Klimek et al, 2017).

6.2.2 Secondary objectives

The study aimed to compare and evaluate the change in health behaviours, diet and lifestyle in COPD patients using GENIE alongside usual care after leaving the COPD service.

Furthermore, the study aimed to observe and understand the uptake and utilisation of the GENIE recommendations by COPD patients. The secondary objectives will be delivered in the form of a nested feasibility study, within the overarching pilot study.

Secondary outcomes measures in this study were change in current alcohol consumption status, change in current smoking status, change in BMI, change in appetite score, change in physical function score, and change in total physical activity. Change was expressed per month, from baseline to follow-up; change in status for alcohol consumption and smoking was expressed over the entire follow-up period.

In terms of behaviour change, diet quality and nutritional status were the primary outcomes measures. Diet was assessed using a short food frequency questionnaire (FFQ), which has been validated to assess diet quality in older adults (Robinson et al, 2017). A 'prudent' diet score can be calculated from a small number of discriminating foods. In this pilot study, prudent diet scores were calculated for each participant based on their consumption of 19 indicator foods, indicating the participant's compliance with the prudent pattern, and was used as an indicator of diet quality (Robinson et al, 2017). High prudent diet scores indicate diets characterised by frequent consumption of fruit, vegetables, wholegrain cereals and oily fish but low consumption of white bread, added sugar, full-fat dairy products, chips and processed meat (Robinson et al, 2017). Prudent diet scores were calculated to describe diet quality at baseline and follow-up. Change in prudent diet scores (representing change in diet quality) were expressed per month, from baseline to follow-up.

Alcohol consumption status was assessed by asking whether the participant currently consumed alcohol. Smoking status was assessed by asking whether the participant currently smoked.

Height (cm) and weight (kg) were obtained from participants' most recent clinical records (where this was not possible, participants were weighed by researchers), and BMI (kg/m^2) was calculated for each participant.

Appetite was assessed using the Simplified Nutritional Appetite Questionnaire (SNAQ), which is validated to predict weight loss in community-dwelling older people (Wilson et al, 2005). The SNAQ is a 4-item questionnaire that includes questions about appetite and issues around food intake. Results were presented as a total SNAQ score (continuous) and categorised into two categories, with a total SNAQ score <14 indicating low appetite.

Data were collected on physical function using self-reported assessment of physical function (SF-36 physical functioning (PF) domain – SF-36 PF), which involved asking participants questions about ten activities that they might typically perform, specifically how much their health limits them in carrying out these activities (Syddall HE, 2009). This was presented as a continuous physical function score (SF-36) and participants' scores were also categorised to reflect whether they had 'poor physical function' (if their physical function score was in the sex-specific bottom fifth of the distribution).

Physical activity was assessed using a series of questions that were derived from the International Physical Activity Questionnaire (IPAQ) Short Form. The IPAQ short form has been validated for use in 15-69 year olds (IPAQ, 2005). The IPAQ short form includes questions about the time spent walking, in vigorous- and moderate-intensity activity and in sedentary activity. Physical activity scores were categorised into three categories (low activity, moderate activity or high activity) based on the protocol for the IPAQ Short Form (IPAQ, 2005).

6.2.3 Implementation Design

The researcher (LW) and research colleagues delivered the GENIE intervention with the patients participating in the study at leaving points, during the patient's journey through the COPD service, as specified in the diagram below.

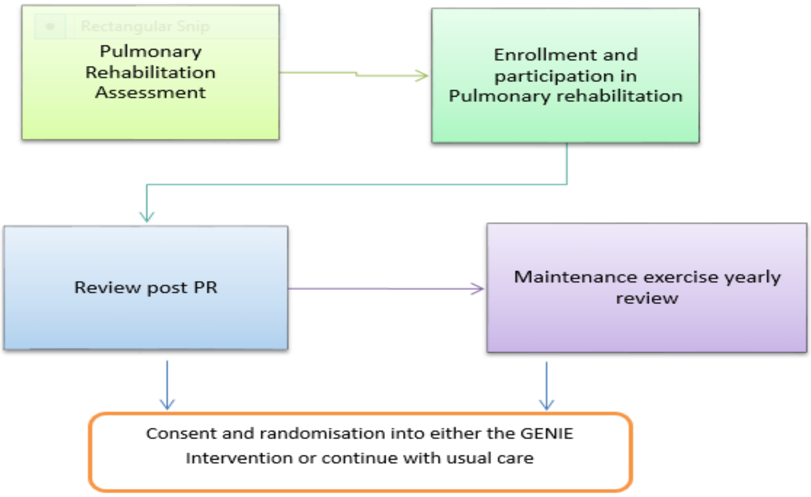


Figure 4. Study enrolment

Patients enter the pulmonary rehabilitation (PR) section of the COPD service post-acute episode or by GP referral. Patients are then clinically assessed for suitability to continue in the exercise component of the service. If patients are deemed suitable for exercise, then they continue onto PR. Post PR patients are reviewed by a clinician to ascertain their progress through the programme and to recommend appropriate continuation of exercise. At this point patients can also leave the programme.

6.2.4 Building capacity to carry out the evaluation

Ensuring the GENIE database contains an appropriate library of social and health activities suitable for the Southampton COPD patient. The lead researcher (LW) restructured the GENIE database to ensure it included a broad spectrum of activity in the east of Southampton. This included linking with local community solutions group, ''Itchen to Bridge the gap'', who provided many community activities suitable for COPD patients or those people isolated with long term conditions. The local BLF sponsored patient support groups were also invited to input their details into the database. However, this highlighted the need to restructure some of the existing Breath Easy groups, with support from the British Lung Foundation (BLF). The BLF are a charity concerned with the wellbeing and support of those people suffering from long term respiratory illness. The charity supports local groups, led by those with respiratory illness, to provide peer support. However, at the time of preparing to deliver this study these groups had become very inclusive and were struggling to attract new members or to organise suitable monthly activities for their members. Working alongside the BLF enabled the restructure of these groups to work as functional peer groups linked to community respiratory services. Therefore, providing assurances that the GENIE database was appropriately signposting people to contemporary and appropriate activity.

6.2.5 Introducing the intervention

In order to successfully implement the GENIE tool into clinical practice the clinical team needed to be at the core of the process in order to ensure appropriate and effective facilitation of the study. Therefore, the clinical team was briefed as the study progressed, through question and answer sessions and direct learning opportunities in how the tool works and the objectives of the study. This part of the study is part of the feasibility outcomes. Diary accounts and observations, kept by researcher (LW) were kept, and triangulated to understand the clinical, operational and patient response to network SMS.

6.3 The Genie Intervention

The overarching concept of GENIE is to 'initiate positive disruption of established self-management practice through mapping and reflection on personal network membership and support', which presents 'possibilities for reconstructing self-management differently from current practice' (Kennedy et al, 2016). Some of the elements that have been identified as key to GENIE's success are the visual maps of networks and support options, the guided help to assist engagement and discussion of support and preferences for activities, and a reliable database (Kennedy et al, 2016). The GENIE intervention is envisaged to be co-produced with the user, in which a facilitator (in the present study, a researcher) guides them through the process.

The process of delivering the GENIE intervention consists of the following stages:

- Filter questions: The participant is prompted to enter background information about their postcode, gender, age, and health condition. This helps the tool to tailor results to the participant.
- Stage 1: Mapping of the participant's current social support network using a concentric circles method, to gain insight into the participant's current situation regarding social networks and social support and then to suggest people and groups who could potentially provide extended support. In this stage, social network members (family, friends, groups, professionals) are represented and mapped onto three concentric circles, depending on their importance to the participant (an example is shown in **Figure 5**). Details of relationship and frequency of contact are recorded.
- Stage 2: Choices are tailored using a series of questions to elicit the participant's values and preferences for activities and support resources, this is based on preference and enjoyment rather than on health-based needs.
- Stage 3: This section links the participant to prioritised and valued activities and resources, from a pre-created database where local organisations/resources have

been listed and categorised. Suggestions for activities include exercise groups, hobby groups, and volunteering and educational opportunities. Network members can be selected as potential buddies to accompany participants to new activities.

- Stage 4: The GENIE tool then presents options to the participant in a user-friendly way with clear details about location and access; locations of activities are shown on a Google-based map (an example of this is shown in **Figure 6**).

Figure 5. An example of a concentric circles diagram, which maps the personal community of support of GENIE tool users.

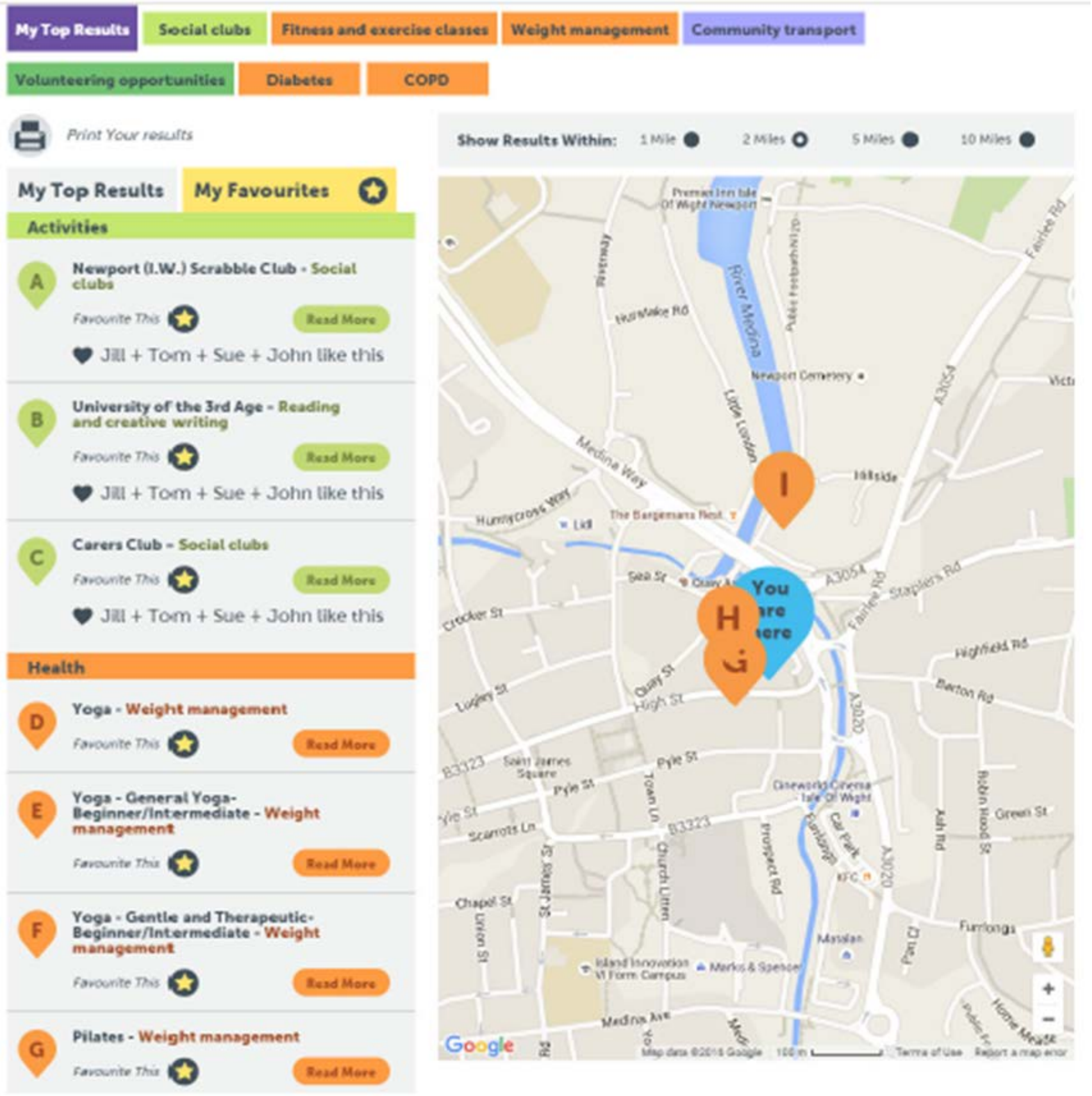


Figure 6. An example of suggestions of local activities and groups that are presented to GENIE users, based on their preferences, with location and further details.

6.4 Selection and patient information

Patients were selected from the COPD service; at the outset of their assessment or the end of their PR programme or during maintenance exercise sessions. These patients were offered the opportunity to volunteer for the study, by the clinical team. If patients were interested, they then volunteered their names to the clinical staff to keep on a secure NHS database. Then the lead researcher (LW) was able to send out and meet patients to explain or talk through patient information sheets and accessible information about the study. Ideally, patients were provided with information in their clinical visits and are returning for clinical visits then appointments for research could be amalgamated with usual clinical visits. In this way extra study visits can be reduced. Patients, now participants, were then invited to consent and be randomised at the point of leaving usual clinical care. Furthermore, everyone was given the option to opt out of the study at any time. At this point the first 30 participants where offered to opt into the nested nutritional feasibility study.

Once participants were randomised, using block randomisation technique, whilst in clinic. Block randomisation technique, is a technique used to reduce bias and achieve balance in the allocation of participants to treatment arms, especially in this case when the sample size is small (Efird, 2011). Therefore, it was an appropriate method of randomisation for 60 participants.

Once randomised, if in the usual care arm, clinical care was maintained, which included discharge planning with suggested activities. If randomised, then participants stayed for another hour to have a facilitated session using the GENIE intervention. The session was facilitated by either the lead researcher (LW) or research support (EJ, CA) who were part of the wider GENIE research group. Baseline questionnaires were also administered at this visit, prior to the intervention.

In order to reduce unconscious bias of the researcher, pre-prepared envelopes containing the possible combinations of group allocation, were stored in a locked drawer in Bitterne Health Centre. The intention is to randomise in blocks of four, as this will complement the clinic structure. Therefore, each envelope contained a pre-determined allocation pattern for that clinic (AABB, ABAB, BABA etc.).

The researcher team (LW, CA, EJ) shared an excel spread sheet to be set to generate a random number sequence. Then the next sequential number was selected, which corresponded to an envelope with the predetermined sequence. In this way the envelope selection was random, and sequence in the envelopes in also random, but ensures 50/50 grouping of participants. Baseline data for descriptive statistics were also collected. (Paper 1). The follow up period was 3 months (12 weeks) (+/- 1 week) from the day the GENIE tool was initially delivered. Participants had their 3-month appointment made, at their baseline visit. The appended protocol suggests an optional 1 year follow up period, to obtain more longitudinal data, however this was not feasible for several reasons; Study funding and recruitment schedules did not allow the time for what would be a 2 year data collection period, patient retention and motivation in this population was limited due to frequent exacerbations and hospitalisation. Furthermore, data recall was poor for health utilisation after 3 months, therefore there was a risk of poor data capture at 1 year, (increased attrition rates and poor recall of health utilisation).

In order to conduct meaningful analysis recruitment needs to reach at least 30 patients, in each group, however the maximum could be 60 in each group, 120 patients in total. Therefore, recruitment could take between 6-9 months. The timeframe can be increased if necessary.

6.4.1 Initial / Baseline data collection

The socio-economic data collected included; disease severity (FEV1), gender, EQ-5D, health care utilisation questionnaire, HEIQ and wellbeing questionnaires (CAT, GAD, PHQ-9), as well as an optional health behaviour questionnaire, from both the usual care group and the interventional group. Please note CAT, GAD, PHQ-9 FEV1 and gender are already captured routinely during clinical consultation. Baseline data was collected for those participants who opted into the nutritional sub-study (reported in detail in chapter 8) this included the short food frequency questionnaire (FFQ), which has been developed to assess diet quality in older adults (Robinson et al., 2018). Food frequency questionnaires (FFQ), participant-reported changes in alcohol consumption, smoking status, body mass index (BMI), appetite, physical function, and total physical activity were used at baseline and 3 months.

6.5 Adaptation of the GENIE tool

Health technology, or telemedicine has been studied in COPD with no definitive conclusion, it certainly does not improve patient quality of life (Gregerson et al, 2016). Therefore, any technology-based intervention will require consideration and other delivery options to ensure patient inclusion and safety. The GENIE tool can be delivered both offline and online and is a facilitated. Therefore, potential participants do not necessarily need to be computer literate or indeed literate to be able to benefit from the intervention. Resource connection can be made both online and offline, presenting both the choice of perhaps online anonymity (Allen et al, 2016) or off line face to face groups and interest clubs. Furthermore, the GENIE tool is accessible as a researcher or clinical team from both the front end (patient facing) and the back-end database. Therefore, GENIE can be ‘filled’ with resources from the local community that are generic (suit the needs of all) and very specific to the needs of a disease group. For example, if you have diabetes and wanted to lose weight and meet people, you could be signposted to resources such as Weight watchers (accessible for all) and face to face or alternatively Sugar buddies (specific to diabetes) and online. This flexibility and ability to map and select resources is valuable in long term disease when symptoms fluctuate and options for travel can be limited.

The GENIE tool was chosen as an intervention because of its flexibility of use and potential for adaptability to COPD. Adaptation were required to the data base to ensure it was set up with appropriate community activities specific to COPD and suitable community activities for an older population, who are less mobile, due to frailty and breathlessness.

A qualitative element of the study was drafted and added to the ethics application, to ensure understanding of the acceptability of the intervention (Zauszniewski et al, 2018). Data was required to gather feedback from the intervention recipients to understand whether the intervention was perceived as appealing, relevant and meaningful. However, the qualitative element was not approved by the ethics committee, despite representation and justification in person. Therefore, more objective quantitative outcomes were developed for the empirical study. A diary and clinical observations were collected to develop a process evaluation; the findings of the process evaluation are described in chapter 8.

6.6 Ethical Considerations, reflexivity and positionality

In order to develop a study design and ethical proposal that meets the needs of the patient population as well as the organisation needs to be considered and any literature tailored appropriately. The study design needs to be adapted to address any literacy issues, psychological or clinical needs of the COPD patients who may volunteer to participate. Moreover, the design needs to collect robust, real world data, reflective of those populations who could benefit the most from a potential social self-management intervention.

6.6.1 Positionality and reflexivity

Considerations of the positionality of oneself as both the researcher required consideration here (Hopkins et al, 2016) (Meyer et al, 2019). Acknowledging that one is both a nurse caring for the people in the study, and the researcher, aiming to obtain the best quality data, can be conflicting perspectives. As a novice researcher the temptation to move into clinical, or nurse 'mode' a challenge, but needs to be avoided or recognised and accounted for the in the study and the data. Positionality is important as a respiratory nurse and as an academic (Hopkins et al, 2016). The influence of my clinical role ensured clinical safety was paramount. Although this contributed positively to the safety of the study, as all the researchers were also clinicians and therefore able to manage any potential risk or challenging clinical issues in this patient group. This could include, non-adherence to ambulatory oxygen therapy or inhalers, or poor clinical presentation with low oxygen saturations. Also, to be able to respond in a clinical emergency.

However, the ethical implications of the clinician, also being the researcher does require a reflective process to ensure a non-biased approach and appropriate study conduct. Therefore a reflex journal approach was developed (Meyer et al, 2019). Reflexive journaling is the opportunity to record and recall field experiences that might otherwise be dismissed or forgotten. The journals can be used to revisit conversations or experiences and contextualise intersubjective aspects of research encounters. The process would involve self-questioning and revisiting decisions with a supervisor and discussing decisions, observations or actions with associated literature. Research (LW) kept a journal in practice and during research field work, noting down key decisions, actions observations and conversations. This was discussed with supervisor (AR) with associated literature. AR also visited and observed research consultations and data collection to ensure parity and triangulation of the notes and discussions. This process occurred for all the data collection visits which were primarily quantitative. In order to reduce any unintentional bias a second researcher, who was not part of the clinical team, conducted the follow up visit at 3 months and to observed research consultations in a range of participants, to further ensure parity in the delivery of the intervention. These observations were then used to form reflective discussion with the researcher.

6.6.2 Ethical issues in study design

The study design also needs to take into account patients' mobility and financial capacity and reduce any inconveniences of having to make multiple journeys to a health centre or community venue, therefore the ability to make home visits within the locality or combine usual care with study visits needed to be an option. An ethical application was submitted to both the University ethics team, and then the NHS ethics team.

During this process it appeared there was disconnect between the perceived requirements of the university and the NHS ethical committees. The NHS team was concerned with patient safety and comfort and accessibility of the literature; but did not fully understand all the needs of the COPD population, or the structure of the community services, which limited the scope of their decision making. This in turn narrow the potential recruitment area and population to the east of Southampton only. The NHS ethics committee were reluctant to approve the study with;

1- Multiple primary care sites in the city
2- Qualitative narratives of selected activities

This required amendments to be made to the study design in order to fulfil the requirements of the NHS ethics committee. This included;

1- Using Bitterne Health Centre as the only recruitment venue
2- Removing the qualitative narratives analysis from the study protocol

This did make the study more challenging in terms of recruitment limitations, and methodologically weaker as a quantitative study.

Written informed consent was required from each participant and detailed participant information sheets and consent forms we developed and submitted as part of the NHS and University ethical review process. The patient facing literature designed to University specifications was not at an appropriate level for potential participants to read and understand. Later in the study this became a significant barrier for recruitment and a substantial amendment was submitted to develop an accessible information sheet for potential participants. This information was modelled on literature developed for learning disabilities but retained a language level at around 8 years old. This literature was part of amendment 2, and rapidly increased participant's willingness to volunteer for the study **(Appendix D).**

Furthermore, the open nature of the conversation may be distressing in some patients, conversations around families, friendships and groups, may be deemed very 'personal'. Therefore, the clinical team and those who both knew the potential participants, but had no interest in the study, offer the study to people with COPD attending PR. The aim here was ensure that those people who may already have a heavy clinical burden were not unduly invited to take part in research, ensuring privacy and no further distress or burden. It was noted by the study team that recent bereavement may play a part in distressing people when asking about networks and social ties. Therefore, the clinical referral process was ensured to enable support from bereavement and psychological services to manage any unintended distress that the study may have provoked.

Ensuring patients safety in the primary concern; then study conduct. Study conduct can include the ethics of recruitment, selection, data collection and storage. The duplicate role of the researcher being the direct care clinician, raises the ethical debate of impartiality of the research. The study was designed to ensure the selection process was blinded to the research team, and the group of the participant revealed only when they had completed baseline assessment. In favour of a joined clinical /researcher position the clinical knowledge and skills were required to manage unwell of deteriorating patents, as some people did attend the research appointment and required urgent oxygen of clinical intervention. However, conversations were sometimes tailored to support people with literacy skills and cognition, which may not have been intuitively known by the researcher, of they did not have clinical skills.

In contrast though it does reduce the impartially of the researcher, and certainly the participants view of the research, perhaps increasing their confidence to participate.

Chapter 7 Findings from a community-based pilot study of a social network self-management intervention in COPD.

Summary- This chapter is in paper format. This is the findings and recommendations from the pilot study of the GENIE intervention in COPD. This paper adds to the evidence in terms of implementation of a clinical tool into practice, recommendations for practice in terms of building social infrastructure into the transition between statutory and voluntary services.

7.1 Background

Chronic obstructive pulmonary disease (Celli et al, 2015) is a progressive, life limiting condition, clinically characterised by airflow limitation, sputum hypersecretion and persistent breathlessness (Wedzicha and Donaldson 2003). These enduring daily symptoms have a further impact on mobility, nutritional intake and mental health. The disease is further complicated by 'exacerbations' or worsening of symptoms, and compounded by multi-morbidity (Agboado, Peters et al. 2012) (Almagro et al, 2012). As COPD prevalence and the related social burden grow, this in turn has a multifactorial impact of society, families, and health systems. This is further augmented by deprivation (McAllister 2013), poor housing, continued tobacco use and poor literacy levels often prevalent in COPD (Donaldson and Wedzicha, 2013) (Andreas et al., 2009).

Traditional approaches to COPD management have focused on clinical pharmacological approaches alongside self-directed action planning to manage exacerbations (Walters et al, 2010 Taylor et al, 2014) or therapies such as pulmonary rehabilitation to maintain muscle strength, increase mobility, and manage breathlessness. Pulmonary rehabilitation is a clinically proven and well evidenced intervention (Bolton et al, 2013). However, post pulmonary rehabilitation access to further community resources are required in order to continue any positive behaviour changes, activity or peer support that is encompassed by the six-week intervention. Furthermore, a longer-term solution is required to sustain the personal self-management activities required by individuals to manage everyday life with COPD symptoms and remain well (Cramm and Nieboer, 2012).

In this paper we use the concept of socially supported self-management in COPD. An approach designed to shift the focus to a patient centred care model, through the prioritisation of the psycho-social management needs, which implicates links with other people and range of resources to support illness and wellbeing activities. Socially supportive self-management works on the premise of a ‘whole systems model’ of self-management (Reeves et al., 2014, Cacioppo and Hawkely, 2003).

Social networks are comprised of social ties, these include both strong and weak ties - strong ties consist mainly of family and close relations who are seen frequently and viewed as core informal care givers, who provide the most support. Other connections with less intense involvement with the person (weak ties) such as neighbours or people running groups in the community also have a place in long team illness management in so far as diverse social contacts provide the potential for providing sources of support that can enhance health and wellbeing (Kennedy et al, 2016).

The current mainstream delivery of SMS is through educational programmes focussed on action plans to manage symptom flare ups. These plans address the physical aspects of long-term illness management in COPD and do not tackle the complexities of day to day living with breathlessness or sustaining wellbeing. In contrast a social network approach works with the recognition that patients with long-term health conditions spend relatively little time in contact with health professionals in comparison to the time they spend managing their disease alone or with their family. Therefore, this requires a focus on the connections and activities needed to manage their condition in day to day life (Rogers et al., 2014). Building and linking to social network support can potentially draw in a broader set of resources (e.g. exercise, group activities) which can support individuals to manage their life around a complex condition and gain meaningful connections to others in the community (Kennedy et al, 2016). The Generating Engagement in Network Support (GENIE) tool is a social network intervention designed to broaden network support and diversify existing networks (Kennedy et al, 2016). GENIE is based around network mapping, user centred preference elicitation and needs assessment.

In this pilot study, we hypothesised that, in line with social environmental approaches such as social prescribing (Bickerdike et al., 2017) the use of a social network intervention (GENIE) in people with COPD would address personal social needs through enlisting network support in a way designed to engage users. In turn this might influence long term behaviour change through participation in valued activities and provide long term SMS through the enlistment of wider resources and links to personal networks. The main aim here is to test this approach in a pilot study with COPD patients in a local primary care context.

The use of GENIE as a social network approach has been evaluated in relation to other long-term conditions such as diabetes, heart disease and chronic kidney disease (Kennedy et al, 2016). These studies demonstrated positive results in terms of the tools impact on NHS costs and patient outcomes. These included; improved blood pressure control, improvement in quality of life and the uptake of new activities identified through the GENIE tool (Blakeman et al., 2014, Kennedy et al., 2016). The difficulties of managing breathlessness, frequent exacerbations, and a declining disease trajectory pose challenges for people suffering from COPD. The latter warrants conducting a pilot study to ascertain the potential benefits of the application of a socially supported SMS tool in the respiratory population. This study will build an understanding of the value and impact on health care use of a social network intervention for the improvement of SMS for people with COPD.

7.2 Methods

7.2.1 Study Objectives

The study was designed as a pilot study. A pilot study was selected to understand if the main components of the study design work well together (Arain et al., 2010). The main aim here is and to answer the research question: to understand the potential clinical and financial benefits of increasing long term health care management options through a social network approach in a primary care context using the GENIE network intervention to build social capacity to support self-management.

The study objectives are, (1) to use social network mapping techniques, activity and resources preferences to engage participants in considering their current support preferences and further needs. (2) To engage participants in wider social activities and linked health resources. (3) To clinically evaluate patient reported symptom improvement in COPD patients using the intervention in comparison to the usual care control group. (4) To evaluate quality of life in participants using the GENIE intervention in comparison to the usual care group and (5) to review health utilisation and relative cost in the GENIE intervention with a view to upscaling for broader application.

The study was delivered in the local community COPD team. The team was a mix of clinicians, physiotherapists, nurses and medical consultants delivering care to COPD patients in a deprived inner-city area falling within the 20-30% decile of deprivation (government 2015), with a known higher than average prevalence of COPD (Council 2015). This area was purposefully selected as deprivation is associated with: isolation, poor health literacy; poor access to health resources, information and sources of influences; insufficient social capital; low personal confidence and higher differentials in power with professionals (Bo et al, 2014) (Kennedy et al 2016).

The clinical team invited patients to participate in the study either towards the end of their 6-week pulmonary rehabilitation classes or at the review appointment at the end of the programme, after the completion of pulmonary rehabilitation. Researcher (LW) was also a clinician in the team and was involved in offering the study to PR patients.

7.2.2 Study Design

The study follow-up phase was three months. Sixty people were recruited from the pulmonary rehabilitation groups. This number was small enough to be delivered in a short time frame, and large enough to have groups for analysis (Brown 1995).

The aim was to collect health utilisation data reducing the possibility of recall bias (i.e. how many times have you been into hospital over the last 3 months), therefore a longer time frame would require an alternative data collection method to maintain accuracy, such as the diary method.

Block randomisation was used, a commonly used technique in clinical trial design aimed to reduce bias and achieve balance in the allocation of participants to treatment arms, especially in this case when the sample size is small (Efird, 2011). The sequence was allocated at random in blocks of 4 to ensure an even grouping of participants and to fit with the timing and blocks of consultations. The allocation sequence preselected the random group for the block of 4, so if A=intervention and B=control then sequences were selected at random; AABB, ABAB, BABA etc. In order to further reduce unconscious bias of the researcher, the clinical administrative assistant (not included in the research) created pre-prepared envelopes containing the possible combinations of group allocation, that were stored in a locked drawer on site at the health centre.

The research team shared an Excel spread sheet set to generate a random number sequence. The next sequential number will be selected, which will then correspond to an envelope with the predetermined sequence. In this way the envelope selection is random, then sequence in the envelopes in also random, to ensure the 50/50 random grouping of participants.

Socio-economic baseline data was collected, after randomisation included; disease severity (from existing medical records), age, gender, previous employment, educational level, and smoking status and descriptive statistics were then calculated. This data was captured to ensure the study demonstrated a balance of the groups for health literacy and possible existing abilities to understand, socialise and navigate services.

7.2.3 Eligibility

People were eligible to participate if they were over 18 and with a previously confirmed diagnosis of COPD through objective testing, usually by spirometry. There were also required to be currently receiving care through the selected COPD community service. People of all COPD disease severities (categorised by airflow obstruction (GOLD., 2018) were included.

Inclusion Criteria	Exclusion Criteria
• Older than 18 years of age; • Patients with a diagnosis of COPD according with NICE or GOLD guidelines – all severities were included (GOLD., 2018). • Currently in the Community COPD team service. • Completed a pulmonary rehabilitation programme in the service in the last 3 months.	• No formal diagnosis of COPD; • Unable to fully express himself/herself in English; • Diagnosis of a mental health condition, or poor cognition. • Extreme anxiety, agitation and/or depression.

7.2.4 The Intervention

Generating Engagement in Network Support (GENIE), is comprised of 4 main stages; each of which work alone or together as a complex intervention. **Picture 1 (see Appendix 1).** GENIE has been developed to be an intervention which is co-produced. Co-production in this sense refers to the process of delivery, as the participant themselves builds their own social network and selects their preferences, then retains ownership of the network map and links to favoured activities. The facilitator, who can be from either a lay or professional background, is there to guide the process, not to direct the process. In this way by talking through the GENIE mapping process, individuals can visualise their network. They then can reflect on connections and resources that provide value, and where there may be gaps in their support. The support can be in the form of social, practical or emotional as well as being specifically related to a health condition, in this case COPD. GENIE's third stage is the link to the database of locally tailored online and offline groups and resources. The GENIE tool is delivered face to face as part of a consultation, and can be broken down into distinct stages:

Stage 1: Mapping of the individual's current social support network using a concentric circles method.

Stage 2: Eliciting values and preferences for activities and support resources.

Stage 3: Linking individuals to prioritised and valued activities and resources. (Links are to a pre-created database where local organisations and resources have been categorised).

Stage 4: The GENIE Tool then presents options in a user-friendly way, on a Google map with clear details about access. **Picture 1 (see Appendix 1)**

The intervention is usually delivered face-to-face as the facilitated discussion is part of the interventional process. For the purposes of this study the facilitator was the researcher (LW). Researcher LW is a respiratory nurse and the COPD service lead. So was experienced in delivering COPD care. The delivery took 45 minutes to 1 hour.

Building community engagement to carry out the evaluation: The GENIE data base needed to contain an appropriate library of social and health activities suitable for local COPD patients. Therefore, the data base was adapted by LW to include links to local exercise groups, social and community activities. The groups included generic actives including; reading, arts and special interest groups. Walking, Tai Chi and more exercise orientated groups or classes. The links and resources were further stratified to include disease specific activities and generic interest groups and clubs. Support for this data base was provided by a local councillor, who had already compiled an offline data base for his constituents. In addition to this the local voluntary Breathe Easy groups, groups designed specifically for peer support with respiratory illness, were enrolled in an Integrated Breathe Easy project, funded by the British Lung Foundation (Merrit et al, 2018). This provided the groups with professional support to develop as functioning patient groups and be equipped to accept new people.

Briefing the clinical team: In order to successfully implement the GENIE tool into clinical practice; the clinical team were placed to be at the core of the process in order to ensure appropriate and effective facilitation. Therefore, the local COPD clinical team was briefed at an early stage in the study development and included in the study progress. This was delivered through question and answer sessions and direct learning opportunities in how the tool works and the objectives of the study.

7.2.5 Usual care

The aim was to introduce the tool into the local COPD community team in a primary care context, with a view to eventually embed it as part of an integrated clinical consultation. In terms of usual care, the COPD team already had in place a post pulmonary rehabilitation discharge pack. All patients leaving pulmonary rehabilitation received a discharge pack which contained a: British Lung Foundation (BLF) exercise DVD and guidance; advice about local BLF Breathe Easy support groups; and information regarding walking groups. These items were routinely provided either during the rehabilitation programme, or at review at the end of the programme. All these links were added into the GENIE tool data base to ensure all patients received the same information.

7.2.6 Outcome measures

The primary outcomes were participant reported symptom scores and quality of life scores. Secondary outcomes included health care utilisation and health care cost.

7.2.7 Data Collection

Five questionnaires were administered. Clinical symptom questionnaires including the COPD Assessment Tool (CAT), a validated twelve point questionnaire to asses COPD health status (Jones et al., 2009), the nine point Patient Health Questionnaire (PHQ-9), a validated diagnostic and research tool for depression scoring (Kroenke et al, 2016) and the 7-item anxiety scale (GAD-7) for the assessment of generalized anxiety disorder a validated tool for assessing anxiety in clinical practice and research (Spitzer et al, 2006). In addition to the clinical questionnaires, the validated EuroQoL instrument EQ5D was administered to describe people’s quality of life in terms of mobility, self-care, usual activities, pain/discomfort and anxiety/depression (Group. 1990) (Nolan et al,2016). Health utilisation data was collected using a healthcare utilisation questionnaire adapted from Client Service Receipt Inventory (CSRI) (Beecham et al, 1999) (Mayer et al, 2017). The Client Service Receipt Inventory (CSRI) is an economic research instrument developed by Martin Knapp and Jennifer Beecham to collect information on service utilisation, income, accommodation and other cost related variables and is a valid measure (Beecham et al, 1999).The main purpose of the instrument is to allow resource use patterns to be described and support costs to be estimated using an appropriate unit cost. The instrument was selected for this study to monitor the shift of healthcare usage away from formal care and to investigate the GENIE tools potential abilities to redirect healthcare use away from formal health care activities to voluntary sector resources.

Health utilisation was chosen in preference to admission rates, as it was applicable to a primary care and community context. Furthermore, the utilisation data ‘followed the person' and the participants were asked to recall their activity over the past 3 months, at baseline and at 3 months follow up. The study measured the participants' attendance and use of NHS services at baseline and at three months cost (primary care, secondary care, community care) and explored the changes before and after using GENIE (Xu 2014).

These five questionnaires were administered at baseline and re-administered at three months follow up post intervention (+/- 2 week). Furthermore, for those in the intervention arm, feedback and discussions were initiated using the network diagrams. Participants were asked again for their permission to record these discussions to ensure parity and quality assurance between researchers.

7.2.8 Ethical Considerations

This is a new research trial of an existing social networking tool already used in the management of other long-term conditions, but not yet specifically with COPD. Prior to introducing this to a clinical team, the local NHS research clinical effectiveness group supported the proposal for a pilot study within their organisation.

As this is an intervention within a clinical service and the evaluation was conducted with NHS participants and on NHS properties, therefore University ERGO (Ethics) and HRA full NHS ethics application was sought and granted, for quantitative data collection in one area of Southampton only. Information about the study was provided in an accessible information format, in addition to the usual format for patient information. The study was ethically approved by Hampshire Ethics B REC: 16/SC/0627 and an amendment was passed to enable to use of the revised accessible patient information sheet. The ethical review further evaluated the social and scientific value of the study. Further to this it ensures adequacy of patient information, the informed consent process, recruitment arrangements and access to information.

The service implementation and evaluation were presented at the local NHS clinical effectiveness and audit group and approved, as per local NHS policy. Each participant was offered a patient information sheet and time to take this away and read the information. Written informed consent was gained from each participant either prior to or at the baseline study visit.

7.3 Results

7.3.1 Analysis

The study analysed data using SPSS and R, from the intervention arm and the non-intervention arm at baseline and at 3 months post intervention. The findings were compared between the groups at baseline and 3 months post intervention. Clinical comparative analysis of the CAT score, the PHQ-9

GAD-7 scores and EQ5D score pre and post intervention was analysed using Wilcoxon Ranked tests.

Pre intervention symptom scores and quality of life were then correlated with the follow up score (+/- 1 week) symptom scores and quality of life, with significance. These were compared at baseline and at three month follow up in both groups, as well as the differences between the two groups (Gertler et al, 2011). Since these variables under investigation are not normally distributed, the nonparametric Mann-Whitney test was used to detect the significant difference (before and after) and between the two groups for intervention effect. A 5% cut-off point ($p = 0.05$) was used for significance.

Health service utilisation was captured using a modified version of the CSRI (Beecham, 1999a). Unit cost was attached to each data entry, an average value was computed at each label costing. The sample size of 60 participants was too small to extrapolate enough longitudinal data to measure quality adjusted life years. Therefore, the costing trend was reported both across groups and pre and post intervention.

Participant uptake of the social activities was recorded on paper using the Genie tool and compared between groups using network typology counts. Network counts have been previously identified and described by Vassilev in 2018. Networks types were defined by the number of members and frequency of association (Vassilev et al, 2018).

7.3.2 Study flow and baseline characteristics

Patients were recruited from an inner city region, containing the areas of highest deprivation (Council, 2015) and COPD prevalence (Primary Care Framework., 2010-11).

The study was delivered over 6 months and participants were enrolled for 3 months. Three months was chosen as this relatively short time frame would reduce the risk of recall bias.

Figure 7. Study consort diagram

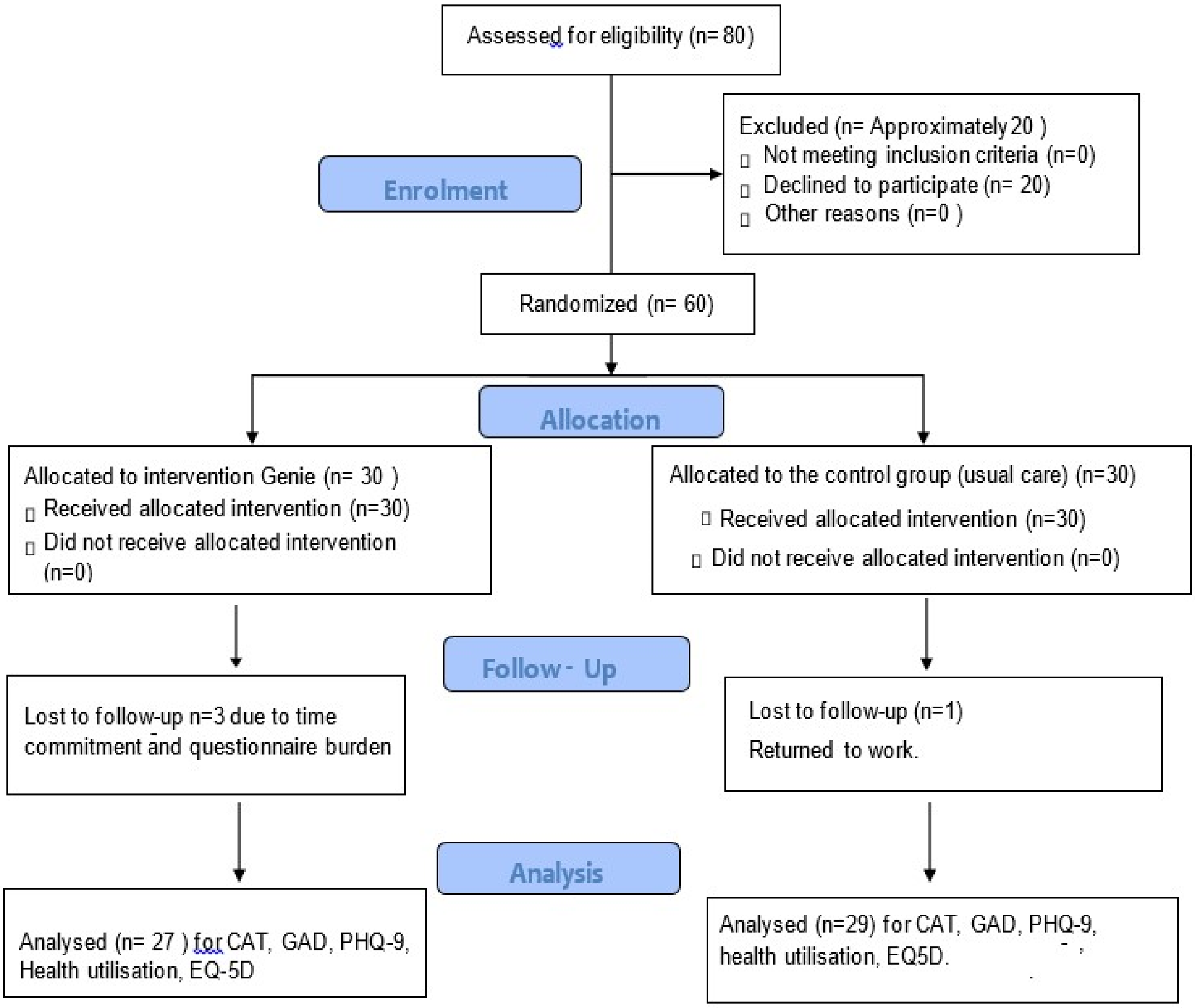


Figure 1: Study flow diagram CONSORT 2010

Eligibility for the study was assessed throughout pulmonary rehabilitation. However, 20 people declined to participate. Reasons included; time commitments (feeling they had already dedicated time to PR), and concerns about participating in a research study. These concerns did prompt a study amendment, to include a more accessible information sheet. This then encouraged more people to enrol. During the three months study period, three people dropped out of the intervention arm, this was due to time commitments, questionnaire burden and overall frailty. One person dropped out of the control arm because of a return to work.

The baseline characteristics of the study showed that both groups were broadly similar in respect of age, sex and disease severity, with no statistically significant differences. The mean age in the intervention group was 68.87 and 71.87 in the control arm (not significant). At least half the participants in each arm lived alone. However, a higher percentage of people in the intervention group (83.2 %) had one or more regular visitors. In comparison 66.6% of people in the control group received regular visitors.

The groups were matched in terms of qualifications and previous employment. There are slightly more smokers in the interventional arm (23% in the interventional arm and 13.3% in the control arm), however mean lung function or COPD severity was matched across the groups, slightly more patients with severe disease in control group, however this is moderated with 26.6% intervention, and 13.3% control in the mild group. The moderate group was more balanced with 36.6% vs 30% respectively, 23.33% vs 40% in the severe group, and 13.33% vs 10% in the very severe groups.

Table 7. Baseline Characteristics of the study cohort

CHARACTERISTIC	INTERVENTION GROUP (A) N=30	CONTROL GROUP (B) N=30	P-VALUE ***
GENDER	50 % female	50% female	--
MEAN AGE**	69 ± 6.33	72 ±8.04	0.11
HOUSEHOLD COMPOSITION			0.24
LIVES ALONE	16 (53.3%)	14 (46.6%)	
2 PEOPLE	14 (46.6%)	12 (40%)	
3-4 PEOPLE	1 (3%)	3 (10%)	
INFORMAL CARE RECEIVED AT HOME	2(6%)	3(10%)	
NUMBER OF REGULAR VISITORS*			0.21
0	5 (16.6%)	10 (33.3%)	
1-5	19 (63.3%)	12 (40%)	
6-10	4 (13.33%)	6 (20%)	
10+	2 (6.6%)	2 (6.6%)	
QUALIFICATIONS			0.21
NO QUALIFICATIONS	12 (40%)	9 (30%)	
SCHOOL LEAVING ONLY	5 (16.6%)	6 (20%)	
POST SCHOOL EDUCATION (VOCATIONAL)	9 (30%)	12 (40%)	
UNIVERSITY / HIGHER EDUCATION	4 (13.33%)	3 (10%)	
PREVIOUS EMPLOYMENT			--
MANUAL	18 (60%)	18 (60%)	
SKILLED	12 (40%)	12 (40%)	
SMOKING AND COPD			
CURRENT SMOKER	7 (23%)	4 (13.3%)	0.20
EX SMOKER	23 (76%)	25 (83%)	
NEVER SMOKER	0	1 (3%)	
MEAN FEV1**	0.56 ±0.23	0.51 ±0.21	
COPD SEVERITY		*(ONLY 29 IN DATA SET FOR CONTROL GROUP)*	0.21
MILD	8 (26.6%)	5 (16.66%)	
MOD	11 (36.6%)	9 (30%)	
SEVERE	7 (23.33%)	12 (40%)	
VERY SEVERE	4 (13.33%)	3 (10%)	

*no of family or friends visiting daily to weekly. **Mean ±Standard Deviation. *** P-values are Pearson's chi-squared test results except variable "Age" where t-test is used.

Full data set is available for all baseline data- apart from lung function for 1 participant in the control arm. All other baseline data is complete.

7.3.3 Social Network Outcomes

Network analysis identified the type of social network at baseline, and then compared this at the follow up visit. Unfortunately, a small number of people declined to repeat the concentric circle mapping exercise, so this reduced the number of networks analysed to 27, rather than the original 30 participants. Network types and characteristics have been linked to the capacity of inter-personal environments to mobilise and share resources (Vassilev et al, 2016). Therefore, the wider and more diverse the network the increased potential to negotiate increased support and resources from these avenues.

In this case we are reporting the extension of networks; network type, any additional new activities (Trivedi et al.2012), both online and offline (2). Engagement in networks is also reported in terms of personal reflection of existing network support (Lozano et al.), increased frequency of contact (Trivedi et al.2012), and additional network members (5); scored out of 5.

In terms of network movement 15 people (55%) increased network members, frequency of social interactions, online engagement, and reflection or engaged in additional activities. 12 people (44%) did not further diversify their networks. Therefore, a higher proportion of people increased engagement or activity extended their network.

Table 8. Network changes

Network Changes at Time 2 = 3 months post intervention (n=27 - 3 dropped out)

Baseline		Extending Networks			Network engagement				
Study Participant Number	Type of network at Baseline	Additional new activities	Type of network at 3 months follow up	Online	Reflection on existing support	Increased contact with existing groups/ people	Additional new network members		Change within network Score
002	Family centred	0	family Centred	0	1	1	1	Addition of less frequent contact with distance relatives and a new close friend, seen at least once a week.	3/5
003	Family Centred	*0*	*Declined to repeat the social circles*	0	0	0	0	n/a	0/5
005	Very Small network (4 members only)	0	Very Small network (4 members only)	0	0	0	0	Very severe COPD and hospitalised during the study.	0
008	Small (8 members)	0	Small (8 members)	0	0	0	0	Very severe COPD and hospitalised during the study.	0
009	Small (8 members)	0	Friend supported	0	1	1	1	4 additional network members, greater involvement with the church, reduction in frequency of seeing health providers.	3/5
014	Family centred (18 members)	0	Family centred (18 members)	0	0	0	0	Carer or her grandchildren, no capacity to diversify.	0
015	Very small	0	Very small	0	0	0	0	Did not wish to diversify.	0
018	Diverse	0	Diverse	0	0	0	0	Already diverse.	0

Baseline		Extending Networks			Network engagement				
Study Participant Number	Type of network at Baseline	Additional new activities	Type of network at 3 months follow up	Online	Reflection on existing support	Increased contact with existing groups/ people	Additional new network members		Change within network Score
019	Diverse	0	Diverse	0	1	1	1	Movement post intervention – 2 people left the group, 2 people joined, 3 people became closer and more valued. More value and time attributed to groups.	3/5
021	Very Diverse	0	Very diverse	0	0	0	0	No movement already very diverse network	0
022	Family Centred	0	Friend Supported	0	1	1	0	Valued friends became closer as their support was helpful.	2/5
025	Very small	1	Diverse	0	1	0	0	Joined 3 weekly health related groups	2/5
027	Diverse	0	Diverse	0	1	0	0	Maintained groups and friends- but saw less of her daughter and son in law	1/5
030	Family Centred	1	Diverse	0	1	1	1	Addition of 3 more friends/ neighbours and joined 2 groups.	4/5
033	Friend centred	1	Diverse	0	1	1	0	Increased number of groups and group frequency	3/5
037	Family supported	*0*	*Declined follow up*	0	0	0	0	n/a	0
040	Family Centred	0	Family centred	0	0	0	0	No change- had been unwell in the past 3 months since GENIE	0

Baseline		Extending Networks			Network engagement				
Study Participant Number	Type of network at Baseline	Additional new activities	Type of network at 3 months follow up	Online	Reflection on existing support	Increased contact with existing groups/ people	Additional new network members		Change within network Score
041	Family and Friend Centred	0	Family and Friend Centred	0	0	0	0	Declined to discuss at follow up.	0
043	Small	1	Family and Friend Supported	0	1	1	0	Increase in regular friends visiting and joined an exercise group.	3/5
045	Family Centred	0	*Declined follow up*	0	0	0	0	n/a	0
047	Family Centred	0	Family Centred	0	0	0	0	No change as admission and been unwell over the 3 months follow up period.	0
050	Small	1	small	1	1	0	0	However, this person liked to have a small network due to social anxiety and supported the setup of groups for others and joined a new exercise group	3/5
052	Friend Centred	0	Friend Centred	0	1	1	0	No change – movement in friends – but within the existing network.	2/5
053	Friend Centred	0	Friend Centred	0	1	1	0	Increased health engagement with services and decreased family reliance, however remained in a friend centric network.	2/5
055	Family Centred	0	Family Centred	0	0	0	0	Awaiting lung transplant, currently reliant on family.	0
058	Friend and family supported	1	Diverse	0	1	1	0	Many peripheral friends and addition of 2 health related groups	3/5

Baseline		Extending Networks			Network engagement				
Study Participant Number	Type of network at Baseline	Additional new activities	Type of network at 3 months follow up	Online	Reflection on existing support	Increased contact with existing groups/ people	Additional new network members		Change within network Score
060	Friend Centred	0	Diverse	0	1	1	1	Increase of frequency of group meeting and addition of 2 friends	3/5

Overall, 11 people increased their network frequency and members enough to move up a group. 13 people remained the same. Note that 4 of these people already had diverse or very diverse networks. Time 2 refers to changes 3 months after the intervention

(Vassilev et al, 2018)

Networks have been scored out of 5, those over 3 have reflected on the input they are receiving from existing social networks, and have made changes, within their capacity to do so. Many people were unwell during the study, and therefore did not have the capacity to take on additional activity. The potential impact of acute fluctuations of long-term illness are important considerations for future development of this work.

The social movements are a positive reflection of the changes realised after using the intervention and the value of the concentric circle discussion.

Overall, 55% of the participants increased their social networks and 44% of the participants remained in the same network category. The stability and increase in networks are both positive outcomes in a population who struggles to maintain links and negotiate resources in times of adversity (ill health and declining disease trajectory) (Vassilev et al, 2018).

7.3.4 Clinical Outcomes

Changes in clinical symptom data and quality of life were expressed by the median and the interquartile range (IQR) of each variable.

The measure of overall symptom burden in COPD - the CAT score - remained stable in the intervention group but increased in the control group (demonstrating a higher symptom burden). The Generalised Anxiety Score (GAD-7) score decreased in the intervention group by a marginally significant difference (p=0.1) to that in the usual care group where a rise in anxiety symptoms was recorded. The PHQ-9 score declined slightly in the intervention group (representative of improved symptoms), although not significant from that of the control group, -1 decrease in score in the intervention group with no increase in the control group.

The overall quality of life measured by the EQ-5D showed improvements of 0.04 in the intervention arm over the three months and a fall in quality of life in the usual care arm of -0.001 (p=0.13).

Overall, these findings are not statistically significant, but the trend is in favour of the intervention group in a reduction in anxiety scores.

Table 9. Full table of outcome variables Genie in COPD (median, IQR in square brackets)

Outcome	Intervention group **Pre**	Intervention Group Post	Intervention group Difference (Post-pre)	Control group **Pre**	Control group Post	Control group Difference (post-pre)	Diff in Diff *	P- Value
	Baseline	Follow up		Baseline	Follow up			
CAT	21 [16, 26]	21 [16, 24]	-1 [-5, 2]	18 [10, 22]	15 [10, 25]	0 [-3, 1]	349	0.49
GAD-7	2.5 [1.0, 8.8]	3.5 [1.0, 5.0]	-0.5 [-3.5, 0.8]	2.5 [1.0, 5.8]	4.0 [1.0, 6.0]	0.0 [-1.0, 3.0]	280	0.10
PHQ9	5.5 [3.0, 12.8]	5.5 [2.5, 10.0]	-1 [-3.0, 2.0]	4.0 [2.0, 6.8]	4.0 [1.0, 8.0]	0.0 [-1.0, 2.0]	317	0.32
EQ-5D	0.56 [0.37, 0.71]	0.62 [0.53, 0.69]	0.04 [-0.08, 0.21]	0.64 [0.45, 0.76]	0.67 [0.39, 0.77]	-0.001 [-0.18, 0.10]	484	0.13

*Mann Whitney test is used to calculate control group and intervention group differences in the differences present before and after the intervention. P values are in brackets.

7.3.5 Health Utilisation Outcomes

Health utilisation questionnaire was grouped into subsections (inpatient, outpatient, primary care, community-based specialist or generic health care, or accessing their social worker, if applicable). It was administered twice, at baseline and at three months, in order to track changes over time. The Unit Costs of Health and Social Care report (Curtis, 2016)(PSSRU 2016) was used, as this is a nationally approved and applicable source of data. This compendium is produced annually by the Personal Social Services Research Unit (Curtis, 2016). Inpatient data was costed using National Reference Cost (2016).

The cost of intervention per patient is £94, if Genie is administered by a senior community nurse: Agenda for Change (AFC) Band 8 while for future implementation the cost would be £35 per patient considering an AFC band 3 NHS colleague. Genie is user-friendly and versatile and can be used without health professional guidance, after familiarisation with the tool **(Appendix 2: Costs /saving to the National Health Service).**

Health utilisation in the general COPD population is expected to increase over time, due to the continuing illness trajectory and health deterioration. Therefore, an overall rise in health care costs would be expected in both arms (intervention and usual care). The trend of costs before and after Genie counts of 40% reduction in costs, in the intervention group, with a margin of £7,634. While in the control group the reduction is less than 1%. Costing breakdown comparison in **(Appendix 2).**

The drivers of this dropping cost are inpatient activity and outpatient visits, this accounts around £6,234 and £1,395 respectively in the intervention group over three months.

Control arm counts dropping inpatient activity too, which is reported to be around £2,979 although outpatient and GP visits increased within the three months with a marginal value of around £1,730 and £1,254 respectively. This cost difference is minimal largely because outpatient visits are pre-planned.

Considering COPD, a progressive condition, requiring increasing primary care support, the aim would be to promote stability in cost of GP interactions, or a slower increase than the control arm; therefore, the increase of £180 for GP visits within three months in the intervention group can be considered as a positive effect in favour of the intervention. In order to calculate cost effectiveness a larger sample size would be required with a longer follow-up time.

7.4 Discussion

A social network tool (GENIE) has the potential in terms of engaging people and acting as a complimentary addition to existing clinical management options in COPD. It was hypothesised that using a social intervention would reframe SMS in COPD and address personal social needs through enlisting peer support in a positive pro-active way. In this respect the intervention appears to have had positive results.

The intervention study further aimed to build a continuum for support with self-directed care after discharge from statutory NHS services. The development of a peer supported community care pathway, which links directly to NHS services can utilise the skills and knowledge of peer networks to monitor and provide simple advice if health status deteriorates. Furthermore, people within the peer networks can motivate each other to continue to access voluntary and community resources in order to maintain wellbeing and prevent chronic disease decline over time. This is displayed through the increases in social network reflection and the ability to enlist support and develop new social connections.

Social networking has been utilised and examined in other long term conditions, in particular chronic kidney disease (CKD) (Blakeman et al., 2014). The CKD study used telephone guided access to community resources in primary care. The intervention was referred to as patient-led assessment for network support (PLANS) or the BRIGHT intervention. The intervention utilised tailored information (via the telephone) to sign-post patients to community resources. The intervention was also modestly successful in terms of improvement of blood pressure control and improvements to health-related quality of life. However, these did not directly translate into increased active engagement in life.

In comparison the GENIE in COPD study was a face to face facilitated intervention, rather than telephone guided. Again, GENIE achieved stability on clinical outcomes, rather than measurable improvement in clinical outcomes. However, both studies support the approach of social networking as a tool to support self-management.

The clinical stability was demonstrated by the stability in clinical outcome measures, and a small reduction in anxiety in the intervention group. It is noted however that the reduction in anxiety scores and quality of life were not statistically significant but trended towards the GENIE intervention in a small population of people in a short time frame.

Moreover, by embedding the delivery of the intervention within the clinical team this added further significance in terms of access to community resources for clinicians. Prior to this study voluntary groups for respiratory disease were limited in number and accessibility. The joint working with the British Lung Foundation, local councillors within the community COPD team enhanced care through the promotion of the concepts of network use and valued activities. Therefore, by enhancing and maintaining social networks have in this case demonstrated a pressure reduction in NHS resources in terms of utilisation and cost through socially supportive self-management activity. A second paper (Bloom and Welch et al, 2020) describes the process evaluation; including fidelity, reach and dose and discusses the value of the GENIE intervention as an adjunct to supporting long term health behaviour change.

Furthermore, as a positive consequence of the study the COPD clinical service has shifted in its focus to embrace the more patient centred approach of understanding the valued activities and social worlds of COPD patients within their care.

A larger scale trial has already started to address social isolation in the local communities across the whole city. This study is broadly inclusive of any population that could be isolated due to long term illness or social circumstances.

7.4.1 Limitations

Overall, the study was successful, and participants were pleased to be included in an intervention post pulmonary rehabilitation completion. The study was designed to collect clinical data at the study baseline. However, a limitation of this data collection was not accounting for the prior clinically significant improvements during the participant's recent PR programme. The correlation of these clinical figures may have provided an indication of those people who may have continued to improve in the GENIE programme. Including the PR data in future study design would be beneficial.

However, the nature of recruiting from groups, did lead to peer discussion about the study. Much of this was positive, and encouraged others to volunteer, however some of the peer discussion did lead to some contamination in the randomisation process. However, this was not significant. A larger sample size would have benefitted the economic evaluation and enabled a more robust statistical evaluation, such as a cost effectiveness, or cost benefit analysis. The participants included in the study often struggled with their social and economic circumstances had poor literacy levels and therefore had difficulties with comprehension of the study literature. Therefore, an ethical amendment was required to change the patient facing literature during the recruitment phase of the study. Furthermore, the short follow up period was designed to maintain the ability to recall health use. However, some participants found it difficult to remember activity regarding self-reported health service utilisation, so there is variability in the accuracy of this data due to this potential recall bias. This could have been supported by using a diary method of data collection, or an online data capture device, to improve participant recall.

The short time frame and lack of qualitative ethical approval further limited the depth and length of data capture to only three months. The original plan was to include an additional twelve month follow up and mixed methods. The mixed methods could have enhanced the social network discussion and the generation of qualitative data could have supported the figures in terms of network analysis. However, this study had a limited funding and recruitment window, due to the PhD studentship. The qualitative sections of the study were not approved by the Ethics committee, so unfortunately this data could not be collected. This would have certainly provided greater depth and understanding in terms of socialisation and support needs of the participants. Furthermore the Health Education Impact Questionnaire (heiQ) (Osborne et al, 2007) was to be used and the relevant permissions was gained for its use. However, the heiQ was challenging for participants to complete on their own and every section required reading aloud, this skewed the data as the nature of the questionnaire was to draw out the participant's level of health education. Therefore, the data from the hieQ was not reported. Ideally a self-efficacy measure, such as the Patient Activation Measure (PAM) (Hibbard et al, 2004) would have been a shorter, and more appropriate clinical tool. Unfortunately, the PAM was not available in the NHS trusts during data collection for the pilot study and the feasibility study.

7.4.2 Implications for clinical practice and commissioning

The pilot study suggests that the GENIE social networking intervention could have a positive impact on quality of life, anxiety, and on health care utilisation, and the way people approach and use NHS services.

Therefore, this work could enhance existing community and primary care services to implement and encourage social network engagement, to increase patient confidence and foster peer support to assist complex health related decision making in the community, encouraging safer and appropriate approaches to health care use. Furthermore, GENIE does reduce the costs of health care contacts, by redirecting activity to community and planned GP visits with a reduction in inpatient stay.

The implications for the reduction of NHS costs within the intervention group are of interest, due to the ever-increasing prevalence of COPD and reduction in NHS resources. The future challenge is to ensure the GENIE tool is located at appropriate points in NHS services to ensure appropriate and safe care is provided, and the GENIE intervention serves as a tool to build social capital, community resources and the ability to navigate local support networks in clinical settings. Notably **self-management** is something that most patients with a long-term condition must do every day- not only when they are unwell. The GENIE tool has been used in other long-term conditions, diabetes and kidney disease, and has been implemented on the Isle of Wight, and in areas in Manchester. The concept of social network support is broadly adaptable to any language or region. However local, appropriate and accessible activities will need to be added to the database, to ensure regional and cultural specificity.

The GENIE tool can effectively signpost to resource's online and offline to initiate peer and social support to work through daily solutions to manage long term conditions. These peer 'top tips' – are often more valuable than clinical insight. As many people struggling with implementing regimes into their day to day lives.

7.4.3 Conclusion

The GENIE tool, a social network intervention has yielded positive outcomes in reduction in health utilisation costs and network engagement. This study begins to broaden the understanding of possible new approaches to how to encourage and use social support networks in community COPD patients. Which could now be investigated in a larger population of people with COPD for a longer period.

7.4.4 List of abbreviations

Self-Management Support (SMS)

Chronic Obstructive Pulmonary Disease (COPD)

Generating Engagement in Network Support (GENIE)

British Lung Foundation (BLF)

National Institute of Clinical Excellence (NICE)

Global Initiative for Chronic Obstructive Lung Disease (GOLD)

COPD Assessment Tool (CAT)

Patient Health Questionnaire (PHQ-9)

Generalised Anxiety Disorder (GAD-7)

EuroQoL instrument (EQ5D)

Client Service Receipt Inventory (CSRI)

Ethics Research Governance Online (ERGO)

Health Research Authority (HRA)

Personal Social Services Research Unit (PSSRU)

Agenda for Change (AFC)

7.4.5 Declarations:

Author Contributions

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LW designed, led and coordinated the trial in clinical practice, and authored the manuscript. RO provided the health economic analysis, XL the statistical support, AR and IIV were the project supervisors and reviewed and edited for publication. All listed authors have read and approved the manuscript.

7.4.6 Ethical approval

Submitted and ethically approved by Hampshire Ethics B; Project ID 204159; Rec reference number 16/SC/0627. Informed consent was gained in all participants.

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7.4.7 Disclaimer/conflicts of interest

No conflicts of interest stated by authors

Trial registration: Clinical Trials.gov PRS National Library of Medicine

Protocol ID number: 19175, Clinical Trial ID: NCT02935452

Data Statement: The study data and materials have been made available via the Dryad data repository: https://doi.org/10.5061/dryad.2mn5v02 . A further clean copy of the data sheet has been appended to this submission.

Consent for publication: The data is anonymised, so no direct permissions were required

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Chapter 8 Findings from an exploration of a social network intervention to promote diet quality in older adults with COPD: a feasibility study

Summary – This chapter is in the format of a published paper. This paper provides evidence of the evaluation of the acceptability of the GENIE tool in people with COPD, and the clinical team. It adds further evidence to the acceptability of the GENIE tool and evidences the potential of the tool to be utilised in a wider context; behaviour change and diet quality.

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Authors' contributions: IB and LW have joint first authorship on this paper. LW designed the main study and sought ethical approval for the sub-study, led and coordinated the trial in clinical practice, collated field notes and observational data, interpreted the observational data and contributed to writing the first draft of the paper. IB developed the research questions for the sub-study described in this article and developed the questionnaire that was used to collect data on health behaviours in this study; she performed the statistical analyses, interpreted the results of the analyses, and contributed to writing the first draft of the paper. AR and IV were the project supervisors and reviewed and edited for publication. KJ provided statistical support. CC contributed to oversight of the project and to interpretation of the data. SR and JB conceptualised the work, contributed to the analysis plan and interpretation of the data, and contributed to oversight of the project. All authors helped to draft the manuscript and approved the final version.

8.1 Abstract

Background: Diet quality in older people with Chronic Obstructive Pulmonary Disease (COPD) is associated with better health and lung function. Social factors, such as social support, social networks and participation in activities, have been linked with diet quality in older age. A social network tool – GENIE (Generating Engagement in Network Involvement) – was implemented in a COPD community care context. The study aimed to assess the feasibility of the GENIE intervention to promote diet quality and other health behaviours in COPD.

Methods: Twenty-two community-dwelling older adults with COPD were recruited from a local COPD Service. Participants were offered usual care or the GENIE intervention. Process evaluation methods were used to assess intervention implementation, context and mechanisms of impact; these included observations of patient interactions with the intervention, documented in observational field notes and in films of a patient group discussion. Diet quality was assessed by food frequency questionnaire; 'prudent' diet scores were used to describe diet quality at baseline and at 3-month follow-up. Change in diet quality was expressed per month, from baseline to follow-up.

Results: Feasibility data showed that the GENIE intervention could be implemented in this sample of community-living older people. The intervention was acceptable to clinicians and older people with COPD, especially for those with less severe disease, when facilitated appropriately and considering the levels of literacy of participants. There was no significant change in diet quality in the intervention group over the follow-up period (median change in prudent diet score per month, (interquartile range (IQR)): 0.03, (-0.24 – 0.07)); whereas an overall fall in diet quality was observed in the control group (-0.15, (-0.24 – 0.03)).

Conclusion: The process evaluation findings suggest that this intervention is feasible and acceptable to both patients and clinicians. Although the sample size achieved in this study was small, findings suggest that the intervention may have a protective effect against declines in diet quality, and other health behaviours, in an older COPD population. Findings from this feasibility study indicate that further evaluation of the GENIE intervention is warranted in a larger study, with a longer follow-up.

Trial Registration: ClinicalTrials.gov, NIH U.S. National Library of Medicine, NCT02935452. Registered 17 October 2016, https://clinicaltrials.gov/ct2/show/NCT02935452?term=02935452&cond=Copd&cntry=GB&rank=1.

Keywords: ageing, diet, COPD, feasibility, GENIE, health behaviours, older adults, randomised controlled trial, social networks.

8.2 Background

Maintaining adequate dietary intakes in individuals with Chronic Obstructive Pulmonary Disease, and indeed in older age, is key for health and wellbeing (Hanson et al, 2014, Drewnowski et al, 2001). Better diet quality, broadly indicating greater adherence to recommendations for a ‘healthy’ diet (for example, higher intakes of fruit, vegetables, oily fish, and whole grains), has been associated with better lung health and lung function (Shaheen et al, 2010, Hanson et al, 2014), as well as reduction in disease risk and frailty (Reedy et al., 2014, Milte and McNaughton, 2016). However, despite the recognised importance of diet for health in older age, there is evidence that poor diet quality is common in older adults, including in the UK (McNaughton et al, 2012, Maynard et al, 2006, Irz et al, 2014). Thus, there is a need for effective interventions to promote healthy eating among some older people living in the community.

Cross-sectional studies have found that older men and women who live alone have poorer diet quality than those living with a partner (Dean et al, 2009, Irz et al, 2014). Both living alone and having less frequent contact with friends exacerbated the effect of widowhood on decreasing vegetable variety, suggesting that support from friends may compensate for the lack of a partner (Conklin et al, 2014, Friedman et al, 2014). Social relationships could enhance resilience in older people, when these precede, and continue throughout, periods of adversity (Blane et al, 2011). Moreover, involvement in leisure activities could become increasingly important with age and could contribute to resilience in older people (Nimrod and Shira, 2014). Consistent with these messages, findings from a recent qualitative study suggested that social and psychological factors might mediate the influence of a range of background or contextual ageing-related factors (including bereavement, medical conditions, and environmental factors, such as access to shops) on the diets of community-living older people (Bloom et al, 2017). This study posited that greater social engagement and stronger social relationships may offset the effects of some of the barriers to eating a healthy diet that often come with the ageing process.

The increasing evidence that social factors might be important influences on older people’s diets highlights the potential of aspects, such as social engagement, to be modifiable factors to include in strategies to enhance the diets of older people. Currently, there is limited consideration of social engagement in the design of interventions aimed at promoting healthy eating among older people (Zhou et al, 2018). Interventions to enhance diet quality in older age could add value to the long-term health of older people and those with long-term conditions in the community. Indeed, improving health behaviours, including diet, in patients with COPD could be a valuable clinical intervention for managing the condition.

In the present study, the GENIE (Generating Engagement in Network Involvement) social network intervention tool was used in a randomised controlled trial feasibility study. GENIE is designed to work by ‘initiating positive disruption of established self-management practice through mapping of and reflection on personal network membership and support’, which presents ‘possibilities for reconstructing self-management differently from current practice’ (Kennedy et al, 2016). The GENIE intervention has been shown to improve engagement with resources and connections that support self-management in people with type 2 diabetes (Kennedy et al, 2016); furthermore, there are indications of a positive impact on health outcomes and quality of life (Blakeman et al., 2014).

The Medical Research Council framework for complex interventions sets out various phases in the process of development and evaluation, all the way through to post-evaluation implementation, of a complex intervention (Craig et al, 2008). One of the key phases of this process is assessing feasibility of the intervention, to test procedures, determine acceptability of the intervention, and estimate recruitment and retention. In keeping with this framework, we carried out a feasibility study and an exploratory evaluation of the intervention, in the context of an older population with debilitative respiratory disease, which can restrict mobility and confidence due to tissue wasting and episodes of breathlessness; the next phase would be to conduct a definitive evaluation of the intervention.

Using a randomised controlled trial (RCT) design, the aims of this feasibility study were: 1) to pilot outcome data collection methods and develop process evaluation methods that could be used in a larger study, 2) to assess the feasibility of scaling this study up into a larger future study, and 3) to assess the potential impact of GENIE on diet quality, and other health behaviours and health outcomes, in a group of older community-dwelling adults with COPD and to compare changes in the outcomes of interest with those in a control group. This feasibility study intended to clarify various aspects, including the number of eligible patients; the willingness of clinicians to recruit participants and the willingness of participants to be recruited and randomised (recruitment); follow-up rates, response rates to questionnaires (retention); the practicality of delivering the intervention in a COPD clinic; the acceptability of the intervention to older adults with COPD, to understand what adaptations might be required in this population. In this feasibility study we carried out a small randomised controlled trial for the main purpose of testing trial processes, and the potential of the intervention.

8.3 Methods

Patients were recruited from the east of Southampton, which covers the areas with some of the highest deprivation in Southampton city (Council, 2015) and COPD prevalence (Primary care Framework, 2010-11). Patients were selected for recruitment during attendance at the local COPD Pulmonary Rehabilitation programme. Information about the study was provided in either an accessible information format, or the usual format for patient information.

Patients aged from 18 to 95 years of age, with a diagnosis of COPD, living in the east of Southampton were eligible to participate. Patients of all COPD disease severities were included. Patients without a clear COPD diagnosis or unable to give informed consent were excluded. Patients lacking fluent English language, on an end of life pathway, or with major psychological illness were also excluded.

Community patients were booked for a baseline visit at a local health centre, where informed consent was obtained, baseline questionnaires were administered, and participants were randomised. Participants in the control group received usual clinical care (discharge planning with suggested activities, usually exercise therapy), and those in the intervention group received the GENIE intervention (in addition to usual clinical care). Block randomisation was used, a commonly used technique in clinical trial design that aims to reduce bias and achieve balance in the allocation of participants to treatment arms (Efird, 2011). To further reduce unconscious bias of the researcher, pre-prepared envelopes containing the possible combinations of group allocation (Group A-intervention or B- Control), were stored in a locked drawer on site at the health centre.

This feasibility study was embedded in a larger study that aimed to implement and evaluate the use of the GENIE intervention tool in a Southampton Integrated COPD Service. Participation in the present feasibility sub-study was optional, as it included a further questionnaire that may have added a burden to some participants. In order to prevent biased selection, participation was offered on a first come first serve basis; in this way, the sub-group was also part of the randomisation process above. The sub-study aimed to recruit around 30 people to understand feasibility of the study and usability of the questionnaires. However, due to the large amount of detailed data collection required for the sub-study, after 22 patients had been interviewed, and in discussion with other members of the study team, it was deemed that enough data had been gathered. **Figure 6** shows the CONSORT flow diagram, which also depicts the relationship between this study and the larger study. The CONSORT 2010 feasibility study checklist has been appended (see **Additional file 1**).

A follow-up visit was booked approximately 3 months (12 weeks) from the day of the baseline visit. Participants were invited back, via letter and/or phone call, to attend the three-month follow-up visit at the local health centre. At this visit, questionnaires were administered to collect follow-up data.

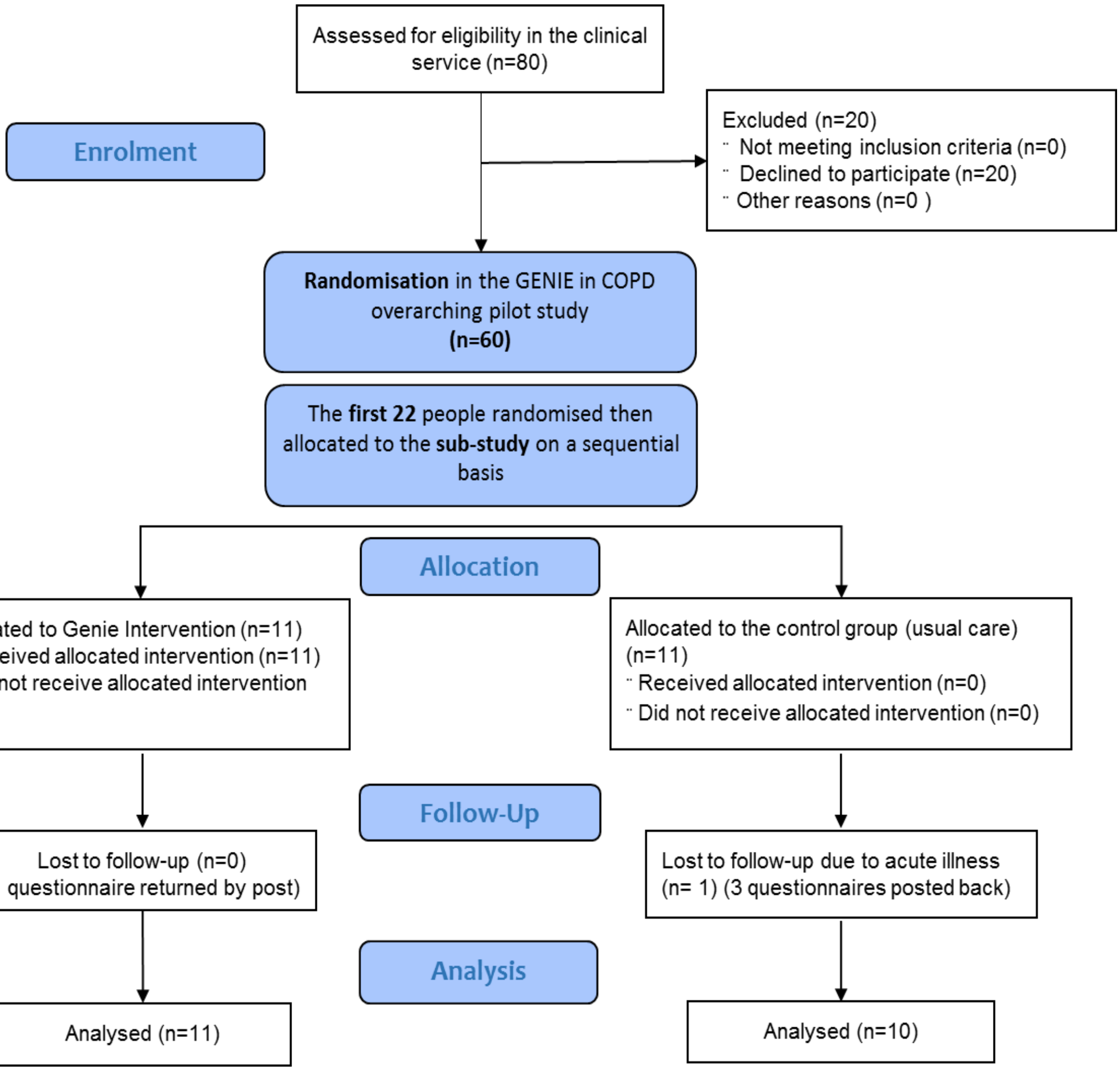


Figure 8. CONSORT flow diagram for the feasibility study (CONSORT).

The Generating Engagement in Network Involvement (GENIE) intervention

Kennedy and colleagues developed the GENIE intervention using an evidence-based and theoretically-driven approach (Kennedy et al., 2016), moving away from the more individualised models of self-management support and behaviour change, towards a more collectively orientated approach, with recognition of the social and environmental influences on self-management and health behaviours. The social network approach has been shown to improve health-related outcomes (Kennedy et al., 2016). The GENIE intervention and web-based tool were developed to take a multi-level, network approach to self-management support, to ‘improve people’s ability to navigate and negotiate support available from within personal social networks and extend this to engagement with local groups and organisations' (Kennedy et al., 2016, Rogers et al., 2011).

The GENIE social networking tool is a facilitated online tool, designed to map an individual's network of support, for reflection on its composition, to elicit preferences and signpost the individual to valued social activities. The tool has a database, which for the purposes of the broader study in which this feasibility study was nested, was manually programmed with COPD-specific (plus existing generic) online and offline resources, groups and organisations. The organisations were recognised charitable and clinical support groups local to the east of Southampton and local community groups recommended by the Itchen Region Councillor, who was supportive of the development of community solutions for residents. **Figure 7** shows the GENIE intervention in a logic model to elucidate the theoretical underpinnings, in terms of promoting diet quality and health behaviours in community-living older adults with COPD.

The process of delivering the GENIE intervention can be broken down into distinct stages (Kennedy et al., 2016) (for visual representation of the stages and examples see **Additional file 2**):

Stage 1: The participant is supported through a mapping process of their current social support with the facilitator, using a concentric circles approach.

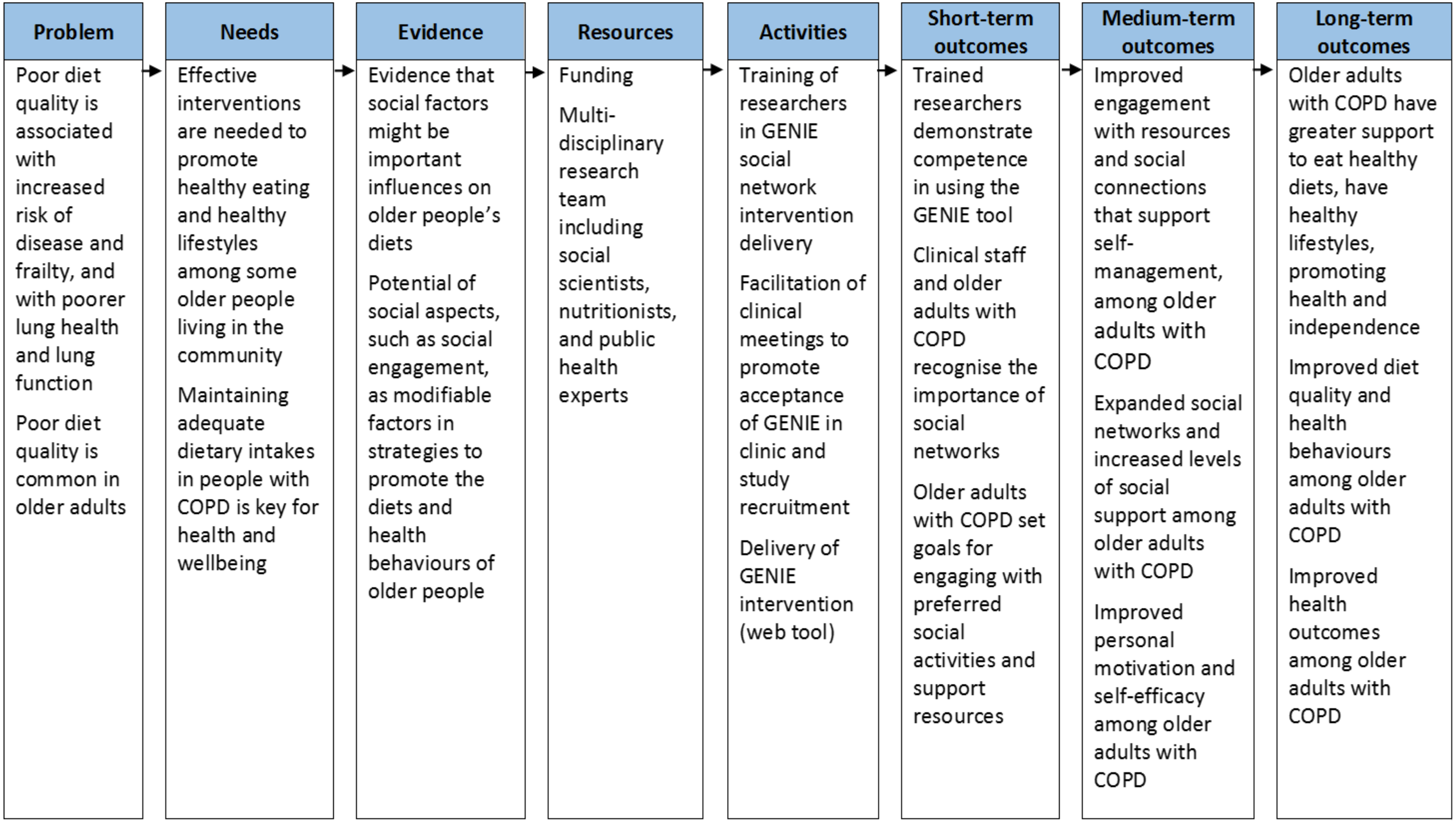
Stage 2: The concentric mapping promotes conversation to elicit values and key preference questions in the intervention highlight preferred activities and support resources.

Stage 3: Linking individuals to prioritised and valued activities and resources (links are to a pre-created database where local organisations and resources have been categorised).

Stage 4: The GENIE tool then presents options in a user-friendly way, on a Google map with clear details about access.

The GENIE tool was delivered face-to-face using a computer, by trained researchers (LW and CA). The delivery of the GENIE intervention took 45 minutes to 1 hour. Participants had the option to have a link sent to their email to log into the website later if they wished.

Usual care was also provided to the GENIE intervention group and the control group. Usual care consisted of the Pulmonary Rehabilitation discharge pack; containing a British Lung Foundation (BLF) exercise DVD and guidance, information about Local BLF Breathe Easy support groups and local walking groups.



Problem	Needs	Evidence	Resources	Activities	Short-term outcomes	Medium-term outcomes	Long-term outcomes
Poor diet quality is associated with increased risk of disease and frailty, and with poorer lung health and lung function Poor diet quality is common in older adults	Effective interventions are needed to promote healthy eating and healthy lifestyles among some older people living in the community Maintaining adequate dietary intakes in people with COPD is key for health and wellbeing	Evidence that social factors might be important influences on older people's diets Potential of social aspects, such as social engagement, as modifiable factors in strategies to promote the diets and health behaviours of older people	Funding Multi-disciplinary research team including social scientists, nutritionists, and public health experts	Training of researchers in GENIE social network intervention delivery Facilitation of clinical meetings to promote acceptance of GENIE in clinic and study recruitment Delivery of GENIE intervention (web tool)	Trained researchers demonstrate competence in using the GENIE tool Clinical staff and older adults with COPD recognise the importance of social networks Older adults with COPD set goals for engaging with preferred social activities and support resources	Improved engagement with resources and social connections that support self-management, among older adults with COPD Expanded social networks and increased levels of social support among older adults with COPD Improved personal motivation and self-efficacy among older adults with COPD	Older adults with COPD have greater support to eat healthy diets, have healthy lifestyles, promoting health and independence Improved diet quality and health behaviours among older adults with COPD Improved health outcomes among older adults with COPD

Figure 9. Logic model for the GENIE intervention, to promote diet quality and health behaviours in community-living older adults with COPD.

8.4 Outcome Measures

Quantitative outcome measures were collected at baseline, and at the 3-month post-intervention follow-up visit.

Diet was assessed using a short food frequency questionnaire (FFQ), which has been developed to assess diet quality in older adults (Robinson et al., 2018). In this feasibility study, ‘prudent’ diet scores were calculated for each participant at baseline and follow-up, based on their consumption of nineteen foods, that indicated the participant’s compliance with the ‘prudent’ dietary pattern, and was used as an indicator of diet quality (Robinson et al., 2018). High prudent diet scores indicate diets characterised by frequent consumption of fruit, vegetables, wholegrain cereals and oily fish but low consumption of white bread, added sugar, full-fat dairy products, chips and processed meat (Robinson et al., 2018). Changes in prudent diet scores (representing change in diet quality) were expressed per month, from baseline to follow-up.

Further outcomes measures included participant-reported changes in alcohol consumption, smoking status, body mass index (BMI), appetite, physical function, and total physical activity. Expressed per month, from baseline to follow-up; change in alcohol consumption and smoking was expressed over the entire follow-up period.

Height (cm) and weight (kg) were obtained from participants’ most recent clinical records, usually within the preceding 6-9 months, or weighed at baseline and BMI (kg/m^2) was calculated for each participant. Appetite was assessed using the Simplified Nutritional Appetite Questionnaire (SNAQ), which has been shown to predict weight loss in community-dwelling older people (Wilson et al, 2005). Data on physical function were collected using self-reported assessment of physical function (SF-36 physical functioning (PF) domain – SF-36 PF); poor physical function was defined as being in the bottom sex-specific fifth. Data on physical activity were collected using the International Physical Activity Questionnaire (IPAQ) Short Form; in accordance with IPAQ, physical activity level was calculated and categorised as either low, moderate or high activity (IPAQ, 2005).

At baseline, demographic data were also collected from participants on age, gender, age they left school, highest level of qualification attained, job or occupation, the number of people living in the participant's household, and the number of regular visitors received. FEV1 values were recorded to ascertain the level of COPD severity.

8.5 Statistical Analysis

Baseline and follow-up descriptive characteristics were reported as mean with standard deviation (SD) for continuous normally distributed variables, median with interquartile range (IQR) for continuous variables with a skewed distribution, or counts and percentages for categorical variables, as appropriate. Descriptive statistics for health behaviours and health characteristics were presented separately by participant group (intervention and control). Given the small sample size of this feasibility study, there was a lack of statistical power to detect differences between the participants groups (intervention vs. control); statistical tests would be performed in an adequately powered future full-scale study. Data were analysed using Stata version 14.2.

8.6 Process evaluation

The process evaluation of this study is guided by the Medical Research Council guidance on process evaluation of complex interventions (Moore et al, 2015). At the feasibility stage, process evaluation is essential to understand the viability of the intervention and to optimise its design and evaluation for a full-scale study (Moore et al, 2015). We assessed the implementation of the GENIE intervention (in terms of reach, recruitment and retention, fidelity, dose offered, adaptations and dose received), the mechanisms of its impact, and context, in interviews with participants and clinicians in the COPD service. Observations of participant interactions with the intervention, during the introduction of the intervention to participants, and the implementation and delivery of the intervention, were captured by one of the researchers (LW). These were documented as observational field notes and captured in video recordings during informal discussions with a group of participants who had received the GENIE intervention and were part of a COPD support group. Further observations were made at clinical multi-disciplinary team meetings, in which the GENIE intervention and online tool were introduced to clinicians. Field notes of subsequent conversations with clinicians were also collated. These observations were discussed with, and triangulated by a second researcher (AR), who also attended clinical team meetings.

Field notes were written into an ethnographical interpretivist account by LW. This account was shared with another researcher (IB) and reviewed in conjunction with the video recordings in order to evaluate the implementation process and draw conclusions regarding the acceptability of the intervention. This was broadly a narrative analysis (Crossley, 2000), making sense of the participant and clinician stories, both in written and video format. These accounts of the implementation of the GENIE tool were applied to the elements of the process evaluation (fidelity, adaptation, reach, dose, recruitment and retention), in order to evidence each component of the process evaluation, through the participant narrative. In order to further contextualise the components of the process evaluation, we aimed to assess the context into which the intervention was introduced. The field notes and observations that were collected spanned the whole process, ranging from early introduction and acceptability of the GENIE tool to the clinical team, to the political and cultural context of the healthcare setting and the process of delivery. In order to enable broader implementation of the GENIE tool in the COPD service (the aim of the wider study), change and change negotiations were required on multiple levels of the service. Local groups and resources in the community around the COPD service in which the patients lived and worked were assessed by a researcher (LW) and, if appropriate, were added into the GENIE resource database. To facilitate an understanding of the mechanisms of impact of this intervention, participant uptake of social activities was recorded, using the GENIE tool, for comparison between baseline and follow-up. For those in the intervention arm, feedback and reflection discussions were initiated using the network diagrams.

8.7 Results

Twenty-two people were recruited to this study; 11 participants were randomised to each group and 1 participant was lost to follow-up in the control arm **(Figure 6)** shows the study CONSORT diagram). For a small number of participants in the control group there are missing data at follow-up, due to participant time commitments outside the study and reported questionnaire fatigue. Some participants were unable to attend a follow-up appointment and therefore questionnaires were posted to them; in some cases, not all the pages of the questionnaires were completed, and some were missed. However, all data relating to diet was captured.

Tables 9 and 10 show the baseline characteristics of the study population. **Table 9** shows baseline and follow-up characteristics of study participants by group, there is a description of baseline health behaviours and other characteristics, for the whole study population combined, in the text below. At baseline, participants were aged between 61 and 82 years and 41% of participants lived alone. In terms of their COPD disease severity, for half of participants this was moderate (n=11), while for 36% (n=8) it was severe. While all participants had smoked at some stage during their lives, only 9% (n=2) smoked at the time of baseline data collection. At baseline, most study participants (82%) consumed alcohol, median BMI was 25.7 kg/m^2 (IQR 21.7 – 29.5), and over a third (36%) of participants had poor appetite. Over a quarter (27%) of participants had low physical activity, at baseline. In this small group, given the sample size, there was a lack of statistical power to detect differences between intervention and control groups at baseline.

Table 10. Baseline characteristics of the study cohort - background characteristics.

	All			**Intervention**			**Control**		
	N	**Median**	**IQR**	**N**	**Median**	**IQR**	**N**	**Median**	**IQR**
Age	22	70	67 - 77	11	70	68 - 71	11	77	66 - 82
	Total N	**N**	**%**	**Total N**	**N**	**%**	**Total N**	**N**	**%**
Gender	22			11			11		
Male		13	59.1		8	72.7		5	45.5
Female		9	40.9		3	27.3		6	54.6
Age left school – category	22			11			11		
<15		3	13.6		0	0		3	27.3
≥15		19	86.4		11	100		8	72.7

	All			Intervention			Control		
Highest Qualification – category	21			10			11		
None		4	19.1		1	10		3	27.3
O/A levels/Vocational qualifications		14	66.7		6	60		8	72.7
Degree or higher		3	14.3		3	30		0	0
Job/occupation – category	21			10			11		
Manual		11	52.4		5	50		6	54.6
Non-manual		10	47.6		5	50		5	45.5
Number of people in household	22			11			11		
1		9	40.9		4	36.4		5	45.5
2		13	59.1		7	63.6		6	54.6
	N	**Median**	**IQR**	**N**	**Median**	**IQR**	**N**	**Median**	**IQR**
Regular visitors	22	4	2 - 6	11	4	3 - 6	11	4	2 - 7
	Total N	**N**	**%**	**Total N**	**N**	**%**	**Total N**	**N**	**%**
Disease severity [a]	22			11			11		
Mild		2	9.1		2	18.2		0	0
Moderate		11	50		6	54.6		5	45.5
Severe		8	36.4		3	27.3		5	45.5
Very severe		1	4.6		0	0		1	9.1

[a] Disease severity (categorised as mild, moderate, severe or very severe based on the GOLD classification (GOLD., 2018)).

	All	Intervention	Control

Table 11. Health behaviours and other health characteristics of participants, by group, at baseline and at follow-up.

	Intervention group						Control group					
	Baseline			Follow-up			Baseline			Follow-up		
	Total N	N	%	Total N	N	%	Total N	N	%	Total N	N	%
Currently drink alcohol	11	8	72.7	11	7	63.6	11	10	90.9	8*	6	75.0
Currently smoke	11	1	9.1	11	1	9.1	11	1	9.1	8*	1	12.5
	N	Median	IQR	N	Median	IQR	N	Median	IQR	N	Median	IQR
BMI (kg/m^2)	11	26.5	21.7 - 29.5	11	26.3	21.9 - 29.4	11	24.2	20.7 - 30.1	8*	23.0	21.3 - 29.7
Prudent diet score	11	0.31	-0.61 – 1.26	11	0.47	-0.04 – 0.70	11	0.96	0.26 – 1.71	10**	0.39	-0.16 – 0.97
Total SNAQ score	11	16	13 - 18	11	14	11 - 16	11	14	12 -16	7*	13	11 -16
	Total N	N	%	Total N	N	%	Total N	N	%	Total N	N	%
SNAQ category [a]	11			11			11			7*		
SNAQ score <14		3	27.3		4	36.4		5	45.5		4	57.1
SNAQ score ≥14		8	72.7		7	63.6		6	54.6		3	42.9
Physical activity category [b]	11			11			11			10**		
Low activity		3	27.3		5	45.5		3	27.3		4	40.0
Moderate activity		4	36.4		2	18.2		3	27.3		3	30.0
High activity		4	36.4		4	36.4		5	45.5		3	30.0

	Intervention group						Control group					
	Baseline			Follow-up			Baseline			Follow-up		
	N	Median	IQR	N	Median	IQR	N	Median	IQR	N	Median	IQR
Total physical activity [c]	11	520	240 - 1500	11	280	60 - 1680	11	920	210 - 1560	9*	245	150 - 440
Physical function score (SF-36)	11	30	15 - 55	10*	40	15 - 55	11	25	20 - 50	8*	30	15 - 40
	Total N	N	%	Total N	N	%	Total N	N	%	Total N	N	%
Poor physical function [d]	11	3	27.3	10*	3	30.0	11	2	18.2	8*	2	25.0

[a] Total SNAQ (Simplified Nutritional Appetite Questionnaire) score <14 (low appetite). [b] Physical activity scores were categorised into three categories (low, moderate or high activity). [c] Total physical activity performed, in minutes, per week. [d] Physical function scores (SF-36) were categorised to reflect whether or not participants had 'poor physical function' (if their physical function score was in the sex-specific bottom fifth of the distribution). * Missing data due to questionnaire non-completion. ** One participant in the control group dropped out of the study due to hospitalisation.

8.8 Outcome analysis

Median change in prudent diet score (per month) in the whole cohort was -0.09 (IQR -0.24 – 0.06). There was no significant change in diet quality in the intervention group over the period of follow-up (median change in prudent diet score per month Inter quartile range (IQR): 0.03, (-0.24 – 0.07)); whereas an overall fall in diet quality was observed in the control group (median change in prudent diet score per month (IQR): -0.15, (-0.24 – 0.03). Although this is suggestive of beneficial effects of the intervention on diet quality, the sample size was limited to detect differences between the groups (**Table 3**).

Table 12. Assessment of the change in outcome variables, between baseline and follow-up, in the intervention and control groups.

Outcome[1]	Intervention group	Control group
Change in prudent diet score	0.03 (-0.24 – 0.07)	-0.15 (-0.24 – 0.03)
Change in BMI	-0.02 (-0.42 – 0.24)	0.18 (-0.13 – 0.20)
Change in appetite score [a]	-0.23 (-0.89 – 0)	0 (0 – 0.45)
Change in physical function score [b]	0 (-2.16 – 3.71)	-2.46 (-3.38 – 0.55)
Change in total physical activity [c]	-51.81 (-66.81 – 54.91)	-167 (-365.62 – -29.53)

[1] All change outcomes are expressed per month, from baseline to follow-up, as median (IQR).

[a] Change in total SNAQ (Simplified Nutritional Appetite Questionnaire) score. [b] Change in physical function score (SF-36). [c] Change in total physical activity performed, in minutes, per week.

There were few current smokers and there was little change in smoking or alcohol consumption status.

There was little change in BMI in either the intervention or control groups over the follow-up period. In the intervention group, there was an overall small decline in appetite over the follow-up period, whereas in the control group there was no change in appetite (**Table 11**). There was no change in physical function in the intervention group over the period of follow-up, while an overall decline in physical function was observed in the control group (**Table 11**). Over the follow-up period, there was an overall fall in total physical activity performed by participants, in both the intervention and the control groups, however the fall was most pronounced in the control group.

8.9 Findings from the Process Evaluation

The implementation of the GENIE intervention was assessed during this feasibility study. Participants were willing to be recruited into the study and appeared to accept the concept of a social tool and recognise the value of social interactions in their disease management. Participants appeared uplifted by the options of choice offered by GENIE and the recognition of the importance of their social world; participants enjoyed discussing their social world rather than constantly focussing on their condition. Participants in the intervention group with less severe disease (mild or moderate) (n=8, 72.8%), were pleased that they had been given permission to socialise more. Participants indicated that the delivery of the intervention suggested to them that clinicians recognised the value of personal social interactions beyond illness management.

However, in the intervention group those with severe disease (n=3, 27.3%) or experiencing frequent exacerbations reported that the intervention was hard to engage with, as their main goal was to 'feel better'. As observed and reported in the field notes, discussions with study participants showed that some of them had low levels of literacy and the language used by GENIE was difficult for many to understand without facilitated support. This points to the key role the facilitator and the face-to-face delivery of the GENIE intervention, which is in line with previous research (Kennedy et al., 2016). Researchers had to read aloud for many of the GENIE tool's online aspects, which made intervention delivery more difficult and time-consuming, as such, in terms of intervention fidelity, the intervention delivery needed to be adapted and the dose of the intervention required adjustment in this population. Some of the participants found it tiring to complete the baseline questionnaires, as well as the online GENIE tool. Researchers found that using lay language to explain the intervention approach (e.g. using the expression 'circle of friends') proved more successful than using the conventional wording on the participant information sheet (PIS). Therefore, an accessible information sheet was prepared and approved to facilitate participant recruitment and retention. The language used in the conventional PIS referred to the study as a student research project, this was reviewed by patients in the service during the recruitment process, who commented that this indicated to them that the study was being conducted for personal gain, rather than patient benefit, and the term 'student' appeared to them to confer less credibility to the study. Furthermore, the digital literacy of participants was also poor; most requested that everything be printed on paper and declined to have the option to log on and use GENIE for themselves online and to interact with any form of technology, this was another adaptation of the intervention delivery in this population, which likely affected the dose of the intervention received. However, the facilitation of GENIE by talking through the process using lay language and providing paper-based printouts of their chosen activities, overcame this for many participants. From our observations, the facilitation process appeared to be cathartic for many of them.

In a discussion with participants, they indicated what they valued about their interactions with GENIE.

> *"Often people are told they've got COPD they go home just sit in the chair and do nothing; therefore the illness takes over, and you just become worse and worse, just wallow in your own self-pity…"* Video quote 1

The GENIE process also encouraged participants to take a step further into friendships, with positive reciprocal gains.

> *"I got all these forms of all different places that I can go in the area which are free … walking and knitting … the GENIE, the idea is for people on their own that don't go out and don't go nowhere, and meet up with people … it's a social circle, the bullseye of the social circle gets bigger…"* Video quote 2

> *"If you're not feeling very well who do you turn to? My mates. … Well family and that are all working…"* Video quote 3

In terms of the context into which the intervention was introduced, clinicians were introduced to the tool prior to the study start. They were initially sceptical, as the tool was patient-led, with the patients guiding the choices of socialisation options, rather than being clinically directed. Over time, and with key clinicians championing the tool, the clinical team started directly referring or signposting patients to the study as they recognised the need for a social intervention as part of COPD patients' usual care. It was through this engagement with the intervention that they were able to reflect on the value of patient networks and the impact that personal social circumstances can have on long-term health, enabling a more holistic clinical appraisal of the multiple needs of patients during routine clinical consultations. Clinician engagement with the GENIE intervention enabled them to develop a more nuanced understanding of its value (e.g. for who it can work, and under what circumstances). Below are quotes from two different COPD clinicians, who spoke to the researchers delivering the intervention at the time of participant recruitment. The first quote is from clinician who is reflecting on their first consultation addressing the social elements of personal care, where they recognised the need for the GENIE social intervention at an earlier stage. The second quote is from a registrar who started to recognise the value of GENIE as a social network intervention.

> *"I have just seen a person who is beyond GENIE. It is so desperately sad that his social world is so confined. He only sees one person; he has no friends and his ex-wife recently died. He feels he no longer has a reason to live. He used to feel comforted to know that his ex-wife was there and alive, even though they didn't interact. I think GENIE is too much, how can we support this man socially?"* *Clinician Quote 1*
>
> *"I have suggested GENIE for this person. There have social needs and are isolated. I have documented this in their notes. Could you see them please?"* *Clinician Quote 2*

The final component of the process evaluation was an assessment of the mechanisms of impact of the intervention. Analysis of the data that was recorded on participant uptake of social activities, to assess the extent to which the intervention might have led to greater engagement with community resources and activities, was not completed for inclusion in this article. However, from discussions with some participants, it seemed that mapping their social world and talking through the concentric circle diagrams was a positive disruption, potentially enough to initiate change in existing habits of socialisation and breaking routines that encroach in long-term conditions.

8.10 Discussion

This paper describes a feasibility study of the GENIE social networking tool used in a population of patients with COPD. The study piloted outcome data collection methods and contributed to the development of the process evaluation methods, both of which could be used in a definitive intervention study. The study assessed feasibility of the GENIE tool in terms of clinician and patient acceptability, and the feasibility of up-scaling into a larger future study. Overall, the study was received positively by participants. Clinicians required time and evidence to fully accept the concept of socially supportive methods into their routine clinical practice. Observations and discussions with clinicians and participants showed that there was a need to address literacy of the study participants and to simplify or modify the language used to introduce GENIE to make it easier to understand in this context.

Process evaluation findings indicate that the health literacy and other characteristics of participants should be an important consideration in the design of a future study. The assessment of intervention implementation suggested that severity of disease may impact the level of engagement with the intervention, including the ability to participate in social/community activities. It is possible that study participants with severe disease interpreted the severity of their COPD symptoms as a crisis; withdrawal from social networks and reduced network engagement can occur in a time of crisis, as a form of self-preservation, and avoidance of difficult relational work (Walker et al, 2018). Hence, there may be a need for an adapted version of the GENIE intervention where the emphasis for people with a higher need for clinical support is not on expanding networks, but rather on reflection on current level of engagement and on the retention of existing social ties. For all participants, thinking or talking through the GENIE mapping tool enabled them to visualize their network and reflect on connections and understand where there might be gaps in social support. A further finding was that early engagement with clinicians, in the conceptual phase, provided a timeframe for discussion and reflection on the study design and conceptualisation of a social network approach to the promotion of health behaviours. Overall, engagement with GENIE was found to be useful for clinicians in the sense that it offered a tangible and manageable process that they could engage with and reflect on the social context of patients. The GENIE tool process evaluation provided valuable insights into the context, reach and accessibility of the tool.

Using a randomised controlled trial design, the study also assessed the impact of GENIE on diet quality, and other health behaviours and health factors, in a group of community-dwelling older adults with COPD and compared changes with those in a control group. Although the sample size achieved was relatively small, the findings suggested potential protective effects of the intervention on diet quality, physical activity and physical function. While in the intervention group there was no change in diet quality over the period of follow-up, an overall decline in diet quality was observed in the control group. For physical function, there was no change in the intervention group over the period of follow-up, while an overall decline was observed in the control group. In addition, while in both groups there was an overall fall in total physical activity performed by participants, the fall was most pronounced in the control group. Against a background of worsening health behaviours, the intervention may have had a protective effect against declines in diet, physical function and physical activity in this population.

While there is some evidence to suggest that social involvement (e.g. links to community groups or organisations) may be associated with the maintenance of healthy behaviours over time in older people (Reeves et al., 2014), there have been few intervention studies with a focus on social components and community engagement that have assessed impact on health behaviours, including diet, in older age.

In the present study, it is not clear why diet quality declined among control participants during the study or why changes occurred in some of the secondary outcomes (including physical function and physical activity) over the course of the study. The study was underpowered to detect differences that might exist between participants in the intervention group and those in the control group, at baseline. Despite random allocation to intervention and control groups, there did appear to be some baseline differences between them. Participants in the control group appeared older than those in the intervention group (median age 77 vs. 70 years), and they had a lower level of education (27.3% vs. 0% left school <15 years; 27.3% vs. 10% had no qualification; 0% vs. 30% had a degree or higher qualification). At baseline, participants in the control group appeared more likely than those in the intervention group to live alone (45.5% vs. 36.4%) and were also more likely to have poor appetite (45.5% vs. 27.3%). Furthermore, participants in the control group appeared more likely than those in the intervention group to have severe or very severe disease at baseline (54.6% vs. 27.3%). It is possible that these differences could potentially account for the decline in diet quality, physical function, and the greater decline in physical activity that were observed among control participants during the study, compared to the maintenance of diet quality and physical function, and overall smaller decline in physical activity, in intervention group participants.

8.10.1 Strengths and limitations

The observational data, patient videos and field notes used in the process evaluation provided insight into the feasibility of the intervention, including the clinical and patient acceptability of the implementation of this novel tool in a clinical setting. The process evaluation helped to identify barriers and challenges of implementation, and possible adaptations that could enhance the design in a full-scale trial (e.g. accessible information, choice of language, possible clinical co-production). The measures that were used to assess the quantitative outcomes were based on self-reported data (except for BMI, for which height and weight were obtained from participants' clinical records or participants were weighed). However, despite their self-reported nature, the measures used to assess diet quality, appetite, physical activity and physical function have been shown to be valid measures within older populations (Robinson et al, 2017, Wilson et al, 2005, IPAQ, 2005, Syddall, 2009). The overarching RCT design is a strength of this study, with the presence of the comparison group helping to clarify what the intervention effects were.

However, researchers collecting the baseline and follow-up data also delivered the intervention, so they could not be blinded to the intervention status of participants. The sample size in this feasibility study was small; so, it was less likely to detect differences that might exist between intervention and control groups. For a small number of participants in the control group there were missing data at follow-up, but there were complete data for diet quality, the main outcome of this study. It is also possible that the follow-up period of three months was too short to capture significant changes in diet and other health behaviours; further data collection, in a larger sample with a longer follow-up period would help to explore longer term behavioural changes. At this feasibility stage, mainly qualitative methods were used for the process evaluation. The methods could be expanded upon for the process evaluation of a larger intervention study. In addition to implementer self-report, semi-structured qualitative interviews could be conducted with participants and clinicians to assess implementation, context and mechanisms of impact. Quantitative measures that include structured observations and audio recordings of the intervention delivery could also be used. In a full-scale study, in addition to recording participant uptake of social activities using the GENIE tool (for comparison between baseline and follow-up), it would be important to collect quantitative data on potential mediating social and psychological factors (see Figure 2) (e.g. measures of social networks, participation in social activities, social support, self-efficacy and motivation), to test hypothesised pathways.

8.11 Conclusions

The process evaluation findings of this study suggest that it is feasible, and that the intervention is acceptable to both patients and clinicians. Implemented in a local COPD service, the GENIE intervention was found to be acceptable and appropriate for older people with COPD, especially for those with less severe disease, when delivered by trained researchers. Overall, this feasibility study suggests that the GENIE tool can help people to think about the links they have with others (local groups, friends, family members, professionals) and to reflect on their involvement in social activities.

Although the sample size achieved in this study was small, the findings suggest the potential for protective effects of the GENIE intervention on diet quality, physical function and physical activity. However, it is not clear why diet quality, physical function and physical activity declined among control participants during the study. The 3-month follow-up period of this study was likely too short, and further evaluation is needed in a larger, more diverse group of community-dwelling older adults, with a longer follow-up period, to evaluate how social network interventions could be used to improve diet and health behaviours in older adults with COPD, therefore preventing declines in nutritional status and associated health consequences.

List of abbreviations: BLF: British Lung Foundation; BMI: body mass index; COPD: Chronic Obstructive Pulmonary Disease; FEV1: forced expiratory volume in one second; GENIE: Generating Engagement in Network Involvement; IQR: interquartile range; NHS: National Health Service; NIHR: National Institute for Health Research; SNAQ: Simplified Nutritional Appetite Questionnaire; VC: Forced Vital Capacity.

8.11.1 Declarations

Ethics approval and consent to participate: This study had ethical approval from Hampshire Ethics B; Project ID 204159; REC reference number: 17/SC/0044 (amendment), Original submission REC Reference: 16/SC/0627. Informed consent was gained from all participants.

Consent for publication: No personal identifying data was used in this study report.

Availability of data and material: The study data from the over-arching clinical trial can be accessed via the ClinicalTrials.gov site as above and via the Dryad data repository.

Competing interests: The authors declare that they have no competing interests.

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Chapter 9 Discussion

9.1 Introduction

This thesis has explored the nature and context of contemporary solutions to self-management in people with COPD. The thesis aimed to explore the self-management context, effectiveness, acceptability and implementation of a social network approach to self-management support in a primary care-based COPD population. The scoping literature review provided a broad view of the current clinical context of SMS in COPD, and what current interventions had been employed to support SMS in COPD. The literature was divided into four main categories to discuss the groups of work as a whole, these included: Interventional *SMS studies, systematic reviews, including meta-synthesis, learning from failure*, *consensus statements and expert opinions in COPD self-management, health economic and cost evaluations*.

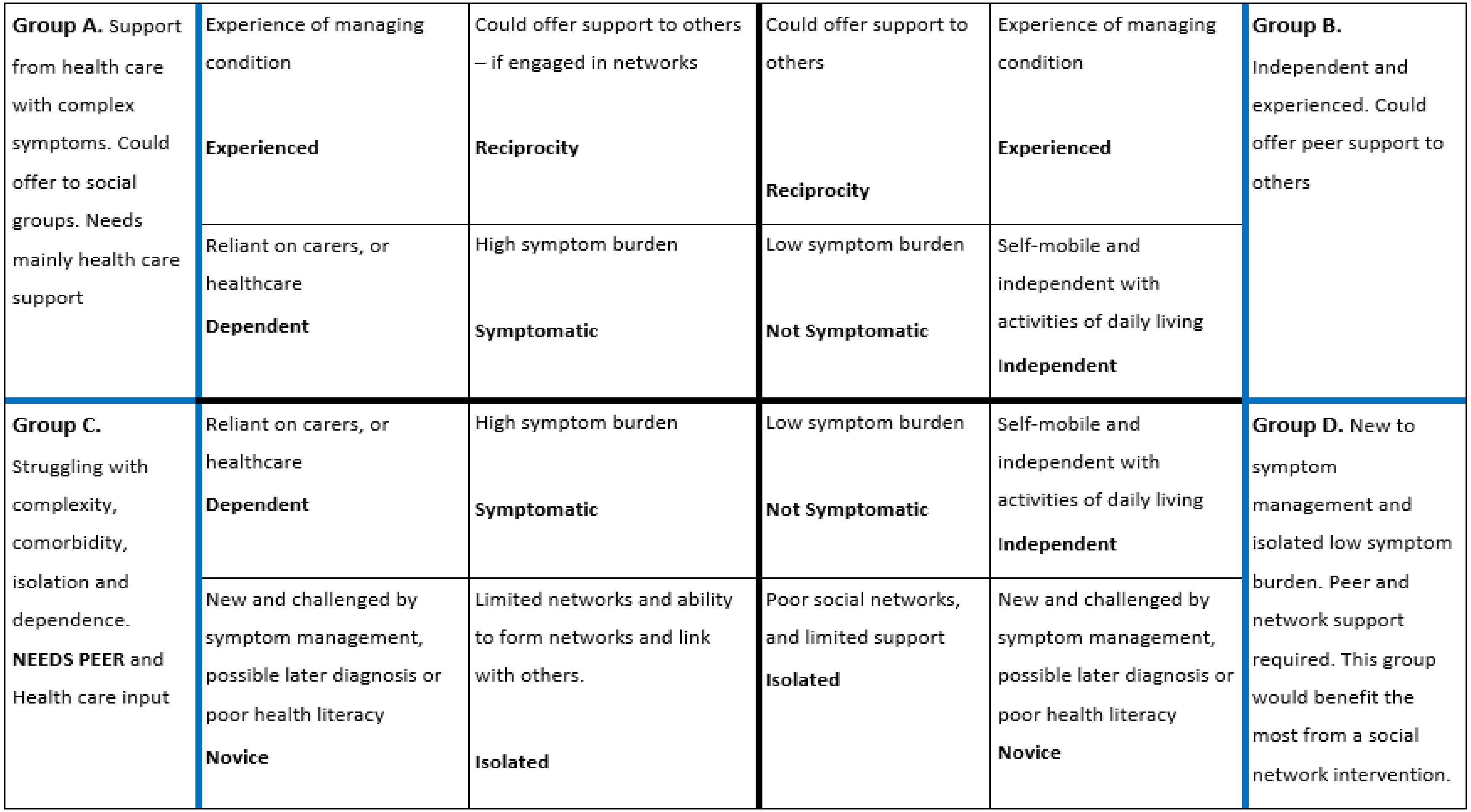
Through these categories SMS support was broadly described in terms of the relative success of SMS interventions, components of success and the cost benefit implications of the interventions. The literature review answered research question 1; in terms of exploring the current challenges with SMS, particularly in people with COPD. However, no one clear solution or intervention existed that can be described as effective and successful in SMS in COPD. Yet, one consistent component that delivered a favourable effect included interventions *with peer contact* (Jonkman et al., 2016). The consensus statement in COPD SMS favoured the targeting of emotional health, and redesigning SMS interventions to promote collective efficacy and increase quality of life and enhance personal wellbeing. The consensus work further supported the concept of building social capital or social infrastructure to positively affect SMS behaviours (Lenferink et al., 2018, Effing et al., 2016).

This body of research was the impetus for this thesis to explore the context in which socially supported SM might be successful, and how it might be integrated into the daily life of a person with COPD. In terms of how and what people with COPD view as success; the qualitative meta-synthesis provided an insight into how people negotiate complex health problems, in order to integrate health behaviours and how they interpret the correct actions, or solutions to these problems.

The meta-synthesis addressed how people with COPD view current SMS support for their condition and explored how people with COPD view current SMS support for their condition and which elements of SMS were valued. In order to do this qualitative literature was analysed to understand the concepts how people with COPD engage and weave aspects of SMS into their daily lives. The meta-synthesis demonstrated that the ability to engage and enact in self-management is driven by a fear of disability and a drive to remain independent for as long as possible, as the disease progresses.

Engagement in self-management is often peer orientated and driven by experience. These personal and peer experiences unconsciously inform choices regarding engagement in SMS activity. Often SMS support is viewed as the management of worsening or deteriorating symptoms (termed ‘exacerbations’), but consensus from the literature suggested that a spectrum of support for COPD was more appropriate and acceptable (Kaptein et al., 2014). The spectrum is a continuum from action planning alone, through education programmes with action planning to SMS which includes pulmonary rehabilitation and the need for health professional support through integrated care pathways (Kaptein et al., 2014). Often the increased levels of care required are suggestive of the need of people with COPD to require increasing level of support with their SMS, at some level, most of the time. This could be either health professional or peer led support.

However the findings of the meta-synthesis further suggest that this is complicated with feelings of culpability for illness, guilt and self-blame (Franklin et al., 2018). These emotions can inhibit full engagement in personal health-promotional activities and contribute to low mood and low self-worth. Furthermore, diagnostic uncertainty and the trajectory of COPD can add to the challenge around having the confidence to engage, at the right time, for the symptoms that are being experienced. Therefore, successful enactment of SMS in COPD is best illustrated using a dependence – experience continuum, in the form of a conceptual model **(Figure 10)**. Successful enactment of SMS is reliant on positive peer networks and a will of the person to strive for independence. Success at SMS is further reinforced by experience, the length of time with the condition,



Group A. Support from health care with complex symptoms. Could offer to social groups. Needs mainly health care support	Experience of managing condition **Experienced**	Could offer support to others – if engaged in networks **Reciprocity**	Could offer support to others **Reciprocity**	Experience of managing condition **Experienced**	**Group B.** Independent and experienced. Could offer peer support to others
	Reliant on carers, or healthcare **Dependent**	High symptom burden **Symptomatic**	Low symptom burden **Not Symptomatic**	Self-mobile and independent with activities of daily living **Independent**	
Group C. Struggling with complexity, comorbidity, isolation and dependence. **NEEDS PEER** and Health care input	Reliant on carers, or healthcare **Dependent**	High symptom burden **Symptomatic**	Low symptom burden **Not Symptomatic**	Self-mobile and independent with activities of daily living **Independent**	**Group D.** New to symptom management and isolated low symptom burden. Peer and network support required. This group would benefit the most from a social network intervention.
	New and challenged by symptom management, possible later diagnosis or poor health literacy **Novice**	Limited networks and ability to form networks and link with others. **Isolated**	Poor social networks, and limited support **Isolated**	New and challenged by symptom management, possible later diagnosis or poor health literacy **Novice**	

Figure 10. Modified conceptual model of self-management engagement and enactment: The independence and experience model

and the success in managing previous SMS issues (but acute and chronic). This success (or in fact experiential failure) enables a depth of personal experiential knowledge, or *'knowing'* to be enacted in personal self-care. This experience can also extend to reciprocal support of others (Rogers et al, 2009). Social comparisons can enable cognitive adaptation to illness and support psychological adjustment to disease (Rogers et al, 2009). Therefore reciprocity, in terms of supporting others with the illness can encourage personal enactment of SMS. People with COPD considered the maintenance of independence, as the ability to continue engaging in their personally valued activities. Notably these valued activities were not necessarily those activities promoted as positive health behaviours by HCP. This mismatch between HCP views on valued or appropriate activities and personally valued activities was described by Hughes in 2017 (Hughes et al, 2017). This work builds on the controversial principles of people valuing unhealthy practices such as smoking in the case of COPD (Graham, 1987). This study indicates that peer support and engagement with one's social network can help negotiate and bridge the gap between different activities and values of individuals.

Building engagement with peer networks to develop SMS was empirically tested through the GENIE social network tool. The GENIE intervention sought to start reflection and engagement with networks thus disrupting normalised relations and allowing for their renegotiation and extension towards the uptake of different or more diverse social activities. The GENIE pilot study and nested feasibility study addressed research questions 2 and 3; whether a social network approach is feasible in the NHS and beneficial for people with COPD. The pilot study offers promise in terms of network extension, improved quality of life and reduction in anxiety for people with mild, moderate and severe COPD symptoms. However, those people with very severe symptoms, had more debilitating symptoms and higher levels of hospital admissions, compared to those people with mild or moderate symptoms. Therefore, making activity engagement and social diversification, using the GENIE tool in any form more challenging for this group of people with more severe symptoms. This finding suggests that building social capital to enhance peer support, although broadly beneficial, does have limitations in the later stages of the COPD disease trajectory. Therefore, suggesting that there is an optimum time in the disease trajectory to introduce a social tool. Similarly there is a time, in the more severe stages of COPD for a more palliative approach (Halpin, 2018).

Moreover, the GENIE tool was cost effective and well received by people with COPD. The tool has promise in terms of NHS capacity building. GENIE is well suited as a clinical stepping stone; to enable people with COPD who have experienced an integrated care pathway to remain supported, but stay within their peer groups, as they move away from NHS care (Kaptein et al., 2014).

Exploring the processes involved in adapting and introducing the GENIE tool to clinical teams enabled an in depth review of the implementation, using process evaluation (Moore et al., 2015). The nutritional sub-study reported on the process evaluation, the acceptability and workability of the GENIE self-management tool. This study reported the implementation of the Genie tool in terms of reach, retention, fidelity, dose and adaptations (Moore et al., 2015). The process evaluation findings indicate that health literacy and intervention delivery options (online and offline) should be important considerations in the design of a future study. The assessment of the implementation of the intervention further suggests that severity of disease may impact the level of engagement with the intervention, including the ability to participate in social or community activities.

Furthermore, early engagement with clinicians in the conceptual phase, provided a useful timeframe for discussion and reflection on the study design and conceptualisation of a social network approach for the promotion of health behaviours. Overall, engagement with GENIE was found to be useful for clinicians in the sense that it offered a tangible and manageable process that they could engage with and helped them to reflect on the social contexts within which their patients lived.

In terms of providing a tool to increase peer social capital and share experiential knowledge, the GENIE tool was also successful in the context of clinical practice. The GENIE tool engaged clinicians in broadening their approach to COPD management, away from the traditional biomedical model. The GENIE social network tool has the potential to engage people and act as a complimentary addition to existing clinical management options in COPD.

In addition, the nutritional sub-study reported dietary and behavioural findings. These include the motivation of positive protective health behaviours, such as exercise and activity maintenance and continued prudent dietary habits. This is a novel finding in terms of evidencing the protective health effects of a social intervention. Social interaction and peer group disruption therefore has the potential to reshape micro level processes that affect health behaviour (Kaptein et al, 2008).

The thesis is centred on the premise that enhancing social capital through reflection, network disruption, renegotiation of relationships, and community reengagement can enable peer reciprocity and meaningful engagement with valued activities and relationships resulting in positive health activities. This concept supports existing literature in terms of the need to re-conceptualising the COPD SMS paradigm to incorporate and understand the value of emotional and social factors and processes. The positive elements of social capacity building are wider reaching than COPD care alone and extend to older age groups and people with other long-term conditions. The findings support the peer supportive approach to care delivery in COPD. This is a novel avenue to target SMS interventions for people with COPD. This approach suggests that including multiple active interventional components as part of a care pathway will be more successful than a standalone clinical SMS intervention. In order to illustrate this the current position in COPD care could be considered.

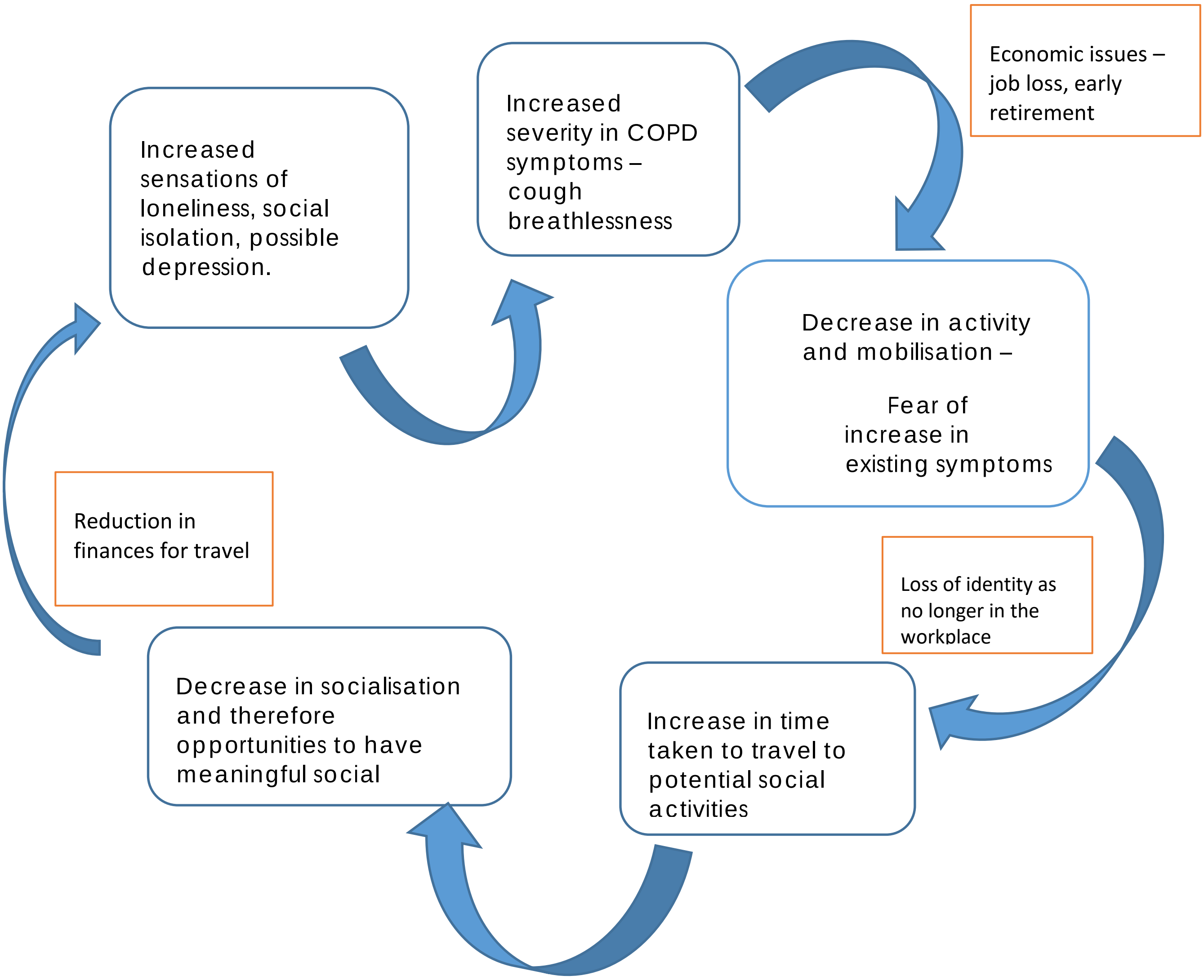
In their patient facing literature, the BLF (BLF, 2012) discuss the nature of mobility decline due to increasing breathlessness and how weak muscles are more oxygen hungry and make more oxygen demands on the lungs thus decreasing mobility and increasing breathlessness are locked in a cycle. If we overlay the biomechanical issues with breathlessness and mobility, with concurrent social decline the requirement for interventions in COPD that target both biomedical needs and address social and emotional issues of living with long term disease are clear.

The theory below is a conceptual model and has been developed by overlaying the known physical concepts of decreasing mobility due to breathlessness with the application of reduction of social mobility and is based on the ‘reduction of weak ties’ theory (Vassilev et al., 2013). The conceptual model created below further illustrates the concept of social decline and social isolation in COPD **(Figure 11. Theory of perpetuation of COPD illness decline and social isolation).**

Figure 11. Perpetuating cycle of poor social interaction in COPD

A conceptual model of the interplay of symptomatic breathlessness and social decline in COPD.

Welch 2018



A conceptual model of the interplay of symptomatic breathlessness and social decline in COPD.

The findings of this thesis are conceptualised through a whole systems approach to supporting self-management. Any effective intervention, should no longer be one ‘thing’ but considered as a continuum of the renegotiation of care needs and personal problem solving involving both health professionals, family and peers (Pinnock et al, 2017). GENIE is a tool to add to the COPD care pathway rather than a standalone intervention. Medical care, medications and respiratory therapies can be complemented with input from social and voluntary support networks which extend beyond the immediate family.

Social networking has been utilised and examined in other long term conditions, in particular diabetes and in the broader capacity of long term condition management (Reidy et al, 2020, James et al, 2020). Furthermore the concept of social network support was applied to chronic kidney disease (Blakeman et al., 2014). This study used telephone guided access to community resources in primary care. The intervention utilised tailored information (via the telephone) to sign-post patients to community resources. The intervention was also modestly successful in terms of improvement of blood pressure control and improvements to health-related quality of life. However, these did not directly translate into increased active engagement in life.

Therefore, the concept of social networking and GENIE are not novel. The adaptions and relative success in COPD are a new interpretation of SMS in this population. The GENIE concept in people with COPD represents an advance in terms of a more sophisticated social networking intervention, which is delivered face to face, with online and offline capabilities. In this way, providing a more accessible platform and with a range of access.

The range of access for GENIE has been brought to the fore in recent months in the COVID-19 pandemic. COVID-19 or (SARS-CoV-2) is a novel global virus, of animal origin which is now transmitted rapidly between people. This virus has posed a huge threat especially for those people who already have a long-term condition, such as COPD. In March 2020 people with long-term conditions, particularly breathing conditions, where advised by the government to ‘socially shield’ (Michie et al, 2020), to remain isolated at home to avoid contracting the life-threatening virus . During the time of the PhD, many people with COPD were entering social isolation between March 2020 and June 2020. At the time of writing (Nov 2020) the COVID pandemic is still a global issue, that has necessitated a second phase of isolation for people with COPD. Therefore, the world into which people with COPD now live in, is confined. The adaptation and move to online technologies have been accelerated by the pandemic. In line with this, and in order to support and reintegrate people with long-term conditions back in to socially fulfilling lives, the GENIE tool could potentially be employed to offer a blended online and offline approach to creating and maintaining social connections. Therefore, a blended adaptation of the GENIE tool enhances the possibilities of using the intervention in clinical practice, in a post-COVID society.

Furthermore, the GENIE intervention demonstrated clinical safety: no participants deteriorated on the trial and the GENIE intervention was successful in protecting positive health behaviours, such as diet and exercise.

Moreover, introducing GENIE into the clinical service has had an impact on the clinical teams. This was an unexpected but a positive finding. The medical and clinical discussions at handover and in multi-disciplinary team meetings began to include reference to a person’s social capacity and related social issues, such as housing, loneliness and engagement with voluntary services. Previously social issues were not considered a priority and were rarely discussed. Physical care needs, and physiological medical discussions were prioritised. The inclusion of this study in the clinical team and the introduction of the scientific evidence for social network engagement, encouraged clinicians to consider the wider holistic needs of the people with COPD in their care. This could have been enabled by the early engagement of the clinical team in the study conceptualisation and design, the team therefore contributed to building a bespoke community resources database, for the GENIE tool, prior to the start of the study.

Enabling and including clinicians in intervention implementation, promoted the possibility of including a social networking tool as part of the existing local COPD care pathway. The GENIE intervention can be timely to deliver, around 45 minutes but does not necessarily require health professionals to deliver the intervention, therefore making this a cost-effective intervention.

Moreover, the GENIE tool has the potential to fulfil a key threshold position in any clinical service. The threshold position could be described as the point when a person is required to step between the care of health professionals and rely on the support of family and voluntary agencies. This means that the GENIE tool could be transferred into several community services, who work in this transitional period of movement between statutory community and voluntary community services. In this way lending itself to a social prescribing model (Drinkwater et al, 2019). Social prescribing can be described as a formalised process of prescribing particular social or physical activities to people, as if it were a medicine. GENIE can be used to redefine how clinicians envisage the COPD pathway and could provide a 'social prescription' as part of a pulmonary rehabilitation discharge plan. Recent work suggests that clinical teams are still not addressing the psycho-social needs of people with COPD. These include wellbeing, stress and fatigue, these are often ignored in COPD education programmes (Siltanen et al, 2020). The GENIE tool has been encouraging in its ability to address wellbeing in people with COPD. There is further evidence to suggest that social involvement (e.g. links to community groups or organisations) may be associated with the maintenance wellbeing and of healthy behaviours over time in older people with COPD, such as diet and exercise (Reeves et al., 2014). Therefore, enabling broader implications and protective care in the current ageing and multi-morbid population.

9.2 Original contributions and impact

This thesis has identified the gap in psycho-social elements of interventions for people with COPD. The original contributions of the thesis to the field of respiratory nursing include the adaptation of an existing social network tool to develop network connections and SMS support for people with COPD.

This thesis has originally conceptualised and modelled,

- Social decline in COPD, overlaid on physical decline and breathlessness cycling.
- Successful adaptation of the GENIE social network intervention in people with COPD.
- A decision table to direct social prescribing, or referral to the GENIE tool/ Social network support; based on the level of symptoms, experience and independence of a person with COPD.

The latter requires empirical testing and development as a clinical intervention.

The work has had a direct impact on clinical practice, through implementation work of a social network tool within the local COPD clinical service. This has changed their clinical approach to COPD care in terms of widening the scope of their clinical processes to include social network support. The acknowledgement, and conceptualization of the value of social network support by health professionals, which extended wider than family and spouses, is an impact reported in the process evaluation. The engagement of medical consultants in maintaining wellbeing, dog walking, groups, breathe easy groups have been a positive impact of the work, that is challenging to objectively measure. The social network concept enhanced my personal clinical practice. It challenged the assumption of the 'holistic' care model in nursing practice. Holistic care is a conceptualised around the inclusion of every part of a person's 'self' being incorporated into clinical care, disease management and clinical decisions. The sense of self, includes the physical, psychological and social self (Ventegodt et al, 2016), when prescribing or directing care all of these aspects should be considered.

However, it could be posited that as a clinical team, we did not truly aspire to a holistic model. Reflecting on the clinical service and my own patient care, we were concerned mainly with the physical health and welfare of people with COPD. People with COPD also came to us wishing to see an improvement in their physical health as they too believed that would enhance their overall wellbeing. However, this was not always possible, as many people were already on maximum treatment. This prompted me to re-direct my own clinical conversations, to address the expectations and values of people with COPD that attended clinic, prior to discussing their physical needs.

Furthermore, the nutritional component of the study, has been valuable in re-conceptualising when clinicians need to intervene and consider dietary interventions in people with COPD. Sarcopenia and later disease muscle and tissue wasting in common in advanced disease (Collins et al., 2012). On further reflection of my own practice, I and other clinicians often visualise the impact of this only when weight loss is measurable, and BMI is falling. Understanding dietary patterns and reduction in nutritional intake earlier on in the disease trajectory provides a modifiable factor to reduce weight loss associated with disease progression. Earlier identification of muscle and tissue loss in people with moderate to severe COPD. This could lead to future development of a nutritional screening tool. The tool could be used in early stage COPD could promote social network diversification as a positive intervention to sustain the protective effects of a varied and quality diet on older age.

9.3 Future Work

The GENIE work has highlighted the clinical need to bridge statutory services with providers from the voluntary and community sector to ensure a continuum of support outside the remits of traditional NHS care. Three opportunities for further research could be taken forward. As the introduction of this tool has been directly within a clinical service there is now the opportunity to re-evaluate the impact of the study on the practice and the values of the clinical team. This could be explored through further qualitative follow up work exploring experiences and continued us of the GENIE tool in people with COPD and their clinicians. The clinical exploration could take the form of research implementation questions to elicit the enduring value of social support networks in COPD. By exploring the nature of clinicians enduring opinions towards social network support is a promising area to understand the long-term feasibility of the GENIE tool as an adjunct to traditional clinical care.

Secondly, in terms of the people with COPD several questions have not yet been addressed through this research. These research questions include who benefits most from social network support; and where on the COPD illness trajectory is the best place to deliver peer network support. This thesis suggests that people with severe COPD, find it difficult to engage in peer support networks, this could be due to the disabling nature of the COPD symptoms (breathlessness and fatigue), but also the extra time required to negotiate more challenging health care routines, increased follow ups, and increased treatment. It is likely to be a combination of the two. However qualitative work will be required to address these questions.

A third avenue for further study could be to develop the conceptual model of enactment and engagement in SMS in COPD; the independence and experience model **(Figure 10),** into a clinical decision-making tool to group people with COPD into either Group A, B, C or D , based on facets of independence, experience, reciprocity, and COPD symptom burden. *Group A* are highly symptomatic yet experienced with their disease management and still socialising. These people may have guidance to offer other people with COPD and would be keen to support others. However, they need advice, guidance and support from health care professionals due to their high symptom burden, so NHS care is still required, in terms of advice and guidance, and therefore this could be at a distance. *Group B* independent, experienced and with a currently low symptom burden, this is the ideal group to engage with peer network support, in a reciprocal manner. *Group B* could reduce their contact with NHS services. *Group C*, this group are symptomatic, dependent on health care, new to having a chronic disease (novice) and extremely isolated. This group requires social network advice and support and face to face NHS care to manage complex symptoms and have the support to negotiate complex symptoms. *Group D,* this group are less troubled by symptoms, and remain independent. However, they have limited social networks and require disease specific guidance. *Group D* would benefit from a social network intervention at this stage, linked to their illness, enabling peer socialisation. As they are independent with a low symptom burden, potentially do not require NHS support at this stage **(Figure 10).**

In this way this model can enable the identification of people who would benefit most from a social network intervention. This tool can enable clinical referral to be independent of the place on the clinical pathway. It could align itself with social prescribing, but would require feasibility work, evaluation and then implementation and follow up (Craig et al, 2008). The main aim in this possible future work would be to develop this model as a nursing intervention to signpost those people with LTC to social support interventions- such as GENIE at the right time in their disease trajectory and mindful of their abilities to negotiate and engage in social interaction and support with others. This could be positioned in primary care and be an integral part of the primary care consultation in people with COPD. Primary Care would currently be an appropriate place to develop the conceptual model of independence and experience, as it aligns with both concepts of social prescribing (Drinkwater et al, 2019) and is in line with the 20/21 enhanced service specifications of the GP Primary care contract (British Medical Association (BMA), 2020). The move to Primary care Networks has influenced to contract favourably towards enhancing social support including the addition of social prescribers and care -coordinators to the workforce (British Medical Association (BMA), 2020).

In order to develop this model to be acceptable and feasible for clinicians and people with COPD, then a co-production approach (Yardley et al, 2015) would enable broad stakeholder input in development and evaluation of the model, in to clinical tool. In terms of social prescribing, this should include both the potential prescribers (the users) and the recipients (the end-users) those people who consider themselves to have an LTC. The tool could initially be developed with both users and end users, clinicians, social navigators, and people with LTCs in a consensus group. Discussing and ranking the key elements that enable a person to be grouped as either dependent, socially networked, novice (length of time diagnosed), and defining symptom burden. In this way the elements of the tool could be combined to identify the correct ‘group’ for someone with an LTC. This process would then need to be piloted in clinical practice, ideally as part of an existing social prescribing model, perhaps in primary care. This future work could be developed as a post-doctoral project.

9.4 Limitations

Several limitations were identified across the project. The empirical study and the literature review were limited by sample size. The empirical work was a pilot and a sub-study and had a limited sample size. Furthermore, the sample group of participants with COPD who volunteered for the study were not representative of the usual ethnic diversity of the wider population of people with COPD. This could have been rectified by recruiting from the whole city, rather than just a region of the city. In this case the ethnicity was representative of the recruitment reach.

Overall, the findings from the pilot study are positive, however, the study was offered to people already engaged in pulmonary rehabilitation (PR). One could argue that they were already motivated and engaged in a form on self-management as they were in a group education and exercise setting. However evidence also indicates that although people with COPD do well in terms of increasing exercise capacity and disease management in PR, the protective effects of PR subside and engagement falls, once people are no longer in the group setting (Bender, 2014) (Collins et al., 2014). So, a post PR interventional study remains justified.

The nutritional sub-study was particularly small (30 people). This did enable a process evaluation and the depth of data was evaluated. Unfortunately, the quantitative findings from this work lacked the statistical power to be reflective of a potentially wider cohort.

The meta-synthesis was limited and only included five papers, however, in its defence did resynthesize the work, so a larger number would be challenging to amalgamate in this way and would have been ambitious for a PhD study.

In order to enhance future work it would be pertinent to include a measure of self – efficacy (Simpson and Jones, 2013), cognitive ability and collective efficacy (Vassilev, 2019). Self-efficacy and its associated methodology were considered during the development of the methods section, but the questionnaire burden was deemed too onerous for participants. The Health Education Impact Questionnaire (HeiQ) (Osborne et al, 2007) was to be used and the relevant permissions was gained for its use. However, the HeiQ was challenging for participants to complete on their own and every section required reading aloud, this skewed the data as the nature of the questionnaire was to draw out the participant's level of health education. Therefore, the data from the HieQ was not reported. Ideally a self-efficacy measure, such as the Patient Activation Measure (PAM) (Hibbard, 2004) would have been a shorter, and more appropriate clinical tool. Unfortunately, the PAM was not available in the NHS trusts during data collection for the pilot study and the feasibility study.

During the study the local NHS health services adopted the PAM. The PAM is a scaled questionnaire designed to measure the activation of a person. Activation is a concept that is developed from a person's knowledge, skills and confidence to engage and enact self-care behaviours (Hibbard and Gilburt, 2014). The tool could have been a valuable outcome measure in the empirical study, as a high PAM score is directly correlated with better long term health outcomes (Mosen et al, 2007, Hibbard et al, 2004). On reflection this would have provided a clearer insight into the knowledge, skills and confidence of people with COPD ability to self-management and would have provided a baseline of self-care abilities prior to and after the introduction of the intervention. This would have enhanced the outcomes measures, providing a more definitive measure of the success of a social intervention, which would be translatable into a quantitative outcome, which is used by clinicians in practice. Furthermore, the influences of health literacy and choice of activities based on these variables would have provided a depth of understanding around the choices of social engagement, based on prior ability and understanding.

The study would have further benefitted from a longer duration of follow up, in which the disease progression was correlated against the ability to engage and socially diversify. The study was originally designed to have a twelve month follow up, see chapter 6, methods. The trial funding did not allow for the twelve-month data collection and study relied on the recall of the study participants. The recall was poor at three months with many people unable to remember dates of their healthcare use. Therefore, the follow up at twelve months was abandoned as it would have been unreliable data and would have been unfunded.

This work has opened an avenue for investigation in socially networked self-management support in COPD, as part of a whole systems approach to COPD care. Ideally the empirical work here could be scaled up to a larger study of using social network support as a 'stepping-stone' out of formal health care services. Outcomes measures could include the PAM tool, health literacy tools and a more in-depth qualitative analysis of which social activities were preferred by this patient group. The pilot study lacked a qualitative arm, this was originally written into the ethical application, but the ethics committee could not be convinced of the use of the qualitative data set, so it was not included in the final study application and delivery.

For a full-scale study to be meaningful, a larger sample size and multi-centres engagement would be required, to ensure a broader representation of people with COPD, in terms of age, ethnicity and severity of illness. In a full-scale study, in addition to recording participant uptake of social activities using the GENIE tool (for comparison between baseline and follow-up), it would be important to collect quantitative data on potential mediating social and psychological factors (e.g. measures of social networks, participation in social activities, social support, self-efficacy and motivation), to test hypothesised pathways.

Furthermore, broadening the application of GENIE into people with multiple long term conditions (multi-morbidity) could be beneficial as many self-management and clinical interventions remain specifically targeted to one illness only, limited their scope and effectiveness in multi-morbid people (Pinnock et al, 2016). Therefore, extending the scope of building social capacity beyond COPD to support people to remain on their independence continuum whilst developing their experiential skills with peer support.

9.5 Conclusion

To summarise, the aim of this study was to identify the specific challenges of SMS in people with COPD, and then tailor and evaluate a tool to address these issues in clinical practice. This has been successful.

The thesis addresses personal perspectives of SMS support through the meta-synthesis and, through this work, clinicians are now better able to envisage that the person with COPD moves between different positions – holding onto their independence while, at the same time, recognising and managing their symptoms and (incrementally) building the repository of experience-based skills.

In terms of feasibility, the social network approach is safe and protective of positive health behaviours, such as diet and exercise. The pilot study demonstrated reduction in anxiety, improvements in health-related quality of life and reduction in NHS activity and costs. It is therefore recommended that social network support is part of the pulmonary rehabilitation pathway, as a step between community NHS services and community peer supported voluntary services. The recommendations for clinical practice were disseminated to the public **(Appendix M)** and detailed the process as part of a step-down option from pulmonary rehabilitation. In this way the GENIE intervention can be added as part of the post pulmonary rehabilitation clinical review, to enable the broadening of social networks and encounters to support the transition away from state services into appropriate supportive community networks.

Appendix A Findings of the scoping review

Literature review SMS intervention in COPD

Table of selected papers for literature review: (n=25)

Health economic and cost evaluations (n=2)

Author	**Title**	**Summary of the Key findings / evidence**	**SMS challenges in health economic studies.**
Baker E; Fatoye F 2 papers **2017** **2018**	Clinical and cost effectiveness of nurse-led self-management interventions for patients with COPD in primary care: A systematic review. Patient perceived impact of nurse led self-management interventions for COPD.	Positive effect of nurse led SMS supports self-efficacy, anxiety and unscheduled physician visits. Limited evidence for improved QoL and cost savings.	Proving economic benefit of SMS interventions. People with COPD require intense personalised face to face support to implements SMS. Patients value psychological and social support as key SMS interventions.
***Found during free search* Taylor, S. Sohanpal, R. Bremner, S. Devine, A. McDaid, D. Fernandez, J. Griffiths, C. and Eldridge, S. **2012**	Self-Management Support for moderate-to-severe chronic obstructive pulmonary disease: a pilot randomised trial	Health economic evaluation of a SMS intervention in primary care. Intervention may increase QoL and exercise levels, but not symptoms. Economic analysis suggests with a £20,000 per QALY. The intervention is cost effective.	SMS implication – QoL improvement with the Bella intervention. Few studies have measured cost effectiveness of SMS, this also needs to be considered.

Appendix A

Consensus statements and expert opinions in COPD Self-Management (n=7)

Author	**Title**	**Summary of the key findings / evidence**	**SMS theories**
Bourbeau, J. Lavoie, KL. Sedeno, M. **2015**	Comprehensive Self-Management Strategies. 2015	Key findings – review of failures in SMS, failure to intervene, failure to act or use education	SMS implication – the 'how' how do we keep well, how do I change behaviour. Using MI for behaviour change.
Bourbeau, J. **2004**	Self-management interventions to improve outcomes in patients suffering from COPD.	Key findings – Summary of Bourbeau's work. Not new findings	SMS implications – Potential benefits of continuing to use SMS in COPD are still worth considering, as it is a fundamental part of long-term conditions care.
Roberts, NJ. Younis, I. Kidd, L. Partridge, MR. **2013**	Barriers to the implementation of self-management support in long term lung conditions.	Survey of clinicians – less than half COPD patients receiving SMS support	Barriers compliance, literacy, understanding. Time and resources.
Nici, L. Bontly, TD. Zuwallack, R. Gross, N. **2013**	**Self-management in chronic obstructive pulmonary disease. Time for a paradigm shift?**	Key findings – Social theory, Self-management is popular, but not well tested.	SMS implications – education and behavioural modification – **how to patients change unhealthy behaviours?**
Simpson, E. Jones, M. **2013**	An exploration of self-efficacy and self-management in COPD patients.	Key findings – higher levels of **self-efficacy** were associated with lower levels of breathlessness, depression and anxiety in COPD. No correlations with self-efficacy and exacerbation rates.	SMS implication – **reducing anxiety and depression** in patient with COPD are important focus points for SMS.
Effing, TW. Vercoulen, JH. **Bourbeau,** J. Trappenburg, J. Lenferink, A. Cafarella, P. Coultas, D. Meek, P. van der Valk, P. Bischoff, EW. Bucknall, C. Dewan, NA. Early, F. Fan, V. Frith, P. Janssen, DJ. Mitchell, K. Morgan, M. Nici, L. Pate, L. Walters, H. Rice, KL. Singh, S. Zuwallack, R. Benzo, R. Goldstein, R. Partridge, MR. van der Palen, J. **2016**	**Definition of a COPD self-management intervention: International Expert Group consensus. 2016**	Key findings – Delphi method used and consensus reached in 5 iterations. An intervention should be: structured, personalised and multi-component. Be concerned with; behaviour change and skills acquisition.	SMS implications – Consensus goals- symptom reduction and functional improvement, increase emotional wellbeing, social wellbeing and QoL. Also establish alliances with health care professionals Family, friends and community.
Lenferink, .; van der Palen, J. **Effing, T.** **2018**	**The role of social support in improving chronic obstructive pulmonary disease self-management.**	Key findings – Mental health and self-efficacy have emerged as possible areas of benefit from social support in COPD patients	SMS implications: Social support in SMS will positively impact on SM behaviours. Interventions to evaluate the nature and type of social support that is required in COPD.

Interventional SMS studies and systematic reviews and meta-syntheses (n=15) *SPACE for COPD 3 in 1 *Ripple and Making Waves 2 in1

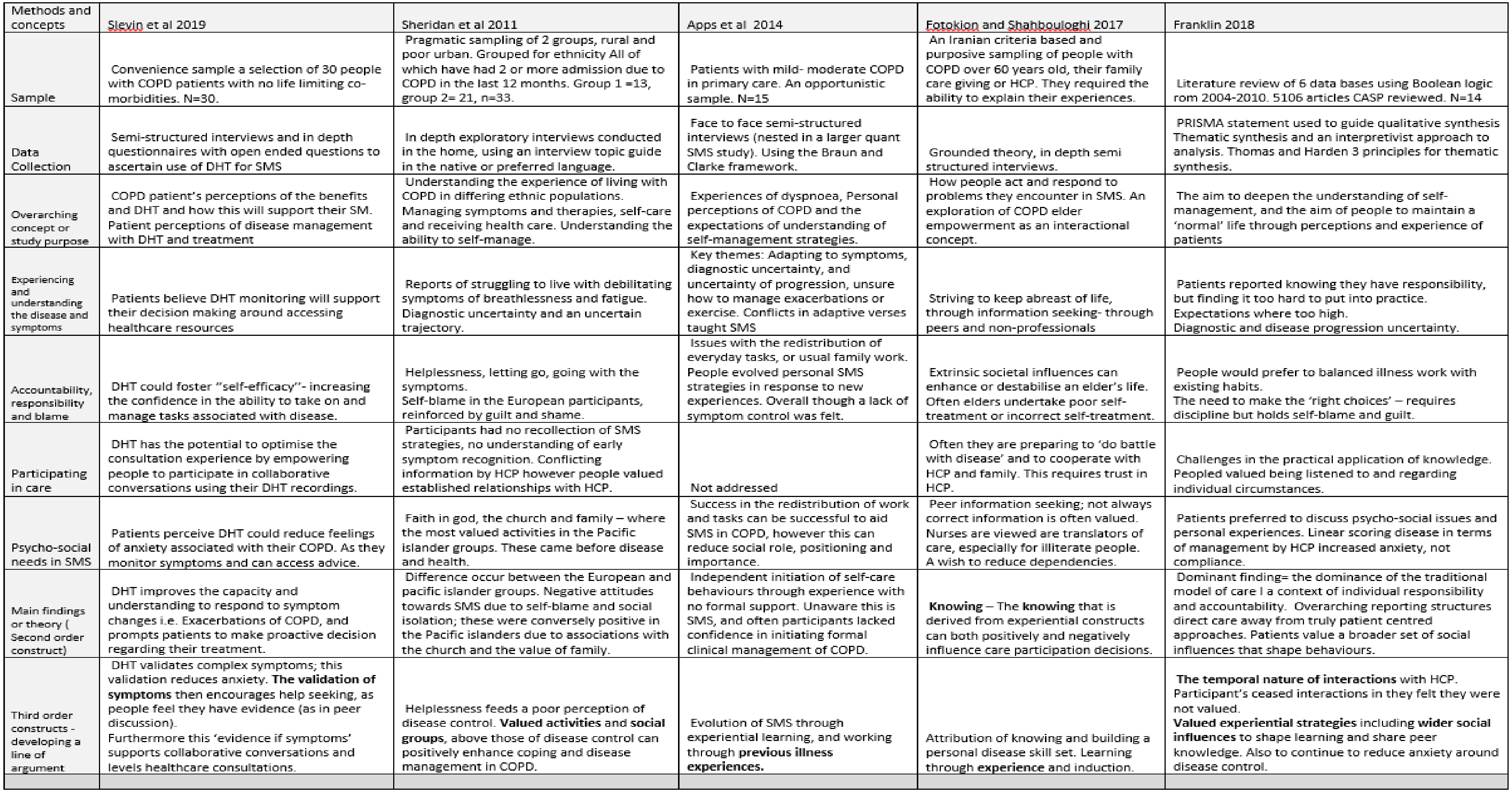
Author	Title	Summary of the key findings / evidence	SMS in COPD challenges
Sedeno MF; Nault D; Hamd DH; Bourbeau J **2009**	A self-management education program including an action plan for acute COPD exacerbations.	Key findings – ''living well with COPD programme'' – action plan based, case manager and medicines at home.	SMS implications – Successful in reducing hospital admission and managing exacerbations at home, in this controlled population (not case-management)
Bucknall CE; Miller G; Lloyd SM; Cleland J; McCluskey S; Cotton M; Stevenson RD; Cotton P; McConnachie A **2012**	Glasgow supported self-management trial (GSuST) for patients with moderate to severe COPD: randomised controlled trial.	Key findings – poor return in HRQoL. No overall impact of SMS on Readmission.	SMS implications- no impact on time to first readmission. Some younger participants **living with others** – were able to reduce readmission risk.
Kennedy A; Bower P; Reeves D; Blakeman T; Bowen R; Chew-Graham C; Eden M; Fullwood C; Gaffney H; Gardner C; Lee V; Morris R; Protheroe J; Richardson G; Sanders C; Swallow A; Thompson D; Rogers A **2013**	Implementation of self-management support for long term conditions in routine primary care settings: cluster randomised controlled trial. Combined with the protocol publication.	Key findings – multiple conditions and a whole systems approach in primary care. Measured self-efficacy HRQoL for 12months	SMS implications- no statistically significant differences
Mitchell KE; Johnson-Warrington V; Apps LD; Bankart J; Sewell L; Williams JE; Rees K; Jolly K; Steiner M; Morgan M; Singh SJ (Includes 3 papers) **2016**	A self-management programme for COPD: a randomised controlled trial. (SPACE for COPD 3 papers published on this programme)	Key findings- measured symptom burden, dyspnoea. RCT for SMP for COPD with a 6 moth follow up. No significant difference between the groups at 6 months in terms of dyspnoea- but gains in exercise performance anxiety and disease knowledge.	Implications for SMS- Evidence for improvement and anxiety and disease knowledge.
Taylor SJC; Pinnock H; Epiphaniou E; Pearce G; Parke HL; Schwappach A; Purushotham N; Jacob S; Griffiths CJ; Greenhalgh T; Sheikh A **2014**	A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – Practical systematic Review of Self-Management Support for long-term conditions	Key findings – PRISMS review 2 qual – 39 Quant	Unfortunately, there is a lack of consistent and clinically significant positive effects of self-management education, on quality of life and health related quality of life
Richardson J; Loyola-Sanchez A; Sinclair S; Harris J; Letts L; MacIntyre NJ; Wilkins S; Burgos-Martinez G; Wishart L; McBay C; Martin Ginis K **2014**	Self-management interventions for chronic disease: a systematic scoping review.	Key findings – OT and PT contributions to SMS OT and PT make moderate contributions based on disease specific and on the principle of behaviour change theories.	N/A
Effing T; Monninkhof EE; van der Valk PP; Zielhuis	Self-management for patients with chronic	Key findings – SMS leads to a lower probability of	SMS - again unable to pool studies to the heterogeneity

Appendix A

Author	**Title**	**Summary of the key findings / evidence**	**SMS in COPD challenges**
GG; Walters EH; van der Palen JJ; Zwerink M **2007**	obstructive pulmonary disease. Cochrane library	respiratory related hospitalisations and Quality of life. Some reduction in dyspnoea, not in exercise capacity	of interventional models, timelines, populations and outcomes measures in COPD – unable to make recommendations
Jonkman NH; Westland H; Trappenburg JC; Groenwold RH; Bischoff EW; Bourbeau J; Bucknall CE; Coultas D; Effing TW; Epton M; Gallefoss F; Garcia-Aymerich J; Lloyd SM; Monninkhof EM; Nguyen HQ; van der Palen J; Rice KL; Sedeno M; Taylor SJ; Troosters T; Zwar NA; Hoes AW; Schuurmans MJ **2017**	Characteristics of effective self-management interventions in patients with COPD: individual patient data meta-analysis.	Key findings – Only able to measure length of hospital stay against intervention, as this was the only comparable outcome measure. The longer the duration of the intervention conferred reduction in all-cause hospitalisation in COPD patients.	SMS implication- Challenges with the heterogeneity of study designs and outcomes measures. Other favourable effects included interventions **with peer contact**, without log keeping, without problem solving and without support allocation.
Khan A; Dickens AP; Adab P; Jordan RE **2017**	Self-management behaviour and support among primary care COPD patients: cross-sectional analysis of data from the Birmingham Chronic Obstructive Pulmonary Disease Cohort.	Key findings – Having a SMP is positively associated with self-reported adherence to medications, attendance at training courses, and support groups and better disease knowledge.	SMS implications- on 40% of the 1078 people had a SMP. Benefits of having one are reported.
Sewell, L.; Taylor, A.; Steils, N.; Gelder, C. **2018** L., Sewell; M., Kerslake; V., Lord; S., Krumins; A., Taylor **2017**	Outcomes from an asset-based community development approach to improve mental well-being in people with COPD: Is there a 'RIPPLE' effect? Making Waves: Asset Based Community Clinics for People with Chronic Obstructive Pulmonary Disease...RCOT (Royal College of Occupational Therapist) Annual Conference	Key Findings- *note neither of these are published papers, both are in abstract form only.* Mental wellbeing increased significantly using an asset-based approach. Larger scale studies are required.	SMS implication – Ripple and Making waves are asset-based community development clinics – focused on mental wellbeing, delivering peer support and self-management advice.
Wang T; Tan JY; Xiao LD; Deng R **2017**	Effectiveness of disease-specific self-management education on health outcomes in patients with chronic obstructive pulmonary disease: An updated systematic review and meta-analysis.	Key findings – systematic review was required as education in COPD was unequivocal. SME in COPD can improve QoL and disease specific knowledge and reduced ED visits.	Implications for SMS – education has success in COPD in terms of QoL and knowledge attainment. *Note – PR provides SME.*

Author	**Title**	**Summary of the key findings / evidence**	**SMS in COPD challenges**
Joglekar S; Sastry N; Coulson NS; Taylor SJ; Patel A; Duschinsky R; Anand A; Jameson Evans M; Griffiths CJ; Sheikh A; Panzarasa P; De Simoni A **2018**	How Online Communities of People With Long-Term Conditions Function and Evolve: Network Analysis of the Structure and Dynamics of the Asthma UK and British Lung Foundation Online Communities.	Key Findings – Super users in the BLF community facilitate direct tie formations. Over time the more active users became the more likely they were to reply to posts, rather than write new posts.	Implications for SMS – Role shift to peer support. Online super users in health care warrants further research, online communities may provide useful peer support.
Found during free search Jolly.K, Sidhur,M.S. Bates,E. Majothi, S. Sitch,A. Bayliss,S. Kim,S. Jordan,R. **2018	Systematic review of the effectiveness of community-based self-management interventions among primary care COPD patients.	Key findings- not statistically sig improvement in primary care SMS interventions in COPD. Emotions and mastery in favour of the intervention but not significant. No benefit for SMS for COPD in primary care- as it is currently delivered.	4 out of 12 using action plans – in 2014 Conchrane review (included secondary care and all action plans) shift in paradigm – Qualitative review on SMS in COPD highlighted emotional burden – addressing mental health as well as COPD symptoms. Furthermore, life circumstances impacted on SMS abilities. (Social health and Mental health)
Found during reference search Vassilev, I. Rogers, A. Kennedy, A. Koetsenruijter, J. **2014.	The influence of social networks on self-management support: a meta-synthesis	Key findings – using line of argument synthesis -*network navigation* – using existing resources in networks -*Negotiation within the network* -re-shaping roles and expectations and *collective efficacy* – developing a shared perception of capacity and ability to perform tasks.	Challenges of SMS-Focussed on diabetes chronic illness management relies on navigation and negotiation of personal communities. Therefore, maximising social engagement could increase the ability of the individual to self-manage
Bringsvor HB; Langeland E; Oftedal BF; Skaug K; Assmus J; Bentsen SB **2018**	Effects of a COPD self-management support intervention: a randomized controlled trial.	Key findings- higher symptom burden associated with worse SMS scores. Higher pack year of smoking associated with lower scores in self-directed activities.	SMS implications – the ability to self-management becomes harder as COPD disease progresses. Tackling behaviour changes are key in SMS interventions.

Appendix B Qualitative meta-synthesis



Methods and concepts	Slevin et al 2019	Sheridan et al 2011	Apps et al 2014	Fotokion and Shahbouloghi 2017	Franklin 2018
Sample	Convenience sample a selection of 30 people with COPD patients with no life limiting co-morbidities. N=30.	Pragmatic sampling of 2 groups, rural and poor urban. Grouped for ethnicity All of which have had 2 or more admission due to COPD in the last 12 months. Group 1 =13, group 2= 21, n=33.	Patients with mild- moderate COPD in primary care. An opportunistic sample. N=15	An Iranian criteria based and purposive sampling of people with COPD over 60 years old, their family care giving or HCP. They required the ability to explain their experiences.	Literature review of 6 data bases using Boolean logic rom 2004-2010. 5106 articles CASP reviewed. N=14
Data Collection	Semi-structured interviews and in depth questionnaires with open ended questions to ascertain use of DHT for SMS	In depth exploratory interviews conducted in the home, using an interview topic guide in the native or preferred language.	Face to face semi-structured interviews (nested in a larger quant SMS study). Using the Braun and Clarke framework.	Grounded theory, in depth semi structured interviews.	PRISMA statement used to guide qualitative synthesis Thematic synthesis and an interpretivist approach to analysis. Thomas and Harden 3 principles for thematic synthesis.
Overarching concept or study purpose	COPD patient's perceptions of the benefits and DHT and how this will support their SM. Patient perceptions of disease management with DHT and treatment	Understanding the experience of living with COPD in differing ethnic populations. Managing symptoms and therapies, self-care and receiving health care. Understanding the ability to self-manage.	Experiences of dyspnoea, Personal perceptions of COPD and the expectations of understanding of self-management strategies.	How people act and respond to problems they encounter in SMS. An exploration of COPD elder empowerment as an interactional concept.	The aim to deepen the understanding of self-management, and the aim of people to maintain a 'normal' life through perceptions and experience of patients
Experiencing and understanding the disease and symptoms	Patients believe DHT monitoring will support their decision making around accessing healthcare resources	Reports of struggling to live with debilitating symptoms of breathlessness and fatigue. Diagnostic uncertainty and an uncertain trajectory.	Key themes: Adapting to symptoms, diagnostic uncertainty, and uncertainty of progression, unsure how to manage exacerbations or exercise. Conflicts in adaptive verses taught SMS	Striving to keep abreast of life, through information seeking- through peers and non-professionals	Patients reported knowing they have responsibility, but finding it too hard to put into practice. Expectations where too high. Diagnostic and disease progression uncertainty.
Accountability, responsibility and blame	DHT could foster "self-efficacy"- increasing the confidence in the ability to take on and manage tasks associated with disease.	Helplessness, letting go, going with the symptoms. Self-blame in the European participants, reinforced by guilt and shame.	Issues with the redistribution of everyday tasks, or usual family work. People evolved personal SMS strategies in response to new experiences. Overall though a lack of symptom control was felt.	Extrinsic societal influences can enhance or destabilise an elder's life. Often elders undertake poor self-treatment or incorrect self-treatment.	People would prefer to balanced illness work with existing habits. The need to make the 'right choices' – requires discipline but holds self-blame and guilt.
Participating in care	DHT has the potential to optimise the consultation experience by empowering people to participate in collaborative conversations using their DHT recordings.	Participants had no recollection of SMS strategies, no understanding of early symptom recognition. Conflicting information by HCP however people valued established relationships with HCP.	Not addressed	Often they are preparing to 'do battle with disease' and to cooperate with HCP and family. This requires trust in HCP.	Challenges in the practical application of knowledge. Peopled valued being listened to and regarding individual circumstances.
Psycho-social needs in SMS	Patients perceive DHT could reduce feelings of anxiety associated with their COPD. As they monitor symptoms and can access advice.	Faith in god, the church and family – where the most valued activities in the Pacific islander groups. These came before disease and health.	Success in the redistribution of work and tasks can be successful to aid SMS in COPD, however this can reduce social role, positioning and importance.	Peer information seeking; not always correct information is often valued. Nurses are viewed are translators of care, especially for illiterate people. A wish to reduce dependencies.	Patients preferred to discuss psycho-social issues and personal experiences. Linear scoring disease in terms of management by HCP increased anxiety, not compliance.
Main findings or theory (Second order construct)	DHT improves the capacity and understanding to respond to symptom changes i.e. Exacerbations of COPD, and prompts patients to make proactive decision regarding their treatment.	Difference occur between the European and pacific islander groups. Negative attitudes towards SMS due to self-blame and social isolation; these were conversely positive in the Pacific islanders due to associations with the church and the value of family.	Independent initiation of self-care behaviours through experience with no formal support. Unaware this is SMS, and often participants lacked confidence in initiating formal clinical management of COPD.	**Knowing** – The **knowing** that is derived from experiential constructs can both positively and negatively influence care participation decisions.	Dominant finding= the dominance of the traditional model of care I a context of individual responsibility and accountability. Overarching reporting structures direct care away from truly patient centred approaches. Patients value a broader set of social influences that shape behaviours.
Third order constructs - developing a line of argument	DHT validates complex symptoms; this validation reduces anxiety. **The validation of symptoms** then encourages help seeking, as people feel they have evidence (as in peer discussion). Furthermore this 'evidence if symptoms' supports collaborative conversations and levels healthcare consultations.	Helplessness feeds a poor perception of disease control. **Valued activities** and **social groups**, above those of disease control can positively enhance coping and disease management in COPD.	Evolution of SMS through experiential learning, and working through **previous illness experiences.**	Attribution of knowing and building a personal disease skill set. Learning through **experience** and induction.	**The temporal nature of interactions** with HCP. Participant's ceased interactions in they felt they were not valued. **Valued experiential strategies** including **wider social influences** to shape learning and share peer knowledge. Also to continue to reduce anxiety around disease control.

Data extraction table

Appendix C Study Protocol

GENIE

Implementing and Evaluating the GENIE tool in Southampton Integrated COPD Service

: A clinical trial and evaluation to ascertain cost effectiveness and patient benefit.

Introduction

Background

COPD is a life limiting progressive illness punctuated by acute episodes; prompting potential solutions through self-management support. Clinical trials in COPD self-management have yielded mixed results (Fan et al, 2012 and Bourbeau, 2003.) However, self-management support and education can reduce health care contacts when delivered and targeted appropriately, (Taylor et al, 2014).

To date the effectiveness of Self-Management Support (Pinnock et al, 2016) for COPD based for example on action planning alone has been limited (for example changing utilization patterns) and suggests the need for a more elaborate approach to SMS in clinical settings (Walter J. 2010, Peytremann-Bridevaux 2008 and Taylor et al, 2014).

Decision making processes, as in other conditions may be influenced positively by promoting access to connections and resources through social networks. However, to date the concept of socially supportive self-management in COPD has a limited evidence base in terms of how this might be implemented successfully in practice settings.

Long term Conditions (LTC) service within Solent NHS trust includes specialist services for patients with COPD, diabetes and cardiac disease. COPD carries a high symptom burden including mobility limitations and fear of acute episodes of breathlessness; often leading to decreased social interaction, and isolation. Evidence suggests that social interaction acts positively in terms of influencing wellbeing and living successfully with an LTC (Reeves et al 2014). Isolation has a negative impact on health in general and those with a long-term condition. It leads to low mood and an increasing inability to engage with self-care and self-management and has physiological effects on health (Cacioppo and Hawkley 2003). Recent research which explores the nature of consultations with people with COPD suggests that opportunities for engagement with Self-Management Support (Pinnock et al, 2016) are often missed (Chatwin et al 2014). Moreover, social network connections might be a promising avenue for bringing into focus SMS options that have not previously been explored in professional patient encounters. The latter have been shown to have utility for the mobilisation of resources for self-management and for social involvement likely, to have an impact on self-management and health related outcomes.

Theories of Self-management are based around either the ability to manage a single clinical condition or the ability to manage everyday life; success in these is determined by the ability to fulfil ‘normal’ social roles and the ability to seek happiness in one’s life. The element of social interaction forms the theoretical basis of disease management and health care navigation. For example, adult children are often considered as being pivotal to the social network by the person with the condition. However, the person with the condition is often reluctant to impose a burden of care on children and communicating support needs can be difficult to negotiate when it changes the parent/child relationship .The ability to recognise fractured networks are important when organising and supporting care giving. However, creating broader networks within personal trajectories of chronic illness can influence and support people in terms of daily living with a LTC, and support elements of weakness in existing networks.

The maintenance exercise group is a commissioned exercise group post pulmonary rehabilitation. Patients are invited to join a class to ensure they continue to exercise at a prescribed level. This group also provides valued social contact. Continued exercise is vital to ensure physical wellbeing but might be continued outside a clinical setting in a way, which also enhances social contact to replace the social role that the maintenance exercise group currently holds for COPD patients. The current clinical contact time could be replaced by voluntary groups and other exercise providers including informal contacts linked into personal networks of support which might ensure an equivalent or enhanced supportive social environment which is less reliant on existing health care services.

The supportive self-management tool GENIE (Generating Engagement in Network Involvement) has been implemented effectively in a 'My LIFE a Full life' (MLAFL), project, based on the Isle of Wight, (Kennedy et al 2016). The MLAFL programme focuses on people with long-term conditions, older people and those with mental health needs, with three priority areas identified:

- Self-Care and Self-Management
- Crisis Response
- Locality Working

The GENIE implementation purposefully sampled people with type 2 diabetes in order to represent the long-term conditions group. Diabetes is a long-term life limiting condition, with episodes of acute illness- during hypo/hyper-glycemic events. However, COPD is different to diabetes because of limitations caused by breathlessness which can be physically disabling and socially isolating. Therefore, implementing and evaluating this already successful social mapping tool into the COPD service is valuable to understand:

- Differences and similarities in its utility for different Long term conditions
- Barriers to social activity including those linked to a person's physical condition
- Response, uptake and practical benefits of GENIE for COPD patients
- Capacity of voluntary, community and personal network to take on the work previously undertaken in the maintenance clinic.
- Health economic and service utilisation benefits
- Exploration of weak or fractured social networks in COPD

Purpose

The main aim here is to increase long term health care management options in Solent NHS Trust by building social capacity to support self-management. The GENIE tool will be introduced into the COPD service to improve options for social groups and exercise when leaving a pulmonary rehabilitation group, or when clinically unable to participate in exercise.

- to build social networking awareness and the importance of utilising existing social resources in the professional and voluntary members of the COPD service,
- to use social network mapping techniques and preference elicitation to engage COPD patients in reflecting on their support preferences and needs, help them access further resources and knowledge
- Evaluate the success of the social mapping techniques (GENIE) in the COPD patient population
- Evaluate the cost benefit to both to patients and to the health service of the GENIE in the COPD patient population

Objectives

Primary objectives

Compare and evaluate the health care utilisation and quality of life (burden of disease) in COPD patients using GENIE alongside usual care after leaving the COPD service with those offered only a current practice discharge plan.

Secondary objectives

Compare and evaluate the change in health behaviours, diet and lifestyle in COPD patients using GENIE alongside usual care after leaving the COPD service with those offered only a current practice discharge plan.

Observe and understand the uptake and utilisation of the GENIE recommendations by COPD patients.

Explore social complexities in the COPD population.

Implementation Design

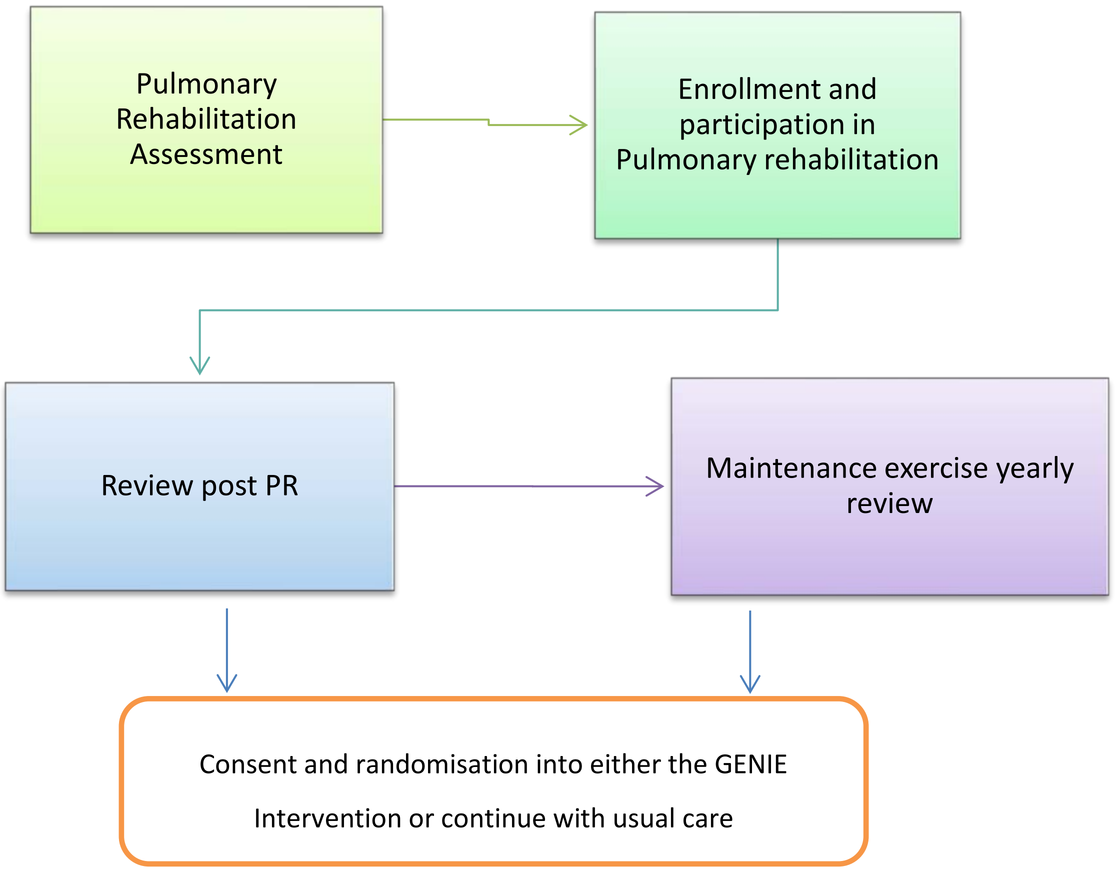
This protocol is concerned with the implementation and evaluation of the GENIE tool in the community facilitated by the COPD team and the subsequent evaluation of the GENIE in direct comparison to usual clinical practice.

The researchers will deliver the Intervention with the patients participating in the study at leaving points, during the patient's journey through the COPD service, as specified in the diagram below. Patients enter the pulmonary rehabilitation (PR) section of the COPD service post-acute episode or by GP referral. Patients are then clinically assessed for suitability to continue in the exercise component of the service. If patients are deemed suitable for exercise then they continue onto PR. Post PR they have a review, 30 minutes with a clinician to ascertain their progress through the programme and to recommend continuation of exercise. At this point patients can also leave the programme.

Furthermore, patients are offered maintenance exercise therapy – and are reviewed yearly, during these reviews other exercise and activity can also be recommended, patients can also leave the service at this point. These transition points in the care pathway; leaving the PR programme, or at yearly maintenance review patients will be offered to participate in the GENIE study and provided with study information.

1. Those patients completing a PR programme, and in whom we wish to provide clear direction and signposting to appropriate social activity
2. Those who have benefitted from maintenance for 1 year or more, but at review could be encouraged to do more and have more social outlets.

Appendix C



Currently, patients leaving PR classes are usually offered the option to join the maintenance exercise class, delivered by the COPD team, other exercise options are considered, however, these options are currently limited or difficult to access in one place.

Building capacity to carry out the evaluation: Ensuring the GENIE database contains an appropriate library of social and health activities suitable for the Southampton COPD patient. The lead researcher will investigate existing exercise, social and community activities, then populate and categorise the GENIE database.

Introducing the intervention: In order to successfully implement the GENIE tool into clinical practice; the clinical team needs to be at the core of the process in order to ensure appropriate and effective facilitation. Therefore, the clinical team will be briefed as the study progresses, through question and answer sessions and direct learning opportunities in how the tool works and the objectives of the study.

Selection and patient information: Patients in the COPD service; at the outset of their assessment, the end of PR and during maintenance sessions will be informed that the GENIE implementation evaluation is in progress.

Patients participating in these aspects of the service will be offered the opportunity to volunteer for the study, by the clinical team. If patients are interested they can then provide their names to the clinical staff to keep on a secure Solent database. Patient information sheets and invitation letters will be given out to the interested patients at their clinical visits to minimise postal and /or extra visits.

Once patients have received an information sheet, they will be allowed at least 72 hours to read and digest the information, (patient information sheets, consent and GP letters are separate documents), and share this with their friends and family if they wish to. Ideally, patients are provided with information in their clinical visits and are returning for clinical visits then appointments for research could be amalgamated with usual clinical visits. In this way extra study visits can be reduced. Patients, now participants, will be invited to consent and be randomised at the point of leaving usual clinical care. Furthermore, all patients at this point will have the opportunity to opt out of the study.

Once the participant is randomised (using block randomisation technique in clinic), then they will all receive normal clinical care (discharge planning with suggested activities), and the GENIE tool intervention, in the GENIE group, this is in addition to usual clinical care. Baseline questionnaires will also be administered at this visit.

The follow up period will commence 3 months (12 weeks) (+/- 1 week) from the day the GENIE tool was initially delivered. Participants will be invited back, via letter and /or phone call to attend their three month follow up visit at Bitterne Health Centre.

Solent NHS Trust will be the overall NHS organisation with one venue for study delivery; Bitterne Health Centre.

Block randomisation technique, a commonly used technique in clinical trial design to reduce bias and achieve balance in the allocation of participants to treatment arms, especially in this case when the sample size is small (Efird, J. 2010). In order to reduce unconscious bias of the researcher, pre-prepared envelopes containing the possible combinations of group allocation, will be stored in a locked drawer in Bitterne Health Centre. The intention is to randomize in blocks of four, as this will complement the clinic structure. Therefore, each envelope will contain a pre-determined allocation pattern for that clinic (AABB, ABAB, BABA etc.).

The researcher team will share an excel spread sheet which will be set to generate a random number sequence. The next sequential number will be selected, which will then correspond to an envelope with the predetermined sequence. In this way the envelope selection is random, then sequence in the envelopes in also random, but ensures 50/50 grouping of participants. Baseline data for descriptive statistics will also be collected. (Data capture form appended)

In order to conduct meaningful analysis recruitment needs to reach at least 30 patients, in each group, however the maximum could be 60 in each group, 120 patients in total. Therefore recruitment could take between 6-9 months. The timeframe can be increased if necessary.

Initial / Baseline data collection:

Socio-economic data will be collected including; disease severity (FEV1), gender, EQ-5D, health care utilisation questionnaire, HEIQ and wellbeing questionnaires (CAT, GAD, PHQ-9), as well as an optional health behaviour questionnaire, from both the usual care group and the interventional group. Please note CAT, GAD, PHQ-9 FEV1 and gender are already captured routinely during clinical consultation.

Intervention

Assessment stratification and feedback:

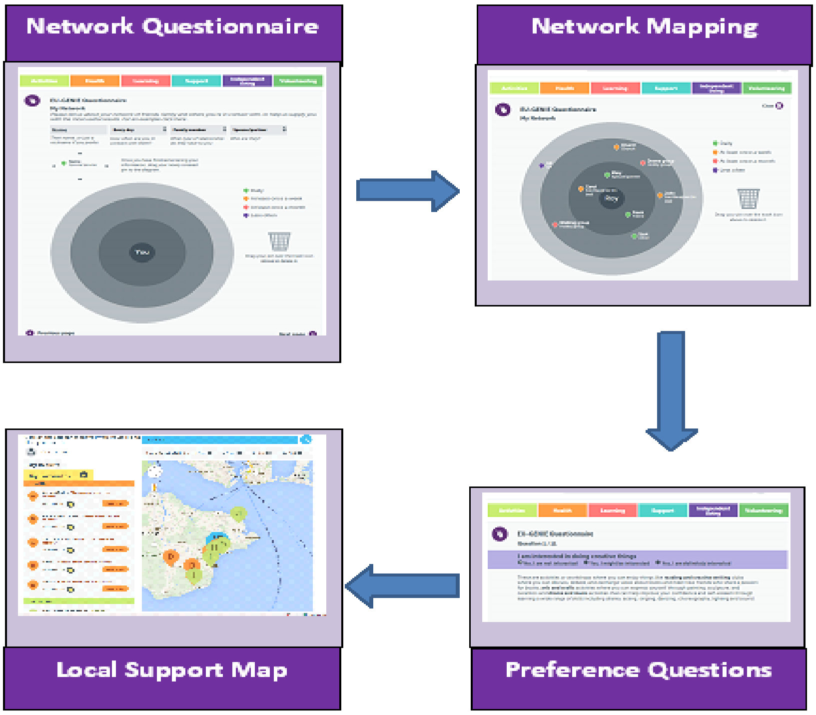
Stage 1: The patient will complete a questionnaire online with the researcher/clinician. The patients will be asked to name the important people and activities in their network, type of relationship and frequency of contact using the concentric circles diagram.

Stage 2: The online process: consisting of series of questions will be used to elicit the participant’s values and preferences for activities and support resources.

Stage 3: This section will then link individuals to prioritised and valued activities and resources (links are to a pre-created database where local organisations and resources have been categorised).

Appendix C

Stage 4: The GENIE Tool then presents options in a user-friendly way, on a Google map with clear details about access, an example below:



Both groups will receive usual care, however one arm will have the addition of the intervention both will be called for a review at:

Three monthly follow up (+/- 1 week)

Six questionnaires will be administered. EQ-5D, health utilisation questionnaire, HEIQ and wellbeing questionnaires (CAT, GAD, PHQ-9), as well as the optional health behaviour questionnaire, so in 30 participants this will be seven, these will be repeated at 3 months post intervention (+/- 2 week). Furthermore, for those in the intervention arm, feedback and reflection discussions will be initiated using the network diagrams. Participants will be asked again for their permission to tape record these discussions to ensure parity and quality assurance between researchers.

Analysis of Outcomes

The study gathers data from the intervention arm and the non-intervention arm at baseline and 3 months post intervention. Results will be compared between the groups at baseline and 3-month post intervention. An economic analysis will be performed using a modified version of the Client Service Receipt Inventory (CSRI) (Beecham and Knapp 1999) Medication, health service use will be measured at baseline, 3 months post implementation and follow up. The modified version has been tailored to capture the needs of the target population (COPD patients). The CSRI has been widely used in previous research studies and has been evidenced as a valid measure of frequency of health service use (Patel 2005). The EQ5D is included to assess health status of patients during the GENIE intervention. Wellbeing score (CAT) and HEIQ and in the optional sub-group health behaviours (dietary intake, appetite, alcohol consumption and smoking habits) will be compared at baseline and 3 months. Furthermore, patient uptake of the social activities is to be recorded on paper using the Genie tool and compared between groups.

Rationale for the service implementation and evaluation design

The implementation and evaluation of the GENIE tool builds on the early GENIE studies indicating that the intervention will work on the premise that finding out about and enhancing network support can be undertaken by a variety of people (e.g. social network members, members of local community groups, health professionals) in a variety of situations (e.g. at home, work, in public and healthcare settings). Further research is indicating the potential of GENIE in existing health care structures but has yet not been fully tested. Furthermore, much of the preliminary work was performed in patients with Type II diabetes, understanding how GENIE is received in COPD patients requires further investigation.

Risks / benefits

Each patient leaving pulmonary rehabilitation will be offered usual clinical care; therefore, no patient is put at risk. However, it is recognised that the process of divulging and discussing networks and social activity in potentially isolated people, may be potentially distressing. Therefore, the study is still therefore very much grounded within the clinical service. If a person did become distressed, then the interviews and questions would be stopped, and the researcher would support the participant in the first instance. The researcher would then be able to refer the participant back into the clinical team, and request psychological support, through the IAPT / Steps to Wellbeing service, a self-referral psychological service. These participants would also have the option to then withdraw from the study.

The patients in the GENIE intervention arm may have increased benefit due to access and signposting to tailored community resources. Therefore, if a benefit is seen in those participants included in the intervention arm of the study with increased access to services then the GENIE tool will be offered to all patients' post study completion. Ideally, the tool will be implemented and rolled out post study by 'expert users' or participants and or patients who could support others in network support and provision.

Population

Participation in the study will be offered to every patient in pulmonary rehabilitation or maintenance exercise programs in the east of Southampton. Participants must also fulfill the inclusion criteria. Patients already referred into pulmonary rehabilitation groups will be approached and asked if they wish to participate in the study at assessment and at the end of pulmonary rehabilitation in their post PR review appointment. The appointments are offered to patients after completion of the patient's PR program, usually after 12 sessions by the clinical team. Therefore, it is envisaged that a minimum of 30 patients per arm will be recruited; these include PR leavers, maintenance reviews referrals. Appointments will be offered in person, via the telephone with confirmation letter or text. The numbers from each of these groups cannot be predicted as it is dependent on clinical opinion, however the aim to have a minimum of 30 participants, with the aim to recruit up to 60 to ensure meaningful analysis.

Inclusion criteria;

- adults between 18 and 95 with a predominant diagnosis of COPD
- Ability to understand spoken English
- Enrolled in PR or maintenance therapy
- Ability and capacity to make their own decision and consent freely

Appendix C

Exclusion Criteria;

- No clear COPD diagnosis
- Inability to consent

The Intervention

This evaluation aims to demonstrate the effectiveness and increase social interactions and community networks in the COPD population in Southampton city.

Rational for GENIE is connecting people to new resources

The aim of using GENIE is to connect people with long-term conditions to local and (in the future) online resources to support them in their everyday lives. Objectives of GENIE:

- Raise awareness of the links and functions that social networks enable (for individuals and local community groups and organisations).
- Use social networks to engage patients in reflecting on their needs and support, support access to further resources and knowledge and introduce practices related to lifestyle, illness management, and behaviour change.
- Strengthen existing individual and community networks and improve patient engagement.

GENIE is a way to help people think about the links they have with others to manage a health problem (local groups, friends, acquaintances, family members, professionals) and to reflect on their involvement in health and wellness activities and their ability to live an ordinary life with a long term condition. By using GENIE and thinking or talking through the GENIE mapping tool, individuals can visualize their network and can reflect on connections that provide value and resources for managing and where there are gaps in support- this might be social, practical or emotional as well as specifically related to a health condition.

Cost of the intervention

The service lead has already secured some funded time to enable the GENIE library to build the initial database and to deliver the initial implementation research project into the service.

Training on building the COPD sections of the database update in Dec 2016: - following this access to the website https://genie.soton.ac.uk/ and the ability to create a database of local organisations that is accessed by the website.

Initial overview session has taken place in a COPD team meeting on the Thursday 14th April 2016.

Training Pre Month 0

Training will be delivered by the self-directed support for self-management team who developed the GENIE intervention. The session will take place over an afternoon.

The GENIE approach consists of three elements

- Personal network mapping

- Identification of needs and personal interests
- Linking to local resources using website and tailoring to needs and interests through facilitation.

1. Personal network mapping using concentric circle tool

This involves, constructing and visualising a personal network of members and contact supporting long term condition management, four types usually emerge from this process (restricted, family, friend, diverse).

2. Identification of needs and personal interests by working through preference questions.

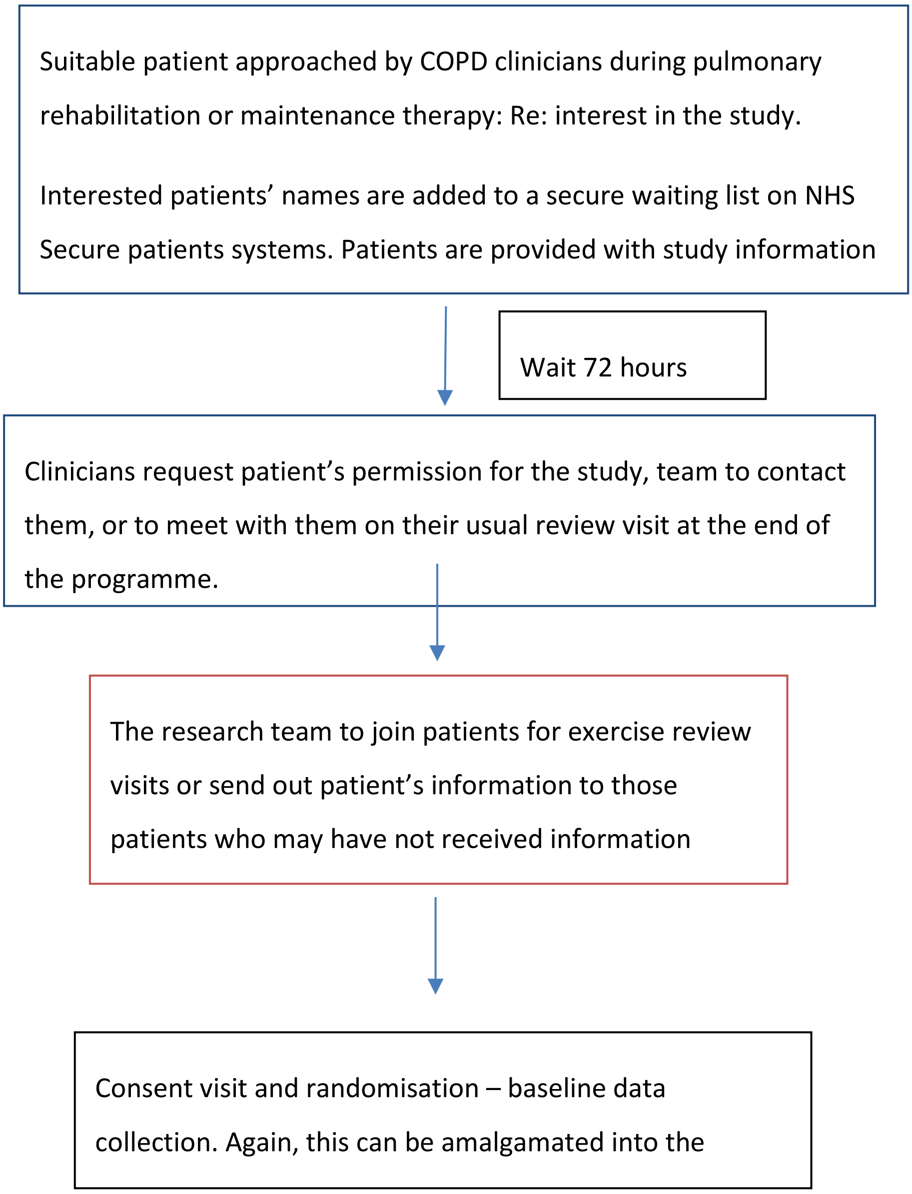
- Key questions centred on well-being and social needs and preferences
- Working with personal preferences and need to articulate a set of personal goals
- Link to potential sources of support in community settings through connecting with a dedicated resource.
- In order to maintain privacy, pseudonyms will be used on the website and the printed preferences stored in a locked drawer in Solent NHS space (including pseudonyms of friends and relatives)

3. Feedback and example

Following the training, the participants will be given the tools required to roll out the intervention

- Paper and web-based concentric circles with typologies and support suggestions
- Guidebook on how to deliver GENIE
- Access to the database and website

Identification, enrolment and randomisation



Suitable patient approached by COPD clinicians during pulmonary rehabilitation or maintenance therapy: Re: interest in the study.

Interested patients' names are added to a secure waiting list on NHS Secure patients systems. Patients are provided with study information

Wait 72 hours

Clinicians request patient's permission for the study, team to contact them, or to meet with them on their usual review visit at the end of the programme.

The research team to join patients for exercise review visits or send out patient's information to those patients who may have not received information

Consent visit and randomisation – baseline data collection. Again, this can be amalgamated into the

Table of Events

	Consent and Randomisation	**Pre – intervention data collection**	**12 weeks post intervention data collection** (+/- 1 week)	**Potential 1 year follow up phase**
Consent form discussion and taking informed consent	**x**			
Randomisation (Block)	**x**			
EQ-5D		X	x	x
Health Care Utilisation Questionnaire		X	x	x
Socio-economic background / demographic data		X		
Gender		X		
Disease severity (FEV1)		X		
HEIQ (Self-management)		X	x	
Optional Health behaviour questionnaire		x	x	x
CAT		X	x	x
Gad-7 /		X	x	
PHQ-9		x	x	x
Uptake discussion / online survey			x	x

Quality Assurance

The delivery of the intervention will be taped in as many cases as consented to ensure that the intervention is delivered consistently by the research team to all patients. The tape recording is for quality assurance and is not intended for research utilisation or publication.

Future work

The participants included in this initial 3 months of the study could be followed up again in 1 year (12 months) to ascertain longer term outcomes and longevity of connections made. This element could consist of a paper or online survey to understand the uptake rates of the social actives 1 year on, and further investigation into QOL, healthcare use and the option of assessing health behaviours. All participants would be given the option of continuing for a year, and therefore those who continue would be decided by participant preference to remain in the study.

Analysis Plan

Primary Outcomes

Descriptive statistics of the cohort,

Descriptive statistics of the cohort will be reported including but not limited to; age, gender, severity of disease then the analysis will be broken down into 5 distinct sections;

a) Pre and post intervention cost utility analysis for the usual care group and the intervention group.

b) Comparative group - pre and post cost utility analysis; calculated cost per QALY (quality adjusted life years) gained and cost of healthcare usage per patient– usual care group at 3 months after leaving the COPD service compared with the post intervention group 3 (+/- 1 week) months after leaving the COPD service, with significance.

c) Clinical comparative analysis pre and post intervention including burden of disease (CAT score) and psychological impact of the disease, using Wilcoxin Ranked tests. Pre intervention burden of disease correlated with 3 months (+/- 1 week) disease burden post intervention (CAT), with significance.

d) Clinical comparative analysis between groups at 3 months (as above) Wilcoxin Ranked tests.

12 months follow up survey

a) Pre intervention burden of disease compared with 12 months disease burden post intervention (CAT).
b) Activity uptake rates; recorded at 12 months post intervention, proportions of patients engaging in recommended activities.

Ethical Considerations

This is a new research trial of an existing social networking tool already used in long term diseases but not yet specifically in COPD. Prior to introducing this to the entire clinical service, clinical effectiveness recommends changes are trialled on a smaller proportion of the patient population in order to understand the benefits of time and cost prior to full scale implementation.

As this is an intervention within a clinical service and the evaluation is conducted with NHS participants, on NHS properties therefore University ERGO (Ethics) and HRA full NHS ethics application has been sort. The Ethical review number will be on all patient facing documentation. This ethical review has evaluated the social and scientific value of the study. Further to this it ensures adequacy of patient information, the informed consent process, recruitment arrangements and access to information.

The service implementation and evaluation will also be presented at the Solent Adult service line, clinical effectiveness and audit group for Solent NHS Trust approval.

Appendix D Accessible Patient information sheet

COPD Research Study – GENIE in COPD

The COPD Research Study is about gathering your thoughts about your healthcare. It is an investigation to help Doctors and nurses understand how much your family and friends help you with you COPD.

Lindsay is a nurse, and the lead of the COPD service. The University of Southampton is helping Lindsay to test a computer programme. The computer programme is designed to find you more support from friends in the area that you live.

In order to test this computer programme, Lindsay is looking for volunteers, to talk to her and answer questionnaires about how you manage your illness and how your friends and family may or may not help you.

If you volunteer you see and you will spend about 1.5 hours with her in Bitterne Health Centre, going through questionnaires, and using the tool. You will be helped with all of this.

Then you will be asked to return in 3 months to Bitterne Health Centre to repeat the same questionnaires

.

Appendix E Participant Information Sheet

Genie in COPD PIS Amendment larger Font **June 2017 V11**

Study Title: Implementing and Evaluating the GENIE tool in Southampton Integrated COPD Service: A clinical trial and evaluation to ascertain cost effectiveness and patient benefit.

Researcher:Ms Lindsay Welch **Ethics number**: 17/SC/0044

Please read this information carefully before deciding to take part in this research. If you are happy to take part, then you will be asked to sign a consent form.

What is the research about?

This research is part of a student project by Ms Lindsay Welch. Lindsay is also the lead of the Integrated COPD service at Solent NHS Trust.

People with long term health conditions can cope better with their health problems if they have support from family and friends.

When you become unwell it can be difficult for you to see people as much because you are unable to travel as far or have less energy to go out. This means that your circle of friends and family can get smaller and you could have less support.

This study aims to test a facilitated (assisted) online tool that will help you make new connections so that you are able to manage better on a day to day basis despite your symptoms.

The online, social networking tool is called the Genie tool, and it can map your social groups and offer you more and varied social activities. You will be guided through the GENIE tool by a researcher, so you won't need to use the computer yourself if you find this difficult. The researcher will ask you questions about your friends and family and how often you see them. This will be recorded using circles to demonstrate how important certain people are to you.

If you feel this is too personal then you can use a pretend name for both you and your family members, if you wish.

The Genie tool then asks you questions about your preferred social activities, these can be related to your health, but the focus is your preferences.

At this point you can just let the researcher know what interests you have and what sort of activities you prefer. The tool then provides you with a printout of activities and groups you can join on your own or with existing friends in your local area.

We are testing this tool in people with COPD. So, if you have COPD you will then be invited to join the study. Everyone who joins the study will have their usual care after the exercise classes, but some of you will be able to use the GENIE tool as well.

The study has been reviewed by the Health Research Authority NHS Ethics committee. This is to make sure the study is both a safe and a useful study for local people with COPD. If you decide to join in the study the study team will also ask permission to tell your GP.

Why have I been invited?

You have been invited to join the study because you have a lung disease called COPD and you are a patient in the care of Solent NHS Trust. Also, you are a patient that is currently attending pulmonary rehabilitation and / or maintenance exercise classes in the East of the city. Also, you have told the team looking after you that you would like to take part.

What will happen to me if I take part?

You will be approached by your usual clinical team and asked if you are interested in research, information (this information) will be provided for you to read. If after reading this information sheet you will be invited to join the study. You will be provided with information about the study that you can take home to read and share with family and friends. In order to ensure you have enough time to read the information, the research team will allow you at least 3 days. If you need more time to read the sheet or speak to friends and family, you can keep the information for longer.

Once you are happy to take part, your usual clinical team will ask if you are happy to book an appointment with the research team, and if you are happy for the research team to have your details, to enable them to write to you about appointments. You will then be offered an appointment to see the research team, at this appointment you will be asked to sign a consent form.

You will always still be offered all of your usual clinical care by the team and you are still able to withdraw at any time. If you consent to join the GENIE study, this will be in addition to your usual care.

At this point you will be allocated to either join the social network GENIE intervention group, or the usual care only group, in both groups you will always receive your usual care. You will not know which group you are assigned to. Once you are assigned to a group then the intervention or usual care (visit 1) will be delivered. This is to ensure you don't have to make another journey to the health centre.

Consent and Randomisation

The first thing you will be asked is to sign a consent form, to give your permission for us to ask you questions and for you to be part of the study. You will then be 'randomised' – automatically selected by a third party to be in either the social intervention group, or to just receive your usual COPD care. Both groups have usual care.

Visit 1 - Baseline

During this appointment both groups will be asked to complete between four and seven questionnaires, if you have recently completed them as part of your usual care, we won't ask you to do them again. Two questionnaires are about how you currently use health care, and two questionnaires will be about your health and wellbeing. The other questionnaires are about how troubled you are by your COPD and your mood. A further optional questionnaire asks you about your lifestyle and dietary habits.

Depending on which group you have been selected to take part in, you will be given a usual discharge plan alone or your usual discharge plan and support to use the social networking tool. You will be supported through this by the researcher.

The information used in the tool is kept secure, if you are worried about using your own name or your families names, then you can use pretend names (pseudonyms) the tool will then offer you social activities based on your preferences.

The interview and facilitation of the intervention will be tape recorded, with your permission. This is to ensure the intervention is being delivered correctly, and the tapes will not be used for publication or disclosed to anyone outside the GENIE research group. They will be downloaded onto secure NHS computers, and then deleted from the audio recorder.

A date and appointment will be made for you to return in 3 months' time. You will be sent a reminder letter nearer to this appointment and if you have a mobile phone, then a text message amy also be sent. The appointment will take 45- 50 mins and will be held at Bitterne Health Centre.

Visit 2 – 3 months follow up

We will ask you to complete the same six questionnaires and the optional questionnaire you completed at visit 1. You will also be asked whether you have joined any social groups or have become more active in your local community.

You may be asked if you are happy for some of the discussions to be audio recorded. You do not have to be recorded if you don’t want to. The recordings are to assess the researcher and are not going to be directly used for the research.

Visit 3 – 12 months follow up

You may also be asked, via follow up letter and/ or telephone call to come back in 1 year (post visit 1). This will be to repeat the same questionnaires as you completed in your previous visits. Not all patients will be approached to attend this visit.

Are there any benefits in my taking part?

We are unsure whether taking part in the research will help you. However, if you are in the intervention group there may be some benefit to your well-being and an improvement to your COPD. This work may also help other patients with COPD and other long-term conditions by improving our understanding of how social network tools can improve well-being and health.

Are there any risks involved?

We see no potential risk to you. During the study you will always be offered your usual care. However, the tool does ask you about your social networks (friends and families), some people may find this intrusive, or distressing. If this is the case then please do let the research facilitator know so as they can support you, if need be.

Will my participation be confidential?

If you are part of the intervention group you will need to provide your name or pseudonym and post code to enable the online intervention to work, but no other personal details are required.

All clinical information we collect will be kept confidential by allocating you a unique study number. All research paperwork will only have your unique number and your initials on it so that you cannot be identified. All research data will be stored on a secure database within an NHS computer and will not include any personal details. In the GENIE Tool itself we could use a Pseudonym (a pretend name) instead of your name, so as you cannot be identified, you can use pseudonyms for your friends and family if you wish.

For data analysis, the research data will be shared with the University of Southampton. However, this will not contain any personal details only the unique number and initials. Personal details will only be accessible by your usual clinical team, and the direct contact researcher(s) on the study – for them to call you and make appointments for you.

What happens if I change my mind?

You can withdraw from the study for any reason at any time; your usual care will not be affected. If you withdraw from the study the research team will retain the data collected up until the point you withdraw. Again, this will remain numbered and without personal detail.

What happens if something goes wrong?

In the unlikely case of concern or complaint, you are welcome to contact the independent University of Southampton Research Governance office.

Isla Morris

University of Southampton Research Integrity and Governance Manager

Rgoinfo@soton.ac.uk

023 80 595058

Where can I get more information?

If you have any further questions please do not hesitate to contact the lead researcher, Ms Lindsay Welch on:

Mobile: 07789920092 Or COPD Admin: 0300 123 3794

Participant summary V2 Mar 2017

Appendix F Participant Summary

Study Title: Implementing and Evaluating the GENIE tool in Southampton Integrated COPD Service: A clinical trial and evaluation to ascertain cost effectiveness and patient benefit.

Researcher: Ms Lindsay Welch **Ethics number**: 17/SC/0044

GENIE in COPD is a research study designed to help people with COPD connect with social activities.

The GENIE tool is an online tool that can map your social groups and offer you more and varied social activities. You can be will be guided through the GENIE tool by a researcher, so you won't need to use the computer yourself, if you find this difficult.

In order to test the GENIE tool, the researchers will need to gather proof that it works, so we will ask you to;

1- Sign a consent form to say you are happy to participate in the GENIE in COPD study
2- Be put in a group to receive the GENIE tool or not receive the GENIE tool (randomisation)– everyone will get usual care
3- Answer 6 simple questionnaires at the beginning and the end of the study, which will take about 20 minutes
4- We would like to record the conversation you have with the researcher – but you can say no to this
5- Try the GENIE Tool with the researcher to help you

About the Genie Tool

The researcher will ask you questions about your friends and family and how often you see them. This will be recorded using circles to demonstrate how important certain people are to you. If you feel this is personal, then you can use a pretend name for both you and your family members. This information will not be shared with anybody.

The Genie tool then asks you questions about your preferred social activities related and unrelated to your COPD. You can just let the researcher know what interests you have and what sort of activities you prefer. The tool then provides you with a helpful overview of activities and groups you can join on your own or with existing friends in your local area.

Appendix G GENIE in COPD basic data form Baseline visit Jan 2017

Study Title: Implementing and Evaluating the GENIE tool in Southampton Integrated COPD Service: A clinical trial and evaluation to ascertain cost effectiveness and patient benefit.

Researcher: Ms Lindsay Welch **Ethics number**: 17/SC/0044

Question	**Answer**
Postcode	
Sex (male/Female)	
Age at baseline	
Marital Status	
Number in household, children and adults	
Number of regular visitors	
Age at school leaving / highest qualification	
Occupation and previous occupation	
COPD severity using GOLD 2017 Fev1	

Appendix H Consent Form A - Main Study (Version 10, June 2017)

Study title: Implementing and Evaluating the GENIE tool in Southampton Integrated COPD Service: A clinical trial and evaluation to ascertain cost effectiveness and patient benefit.

Researcher name: Ms Lindsay Welch

Study reference: 19175

Ethics reference: 17/SC/0044

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (Version 11, June 2017) and have ☐

I agree to take part in this research project and agree for my data to be used for the purpose of this study**.** I understand that all my details will be kept confidential and my ☐

I understand my participation is voluntary and I may withdraw at any time without my legal rights or usual care being affected ☐

I agree to be audio recorded during the research visit, for quality purposes only; the tapes will be stored securely in the University of Southampton, and destroyed post study termination ☐

I give permission to be contacted as part of the study to participate in a follow up appointment in one year; I understand this is optional part of the study ☐

I give my permission to authorise personnel from the clinical research team to inform my General Practitioner of my participation in the study. ☐

Optional Section

Appendix H

I agree to take part in the optional sub-study investigating diet and lifestyle habits ☐ Yes ☐ No

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected Solent NHS computer and that this information will only be used for the purposes of ethically approved research projects. All files containing any personal data will be made anonymous.

Name of participant (print name)…………………………………………………

Signature of participant……………………………………………………………

Date ……………………………………………………………………

Name of person taking consent …………………………………………………

Signature of person taking consent ……………………………………………

Date……………………………………………………………………………………

Appendix I EQ5D Health Status questionnaire

Health Questionnaire

English version for the UK

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

I have no problems in walking about ☐

I have slight problems in walking about ☐

I have moderate problems in walking about ☐

I have severe problems in walking about ☐

I am unable to walk about ☐

SELF-CARE

I have no problems washing or dressing myself ☐

I have slight problems washing or dressing myself ☐

I have moderate problems washing or dressing myself ☐

I have severe problems washing or dressing myself ☐

I am unable to wash or dress myself ☐

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐

I have slight problems doing my usual activities ☐

I have moderate problems doing my usual activities ☐

I have severe problems doing my usual activities ☐

I am unable to do my usual activities ☐

PAIN / DISCOMFORT

I have no pain or discomfort ☐

I have slight pain or discomfort ☐

I have moderate pain or discomfort ☐

I have severe pain or discomfort ☐

I have extreme pain or discomfort ☐

ANXIETY / DEPRESSION

I am not anxious or depressed ☐

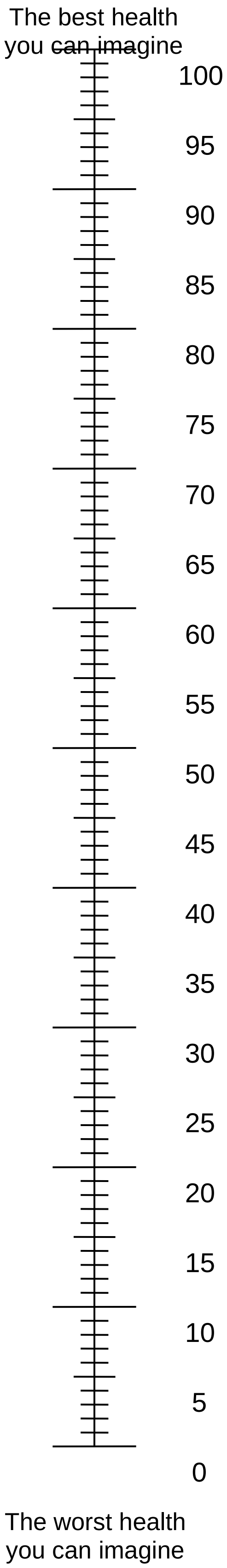
I am slightly anxious or depressed ☐

I am moderately anxious or depressed ☐

I am severely anxious or depressed ☐

I am extremely anxious or depressed ☐

Appendix I



YOUR HEALTH TODAY = ☐

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

Appendix J Health Utilisation questionnaire

Health care utilisation questionnaire

Healthcare Usage Questionnaire

We would like to know how much use you have made of the health and social services over the last 3 months. If you are not exactly sure, we would rather have your best guess than no information at all.

Please answer every question, even if the answer is 'No'.

1) Over the last 3 months, if, and how many times, have you used any of the following:

Type of Service	No	Yes	If yes: Number of visits
GP		At home	
		In the surgery	
		On the phone	
Practice nurse		At home	
		In the surgery	
		On the phone	
Social worker		At home	
		In the facility	
		On the phone	
Visit at home from a community nurse or Dr			
Specialist community clinic –with consultant			
NHS Smoking Cessation clinic			
Other (describe)			

2) Hospital outpatient visit for breathing related issues

Episode*	Name of the hospital	Reason for appointment	Specialty of Department	Number of appointment*
1st				
2nd				
3rd				
4th				

*Episode means a visit or group of visits related to a particular problem. Please write down how many appointments you have had for each episode

3) Accident and Emergency for COPD / breathing issues

Episode	Name of the hospital	Reason for visit	Referral from
1st			GP
			Outpatient
			Self-referral
2nd			GP
			Outpatient
			Self-referral
3rd			GP
			Outpatient
			Self-referral
4th			GP
			Outpatient
			Self-referral

4) Hospital Inpatient for COPD / breathing and chest issues

Episode	Name of hospital	Ward Speciality	Reason for admission	No of nights*
1st				
2nd				
3rd				
4th				

*If you were treated as a day patient (day case), then please write 0 under “number of night”

5) Are you currently in paid employment?

No ☐(please go to question 5b)   Yes ☐(please go to question 5a)

5a If yes, how many days have you been absent from work because of COPD in the last 3 months? Please state how many days ☐ 5b If you are not employed:,

In the last 3 months have you had to stop work completely due to your COPD disease

No ☐

Yes ☐

6) Over the last 3 months has a relative or friend taken time off work to look after you?
   No ☐
   Yes, how many days

7) In the last 3 months, approximately how much additional money have you spent on travel (taxi car park fees and public transportation because of your COPD disease)
   None ☐
   Yes, ☐ I spent £ ________________________

8) If you would like to tell us about any other costs incurred because of your COPD over the last 3 months (club/gym membership, employing extra help, buying extra equipment, food and meal delivery), please write them here.
   No ☐
   Yes ☐ I spent £______________please give details ___________________________________

Appendix K Participant Information Sheet

Participant Information Sheet

Study Title: Implementing and Evaluating the GENIE tool in Southampton Integrated COPD Service: A clinical trial and evaluation to ascertain cost effectiveness and patient benefit.

Researcher: Ms Lindsay Welch

Ethics number: 17/SC/0044

IRAS ID: 204159

Please read this information carefully before deciding to take part in this research. If you are happy to take part, then you will be asked to sign a consent form.

What is the research about?

This research is part of a student project by Ms Lindsay Welch. Lindsay is also the lead of the Integrated COPD service at Solent NHS Trust.

People with long term health conditions can cope better with their health problems if they have support from family and friends.

When you become unwell it can be difficult for you to see people as much because you are unable to travel as far or have less energy to go out. This means that your circle of friends and family can get smaller and you could have less support.

This study aims to test a facilitated (assisted) online tool that will help you make new connections so that you are able to manage better on a day to day basis despite your symptoms.

The online, social networking tool is called the Genie tool, and it can map your social groups and offer you more and varied social activities. You will be guided through the GENIE tool by a researcher, so you won't need to use the computer yourself if you find this difficult. The researcher will ask you questions about your friends and family and how often you see them. This will be recorded using circles to demonstrate how important certain people are to you.

If you feel this is too personal then you can use a pretend name for both you and your family members, if you wish.

The Genie tool then asks you questions about your preferred social activities, these can be related to your health, but the focus is your preferences.

At this point you can just let the researcher know what interests you have and what sort of activities you prefer. The tool then provides you with a printout of activities and groups you can join on your own or with existing friends in your local area.

We are testing this tool in people with COPD. So, if you have COPD you will then be invited to join the study. Everyone who joins the study will have their usual care after the exercise classes, but some of you will be able to use the GENIE tool as well.

The study has been reviewed by the Health Research Authority NHS Ethics committee. This is to make sure the study is both a safe and a useful study for local people with COPD. If you decide to join in the study the study team will also ask permission to tell your GP.

Why have I been invited?

You have been invited to join the study because you have a lung disease called COPD and you are a patient in the care of Solent NHS Trust. Patients invited currently attend pulmonary rehabilitation and maintenance exercise classes in the East of the city. Also, you have told the team looking after you that you would like to take part.

What will happen to me if I take part?

You will be approached by your usual clinical team and asked if you are interested in research, information (this information) will be provided for you to read. If after reading this information sheet you will be invited to join the study. You will be provided with information about the study that you can take home to read and share with family and friends, you be given at least 3 days. If you need more time to read the sheet or speak to friends and family you can keep the information for longer.

Once you are happy to take part, your usual clinical team will ask if you are happy to book an appointment with the research team, and if you are happy for the research team to have your details, to enable them to write to you about appointments. You will then be offered an appointment to see the research team, at this appointment you will be asked to sign a consent form.

You will always still be offered all of your usual clinical care by the team and you are still able to withdraw at any time. If you consent to join the GENIE study, this will be in addition to your usual care.

At this point you will be allocated to either join the social network GENIE intervention group, or the usual care only group, in both group you will always receive your usual care. You will not know which group you are assigned to. Once you are assigned to a group then the intervention or usual care (visit 1) be delivered. This is to ensure you don't have to make another journey to the health centre.

Consent and Randomisation

The first thing you will be asked is to sign a consent form, to give your permission for us to ask you questions and for you to be part of the study. You will then be 'randomised' – automatically selected by a third party to be in either the social intervention group, or to just receive your usual COPD care. Both groups have usual care.

Visit 1 - Baseline

During this appointment both groups will be asked to complete between six and four questionnaires, if you have recently completed them as part of your usual care, we won't ask you to do them again. Two questionnaires are about how you currently use health care, and two questionnaires will be about your health and wellbeing. The other questionnaires are about how troubled you are by your COPD and your mood.

Depending on which group you have been selected to take part in, you will be given a usual discharge plan alone or your usual discharge plan and support to use the social networking tool. You will be supported through this by the researcher.

The information used in the tool is kept secure, if you are worried about using your own name or your families names, then you can use pretend names (pseudonyms) the tool will then offer you social activities based on your preferences.

The interview and facilitation of the intervention will be tape recorded. This is to ensure the intervention is being delivered correctly, and the tapes will not be used for publication or disclosed to anyone outside the GENIE research group. They will be downloaded onto secure NHS computers, then deleted for the audio recorder.

A date and appointment will be made for you to return in 3 months' time. You will be sent a reminder letter nearer to this appointment and if you have a mobile phone, then a text message will also be sent. The appointment will take 45- 50 mins and will be held at Bitterne Health Centre.

Visit 2 – 3 months follow up

We will ask you to complete the same six questionnaires you completed at visit 1. You will also be asked whether you have joined any social groups or have become more active in your local community.

You may be asked if you are happy for some of the discussions to be audio recorded. You do not have to be recorded if you don't want to. The recordings are to assess the researcher and are not going to be directly used for the research.

Visit 3 – 12 months follow up

You may also be asked, via follow up letter and/ or telephone call to come back in 1 year (post visit 1). This will be to repeat the same questionnaires as you completed in your previous visits. Not all patients will be approached to attend this visit.

Are there any benefits in my taking part?

We are unsure whether taking part in the research will help you. However, if you are in the intervention group there may be some benefit to your well-being and an improvement to your COPD. This work may also help other patients with COPD and other long-term conditions by improving our understanding of how social network tools can improve well-being and health.

Are there any risks involved?

We see no potential risk to you. During the study you will always be offered your usual care. However the tool does ask you about your social networks (friends and families), some people may find this intrusive, or distressing, if so please do let the research facilitator know so as they can support you, if need be.

Will my participation be confidential?

If you are part of the intervention group you will need to provide your name or pseudonym and post code to enable the online intervention to work, but no other personal details are required.

All clinical information we collect will be kept confidential by allocating you a unique study number. All research paperwork will only have your unique number and your initials on it so that you cannot be identified. All research data will be stored on a secure database within an NHS computer and will not include any personal details. In the GENIE Tool itself we could use a Pseudonym (a pretend name) instead of your name, so as you cannot be identified, you can use pseudonyms for your friends and family if you wish.

For data analysis, the research data will be shared with the University of Southampton. However, this will not contain any personal details only the unique number and initials. Personal details will only be accessible by your usual clinical team, and the direct contact researcher(s) on the study – for them to call you and make appointments for you.

What happens if I change my mind?

You can withdraw from the study for any reason at any time; your usual care will not be affected. If you withdraw from the study the research team will retain the data collected up until the point you withdraw. Again, this will remain numbered and without personal detail.

What happens if something goes wrong?

In the unlikely case of concern or complaint, you are welcome to contact the independent University of Southampton Research Governance office.

Isla Morris

University of Southampton Research Integrity and Governance Manager

Rgoinfo@soton.ac.uk

023 80 595058

Where can I get more information?

If you have any further questions please do not hesitate to contact the lead researcher, Ms Lindsay Welch on:

Mobile: 07789920092 Or COPD Admin: 0300 123 3794

Appendix L Health Behaviour tool

Health Behaviour Tool (for use in the GENIE in COPD study)

1. Food Frequency Questionnaire

Please complete the table below. Place a tick in the box that shows approximately how often you have eaten each of the particular foods in the table. Think about how often you have eaten those foods in the past 3 months. Please tick one box on every line.

	FOOD AND AMOUNTS	AVERAGE USE IN PAST 3 MONTHS									
		Never	Less than once/ month	1-3 per month	Once a week	2-4 per week	5-6 per week	Once a day	2-3 per day	4-5 per day	6+ per day
	EXAMPLE: Rice				✓						
	White bread (one slice)										
	Brown and wholemeal bread (one slice)										
	Biscuits e.g. digestive (one)										

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	Apples (one fruit)										
	Bananas (one fruit)										
	Melon, pineapple, kiwi and other tropical fruits (medium serving)										
	Green salad eg lettuce, cucumber, celery										
	Garlic – raw and cooked dishes										
	Marrow and courgettes										
	Peppers – cooked & fresh										
	Yogurt (125g pot)										
	Eggs as boiled, fried, scrambled etc. (one egg))										
	White fish e.g. cod, haddock, plaice, sole (not in batter/crumbs)										
	Oily fish, e.g. mackerel, tuna, salmon										
	Bacon and Gammon										
	Meat pies, e.g. pork pie, pasties										

	Boiled, mashed and jacket potatoes (one egg size potato)										
	Chips										
	Pasta e.g. spaghetti, macaroni										
Which is the main spreading fat you have used for example on bread or vegetables?											
	Spreading fat (teaspoons) Please name the spreading fat you use (e.g.Flora) ___________________________										

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Additional dietary questions:

2. Which types of milk have you used regularly in drinks and added to breakfast cereals over the past three months? Please tell us, on average, how much of each milk type you have consumed per day, over the past 3 months.

	Type of milk	**Please tick**	**On average, over the past 3 months, how much milk have you consumed per day?**
EXAMPLE	**Whole milk**	✓	**0.5 pints or ½ pints per day**
1	Whole pasteurised or UHT milk		_______pints per day
2	Semi-skimmed pasteurised or UHT milk (include 1% milks)		_______pints per day
3	Skimmed pasteurised or UHT milk		_______pints per day
4	Other – please specify ___________________		_______pints per day
5	None, go to question 3		

3. Have you added sugar to tea and coffee or breakfast cereals in the past 3 months? Please tick one box.

Yes ☐ **No** ☐

4. If yes, approximately how many teaspoons of sugar have you added each day?

☐

5. Do you ever drink alcohol?

Please tick one box.

Yes ☐ **No** ☐

6. How often do you currently alcohol (lager/cider/wine/sherry/port/ spirits/liqueurs etc.)

0 = never

1 = once every 2-3 months ☐

2 = once a month

3 = once a fortnight

4 = 1-2 times per week

5 = 3-6 times per week

6 = once per day

7 = more than once per day ☐

If more than once, times per day

7. When you drink these, how many pints or glasses would you normally have? (If range given code mid-point)

☐☐ . ☐

8. Do you currently smoke?

Please tick one box.

Yes ☐ **No** ☐

9. Have you ever been a smoker? (at least once a day for a year or more)

Please tick one box.

Yes ☐ **No** ☐

10. Simplified Nutritional Appetite Questionnaire (SNAQ)

a. My appetite is

1 = very poor, 2 = poor, 3 = average, 4 = good, 5 = very good ☐

b. When I eat I feel full after

1 = a few mouthfuls, 2 = 1/3 of a meal, 3 = 1/2 a meal

4 = most of the meal, 5 = I hardly ever feel full ☐

c. Food tastes

1 = very bad, 2 = bad, 3 = average, 4 = good, 5 = very good ☐

d. Normally I eat

1 = less than one meal a day, 2 = one meal a day, 3 = two meals a day

4 = three meals a day, 5 = more than three meals a day ☐

11. Height and Weight

Height (cm) ☐☐☐

Weight (kg) ☐☐☐

BMI (kg/m^2) ☐☐

12. Self-reported assessment of physical function (SF-36 PF)

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, please indicate how much.

	Yes limited a lot	Yes limited a little	No, not limited at all
a) **Vigorous** activities, such as	☐	☐	☐
b) **Moderate** activities, such as moving a table, pushing a vacuum	☐	☐	☐
c) Lifting or carrying groceries	☐	☐	☐
d) Climbing **several** flight of stairs	☐	☐	☐
e) Climbing **one** flight of stairs	☐	☐	☐
f) Bending, kneeling or stooping	☐	☐	☐
g) Walking **more than one mile**	☐	☐	☐
h) Walking **half a mile**	☐	☐	☐
i) Walking **one hundred yards**	☐	☐	☐

j)	Bathing or dressing yourself	☐	☐	☐

13. Physical Activity

Think about all the **vigorous** activities that you did in the **last 7 days**. **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.

13.1. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling?

days per week ☐

Record as 0 days if no vigorous physical activities and skip to qn. 13.3.

13.2. How much time did you usually spend doing **vigorous** physical activities on one of those days?

______ hours per day

______ minutes per day

☐ Don’t know/Not sure

Think about all the **moderate** activities that you did in the **last 7 days**. **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.

13.3. During the **last 7 days**, on how many days did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

☐ days per week

Record as 0 days if no moderate physical activities and skip to qn. 13.5.

13.4. How much time did you usually spend doing **moderate** physical activities on one of those days?

_____ hours per day

_____ minutes per day

☐ Don't know/Not sure

13.5. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?

☐ days per week

Record as 0 days if no walking and skip to qn. 13.7.

13.6. How much time did you usually spend **walking** on one of those days?

_____ hours per day

_____ minutes per day

☐ Don’t know/Not sure

13.7. During the **last 7 days** how much time did you usually spend **sitting** on a weekday?

______hours per day

______minutes per day

☐ Don’t know/Not sure

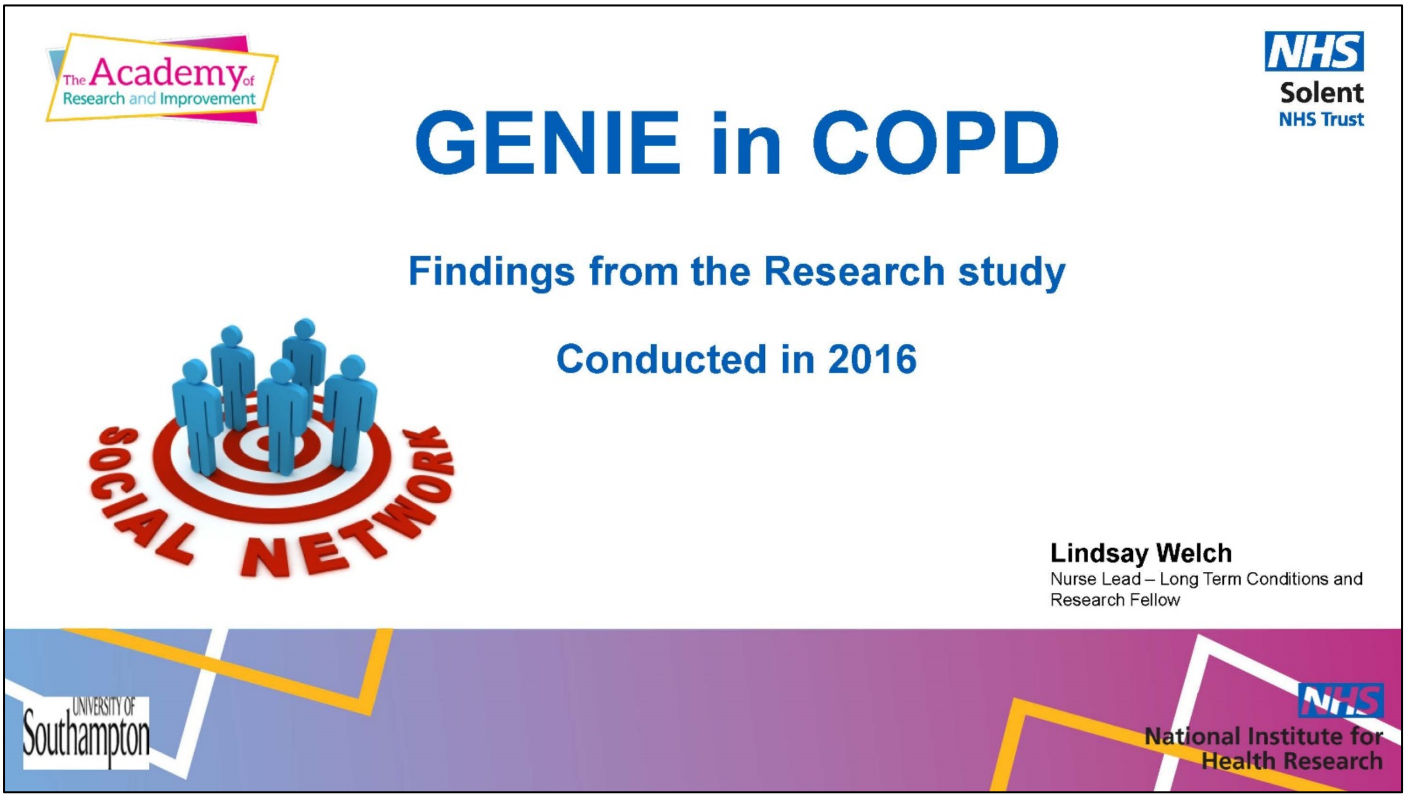
13.8. During the **last 7 days** how much time did you usually spend **sitting** on a weekend day?

______hours per day

______minutes per day

☐ Don’t know/Not sure

Appendix M Participant Dissemination Event



The Academy of Research and Improvement

NHS Solent NHS Trust

GENIE in COPD

Findings from the Research study

Conducted in 2016

Lindsay Welch
Nurse Lead – Long Term Conditions and
Research Fellow

University of Southampton

NHS National Institute for Health Research

The Academy of Research and Improvement

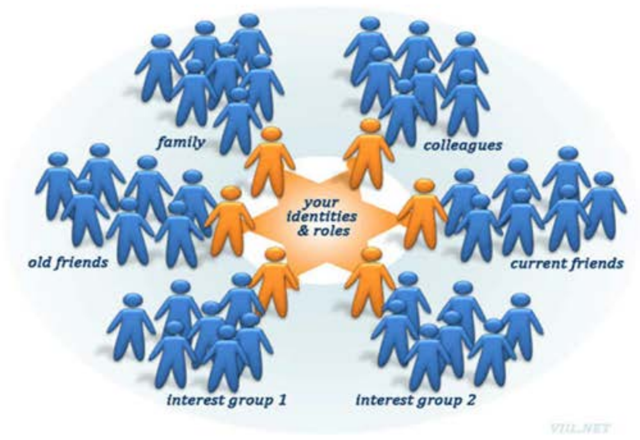
NHS Solent NHS Trust

Thank You

The Academy of Research and Improvement

NHS Solent NHS Trust

What was it all about ?



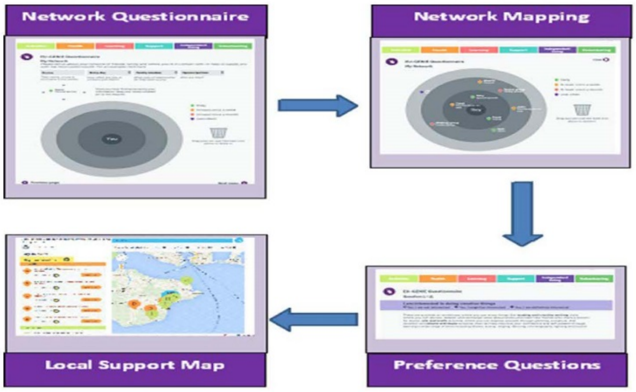
The Academy of Research and Improvement

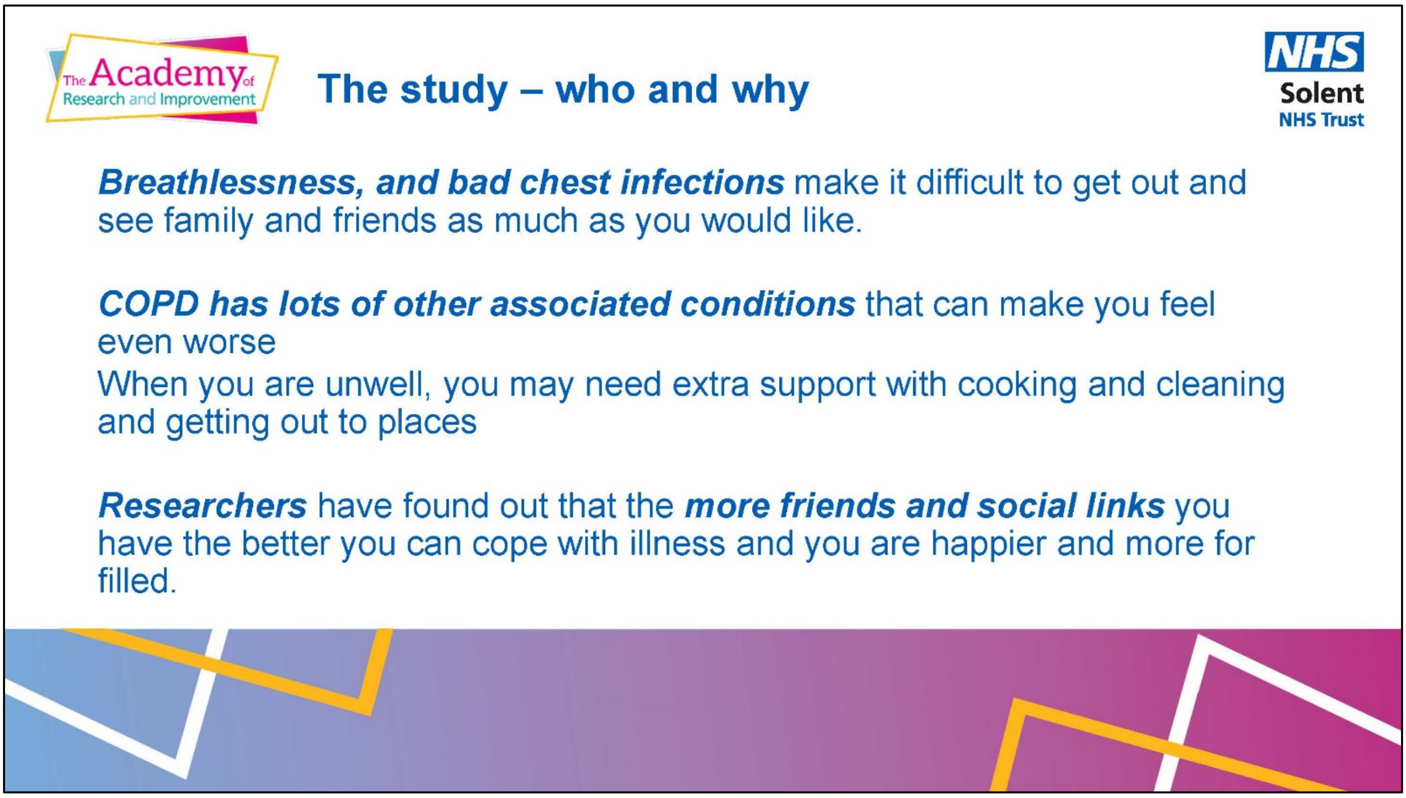
NHS Solent NHS Trust

What is GENIE ?

A social networking tool.

Designed to help open conversations regarding friends and family networks and then think about how much support you provide each to each other
https://genie.soton.ac.uk/





The study – who and why

Breathlessness, and bad chest infections make it difficult to get out and see family and friends as much as you would like.

COPD has lots of other associated conditions that can make you feel even worse

When you are unwell, you may need extra support with cooking and cleaning and getting out to places

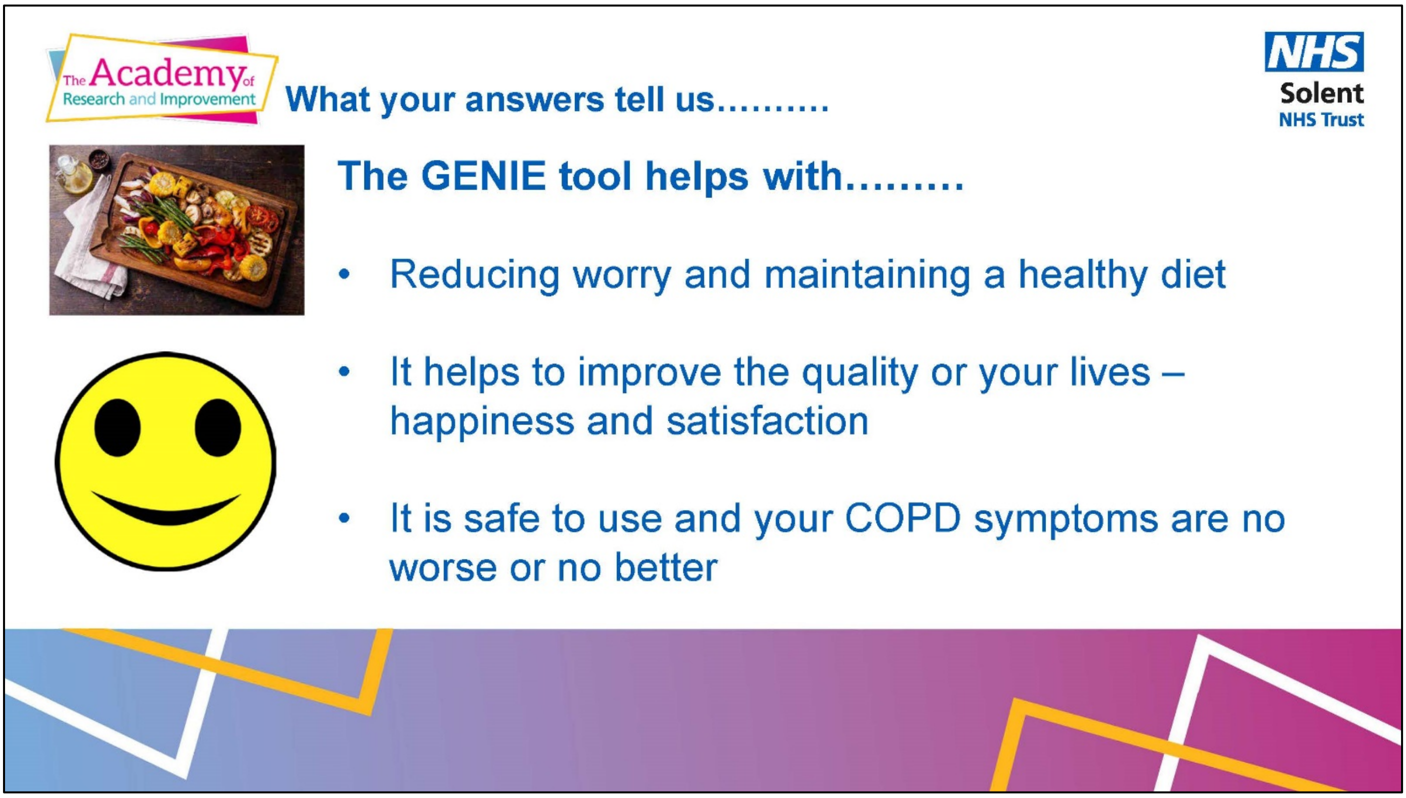
Researchers have found out that the ***more friends and social links*** you have the better you can cope with illness and you are happier and more for filled.

How you helped ....

We asked you questions about:

- Quality of your lives (Happiness, coping and satisfaction)
- Time spend in the NHS and how much you spend on your COPD
- How troubled you are by your COPD symptoms
- Your mood and your worries
- Your diet – what you ate and when you ate it
- Your activity and daily exercise

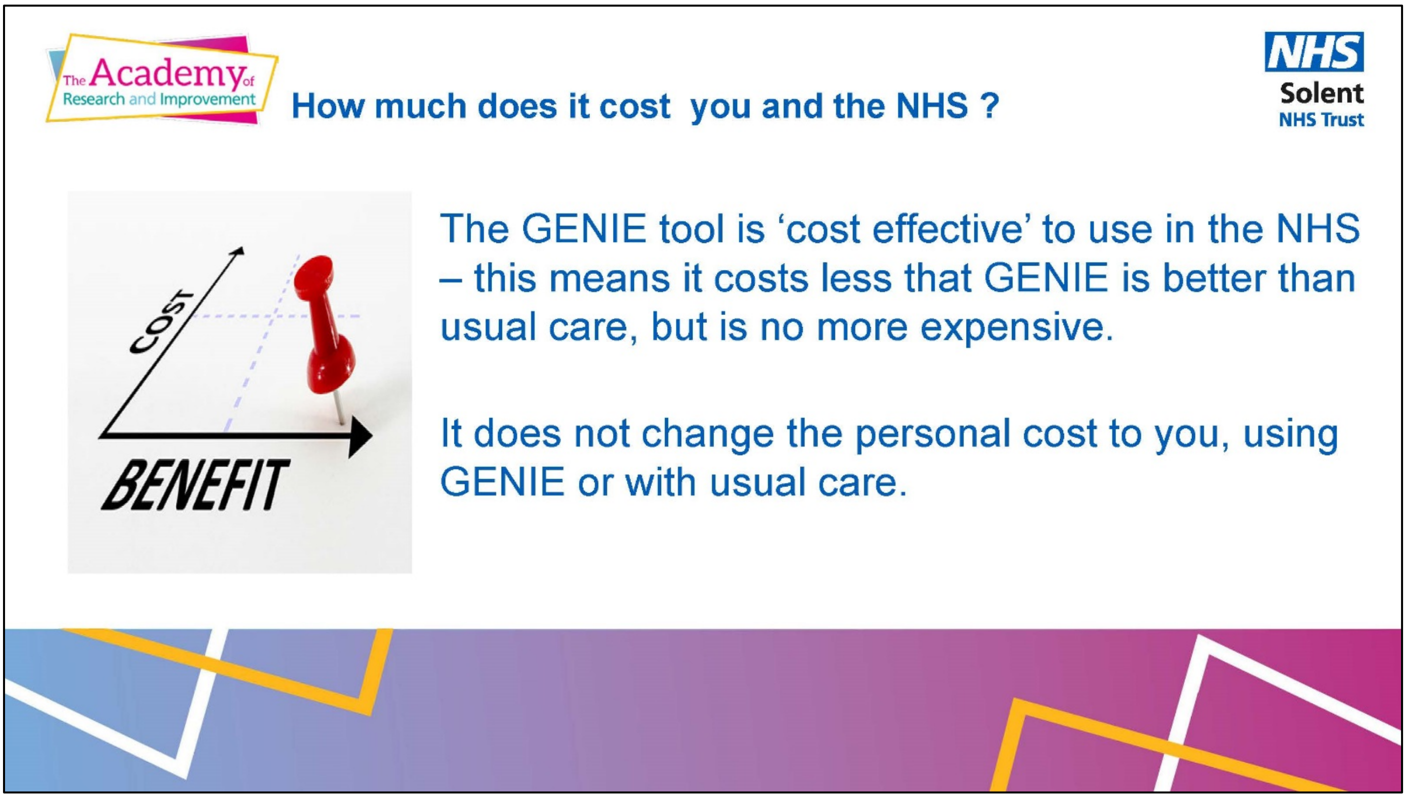
- And ……. Your friends, family and community groups



What your answers tell us……….

The GENIE tool helps with………

- Reducing worry and maintaining a healthy diet
- It helps to improve the quality or your lives – happiness and satisfaction
- It is safe to use and your COPD symptoms are no worse or no better



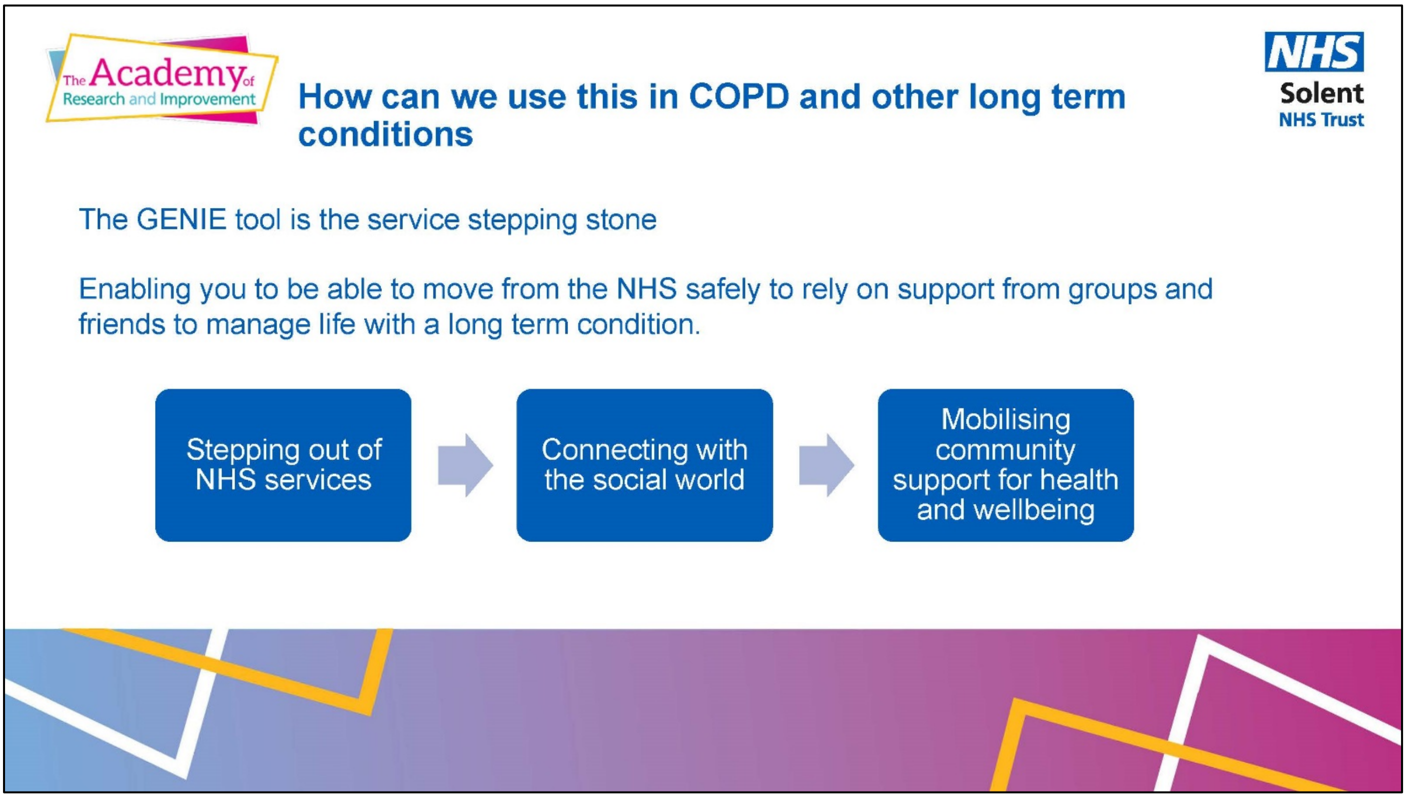
How much does it cost you and the NHS ?

The GENIE tool is ‘cost effective’ to use in the NHS – this means it costs less that GENIE is better than usual care, but is no more expensive.

It does not change the personal cost to you, using GENIE or with usual care.

Discussion – we found out that ……..

- Having more friends and groups in COPD in important
- Your networks of friends help to be less worried and generally happier
- More links to friends means seeing GP less and less visit to hospital
- More friends (social links) may help you eat better diet for longer



How can we use this in COPD and other long term conditions

The GENIE tool is the service stepping stone

Enabling you to be able to move from the NHS safely to rely on support from groups and friends to manage life with a long term condition.

Stepping out of NHS services → Connecting with the social world → Mobilising community support for health and wellbeing

List of References

ABRAMS, T. E., VAUGHAN-SARRAZIN, M., FAN, V. S. & KABOLI, P. J. 2011. Geographic isolation and the risk for chronic obstructive pulmonary disease-related mortality: a cohort study. *Annals of Internal Medicine,* 155**,** 80-86 7p.

ALLEN, C., VASSILEV, I., KENNEDY, A. ROGERS, A. 2016. Long-term condition self-management support in online communities. A meta-synthesis of qualitative papers. *Journal of Medical internet research,* 18**,** 1-17.

ALMAGRO, P., CABRERA, F. J., DIEZ, J., BOIXEDA, R., ALONSO ORTIZ, M. B., MURIO, C. & SORIANO, J. B. 2012. Comorbidities and short-term prognosis in patients hospitalized for acute exacerbation of COPD: the EPOC en Servicios de medicina interna (ESMI) study. *CHEST,* 142**,** 1126-1133 8p.

AMBROSIO, L. G., J.M.S. FERNANDEZ, M.R. BRAVO, S.A. DE CERIO AYESA, S.D. SESMA, M.E.U. NEUS CAPARROS, N. AND PORTILLO, M.C. 2015. Living with chronic illness in adults: a concept analysis. *Journal of Clinical Nursing,* 24**,** 2357-2367.

ANDENÆS, R., BENTSEN, S. B., HVINDEN, K., FAGERMOEN, M. S. & LERDAL, A. 2014. The relationships of self-efficacy, physical activity, and paid work to health-related quality of life among patients with chronic obstructive pulmonary disease (COPD). *Journal Of Multidisciplinary Healthcare,* 7**,** 239-247.

ANDREAS, S., HERING, T., MÜHLIG, S., NOWAK, D., RAUPACH, T. & WORTH, H. 2009. Smoking cessation in chronic obstructive pulmonary disease: an effective medical intervention. *Deutsches Aerzteblatt International,* 106**,** 276-282 7p.

ANTHONISEN, N. R., MANFREDA, J., WARREN, C. P., HERSHFIELD, E. S., HARDING, G. K. & NELSON, N. A. 1987. Antibiotic therapy in exacerbations of chronic obstructive pulmonary disease. *Annals of Internal Medicine,* 106**,** 196-204.

ANTONUCCI, T. C. ARJROUCH, K.J. BIRDITT, K.S. 2014. The Convor model: Explaining social realtions from a multidisciplinary perspective. *The Gerontologist* 54**,** 82-92.

APPS, L. D., HARRISON, S. L., WILLIAMS, J. E. A., HUDSON, N., STEINER, M., MORGAN, M. D. & SINGH, S. J. 2014. How do informal self-care strategies evolve among patients with chronic obstructive pulmonary disease managed in primary care? A qualitative study. *International Journal Of Chronic Obstructive Pulmonary Disease,* 9**,** 257-263.

ARAIN, M., CAMPBELL, M. J., COOPER, C. L. & LANCASTER, G. A. 2010. What is a pilot or feasibility study? A review of current practice and editorial policy. *BMC Medical Research Methodology,* 10**,** 67.

BAKER, E. & FATOYE, F. 2017. Clinical and cost effectiveness of nurse-led self-management interventions for patients with copd in primary care: A systematic review. *Int J Nurs Stud,* 71**,** 125-138.

BANDURA, A. 1997. *Self-efficacy: the exercise of control. ,* New York Freeman.

BEECHAM, J., SCHNEIDER, J. AND KNAPP, M. 1999a. Survey of day activity settings for people with mental health

problems. *Mental Health Research Review,* 6.

BEECHAM, J. A. 1999b. *Measuring mental health needs*, G. Thornicroft.

BENDER, B. G. 2014. Nonadherence in chronic obstructive pulmonary disease patients: what do we know and what should we do next? *Current Opinion in Pulmonary Medicine,* 20**,** 132-137.

BENTSEN, S. B., LANGELAND, E. & HOLM, A. L. 2012. Evaluation of self-management interventions for chronic obstructive pulmonary disease. *Journal of Nursing Management,* 20**,** 802-813 12p.

BHATT, S. P. & DRANSFIELD, M. T. 2013. Chronic obstructive pulmonary disease and cardiovascular disease. *Translational Research: The Journal of Laboratory & Clinical Medicine,* 162**,** 237-251 15p.

BICKERDIKE, L., BOOTH, A., WILSON, P. M., FARLEY, K. & WRIGHT, K. 2017. Social prescribing: less rhetoric and more reality. A systematic review of the evidence. *BMJ Open,* 7**,** e013384.

BLAKEMAN, T., BLICKEM, C., KENNEDY, A., REEVES, D., BOWER, P., GAFFNEY, H., GARDNER, C., LEE, V., JARIWALA, P., DAWSON, S., MOSSABIR, R., BROOKS, H., RICHARDSON, G., SPACKMAN, E., VASSILEV, I., CHEW-GRAHAM, C. & ROGERS, A. 2014. Effect of information and telephone-guided access to community support for people with chronic kidney disease: randomised controlled trial. *PLoS One,* 9**,** e109135.

BLAKEMAN, T. B., P. REEVES, D. CHEW-GRAHAM, C. 2009. Bringing self-management into clinical view: a qualitative study of long-term condition management in primary care consultations. *Chronic Illness,* 0**,** 1-15.

BLANE D, W. R., MONTGOMERY SM, HILDON Z, NETUVELI G. 2011. Resilience at older ages: the importance of social relations and implications for policy.

BLAXTER, M. 2013. Criteria for the evaluation of qualitative research papers. *BSA Medical Sociology Online* 7.

BLOOM I, L. W., BARKER M, BAIRD J, DENNISON E, SAYER AA, ET AL. 2017. What influences diet quality in older people? A qualitative study among community-dwelling older adults from the Hertfordshire Cohort Study, UK. *Public Health Nutrition,* 20**,** 2685-93.

BLOOM, I. W., L. VASSILEV,I. ROGERS, A. JAMESON, K. COOPER, C. ROBINSON, S. BAIRD, J. 2020. Findings from an exploration of a social network intervention to promote diet quality and health behaviours in older adults with COPD: a feasibility study. . *BMC Pilot and Feasibility Studies,* 6.

BOLTON, C. B.-S., E.F. BLAKELY,J.D. CROWE,P. ELKIN,S.L. GARROD,R. GREENING,N.J. HESLOP, K. HULL,J.H. MAN, W.D-C. MORGAN, M.D. PROUD,D. ROBERTS,C.M. SEWELL,L. SINGH,S.J. WALKER,P.P. WALMSLEY,S. 2013. British Thoracic Society guideline on pulmonary rehabilitation in adults: accredited by NICE. *Thorax,* 68.

BOURBEAU, J. 2003. Disease-specific self-management programs in patients with advanced chronic obstructive pulmonary disease: a comprehensive and critical evaluation. *Disease Management & Health Outcomes,* 11**,** 311-319 9p.

BOURBEAU, J. 2009. The role of collaborative self-management in pulmonary rehabilitation. *Seminars in Respiratory & Critical Care Medicine,* 30**,** 700-707 8p.

BOURBEAU, J., LAVOIE, K. L. & SEDENO, M. 2015. Comprehensive Self-Management Strategies. *Seminars in Respiratory & Critical Care Medicine,* 36**,** 630-638 9p.

BRAUN, V. CLARKE, V. 2006. Using thematic analysis in psychology. . *Qualitative Research in Psychology. ,* 3**,** 77-101.

BRIDGES, J., POPE, C., & BRAITHWAITE, J. (2019). Making health care responsive to the needs of older people. *Age and Ageing,* 48(6)**,** 785-788.

BRIDGES, J. P., C. BRATHWAITE, J. 2019. Making health care responsive to the needs of older people. *Age & Ageing,* 48**,** 785-788.

BRINGSVOR, H. LANGELAND, E. OFTEDAL, BF. SKAUG, K. ASSMUS, J. BENTSEN, SB. 2018. Effects of a COPD self-management support intervention: a randomized controlled trial. *International Journal Of Chronic Obstructive Pulmonary Disease,* 13**,** 3677-3688.

BRITISH MEDICAL ASSOCIATION (BMA), G. P. C. E. G., NHS ENGLAND AND NHS IMPROVEMENT 2020. Update to the GP contract agreement 2020/21 - 2023/24. *In:* GROUP, P. C. S. A. N. C. (ed.). NHS England

BRITTEN, N. C., R. POPE, C. DONOVAN, J. MORGAN, M. PILL, R. 2002a. Using meta ethnography to synthesise qualitative research: a worked example. *Journal ofHealth Services Research & Policy,* 7.

BROOKS, H. L. R., A. SANDERS, C. PILGRIM, D. 2015. Perceptions of recovery and prognosis from long-term conditions: The relevance of hope and imagined futures. *Chronic Illn,* 11**,** 3-10.

BROWN, R. 2000. Social identitiy theory: past acheivements, current problems and future challenges. *European Journal of Social Psychology,* 30**,** 745-778.

BUCKNALL, C. E., MILLER, G., LLOYD, S. M., CLELAND, J., MCCLUSKEY, S., COTTON, M., STEVENSON, R. D., COTTON, P. & MCCONNACHIE, A. 2012. Glasgow supported self-management trial (GSuST) for patients with moderate to severe COPD: randomised controlled trial. *BMJ: British Medical Journal (Overseas & Retired Doctors Edition),* 344**,** 16-16 1p.

CACIOPPO, J. T. HAWLEY, L.C. 2003. Social isolation and health, with an emphasis on underlying mechanisms. *Perspectives in Biology and medicine.,* 46.

CELLI, B. R. D., M. WEDZICHA, J. A. WILSON, K. C. AGUSTI, A. CRINER, G. J. MACNEE, W. MAKE, B. J.RENNARD, S. I.STOCKLEY, R. A.VOGELMEIER, C.ANZUETO, A.AU, D. H.BARNES, P. J.BURGEL, P. R.CALVERLEY, P. M.CASANOVA, C.CLINI, E. M.COOPER, C. B.COXSON, DUSSER, D. J. FABBRI, L. M. FAHY, B. FERGUSON, G. T. FISHER, A. FLETCHER, M. J. HAYOT, M. HURST, J. R. JONES, P. W. MAHLER, D. A. MALTAIS, F. MANNINO, D. M. MARTINEZ, F. J. MIRAVITLLES, M. MEEK, P. M. PAPI, A. RABE, K. F. ROCHE, N. SCIURBA, F. C. SETHI, S. SIAFAKAS, N. SIN, D. D. SORIANO, J. B. STOLLER, J. K. TASHKIN, D. P. TROOSTERS, T. VERLEDEN, G. M. VERSCHAKELEN, J. VESTBO, J. WALSH, J. W. WASHKO, G. R. WISE, R. A. WOUTERS, E. F. ZUWALLACK, R. L. ATS ERS TASK FORCE FOR COPD RESEARCH. 2015. An Official American Thoracic Society/European Respiratory Society Statement: Research questions in chronic obstructive pulmonary disease. *Am J Respir Crit Care Med,* 191**,** e4-e27.

CHATWIN, J., KENNEDY, A., FIRTH, A., POVEY, A., ROGERS, A. & SANDERS, C. 2014. How potentially serious symptom changes are talked about and managed in COPD clinical review consultations: a micro-analysis. *Soc Sci Med,* 113**,** 120-36.

COLLINS, E. G., BAULDOFF, G., CARLIN, B., CROUCH, R., EMERY, C. F., GARVEY, C., HILLING, L., LIMBERG, T., ZUWALLACK, R. & NICI, L. 2014. Clinical Competency Guidelines for Pulmonary Rehabilitation Professionals: POSITION STATEMENT OF THE AMERICAN ASSOCIATION OF CARDIOVASCULAR AND PULMONARY REHABILITATION. *Journal of Cardiopulmonary Rehabilitation & Prevention,* 34**,** 291-302 12p.

CONKLIN AI, F. N., SURTEES P, KHAW KT, WAREHAM NJ, MONSIVAIS P. 2014. Social relationships and healthful dietary behaviour: evidence from over-50s in the EPIC cohort, UK. *Social science & medicine (1982).* 100**,** 167-75.

CONSORT. 2010. *CONSORT Flow Diagram: for the standardised reporting of trials.* [Online]. Available: http://www.consort-statement.org/; [Accessed July 2018 2018].

COOKE, A., SMITH, D. & BOOTH, A. 2012. Beyond PICO: the SPIDER tool for qualitative evidence synthesis. *Qual Health Res,* 22**,** 1435-43.

COUNCIL, S. C. 2015. *Index of multiple deptrivation.* [Online]. Available: https://www.southampton.gov.uk/council-democracy/council-data/statistics/imd2015.aspx; [Accessed May 2018 2018].

CRAIG P, DIEPPE. P., MACINTYRE S, MICHIE S, NAZARETH I, PETTICREW M. 2008. Developing and evaluating complex interventions: the new Medical Research Council guidance. *British Medical Journal,* 337.

CRAMM, J. M. & NIEBOER, A. P. 2012. Self-management abilities, physical health and depressive symptoms among patients with cardiovascular diseases, chronic obstructive pulmonary disease, and diabetes. *Patient Education & Counseling,* 87**,** 411-415 5p.

CROSSLEY, M. L. 2000. *Introducing narrative psychology. Self, trauma and the construction of meaning.,* Philadelphia, Open University Press.

CROSSLEY, N. 2010. Networks and complexity: Directions for interactionist Research? *Symbolic interaction* 33.

CURTIS, L. B. 2016. Unit Costs of Health and Social Care 2016. *Personal Social Services Research Unit (PSSRU).* .

DEAN M, R. M., GRUNERT KG, LUMBERS M 2009. Factors influencing eating a varied diet in old age. *Public Health Nutrition,* 12**,** 2421-7.

DISLER, R. T., GREEN, A., LUCKETT, T., NEWTON, P. J., INGLIS, S., CURROW, D. C. & DAVIDSON, P. M. 2014. Experience of advanced chronic obstructive pulmonary disease: metasynthesis of qualitative research. *Journal of Pain & Symptom Management,* 48**,** 1182-1199 18p.

DONALDSON, G. C., MÜLLEROVA, H., LOCANTORE, N., HURST, J. R., CALVERLEY, P. M., VESTBO, J., ANZUETO, A. & WEDZICHA, J. A. 2013. Factors associated with change in exacerbation frequency in COPD. *Respiratory Research,* 14**,** 79-79 1p.

DONALDSON, G. C. & WEDZICHA, J. A. 2013. Deprivation, winter season, and COPD exacerbations. *Primary Care Respiratory Journal,* 22**,** 264-265.

DONESKY, D., JANSON, S. L., NGUYEN, H. Q., NEUHAUS, J., NEILANDS, T. B. & CARRIERI-KOHLMAN, V. 2011. Determinants of Frequency, Duration, and Continuity of Home Walking in Patients with COPD. *Geriatric Nursing,* 32**,** 178-187 10p.

DREWNOWSKI A, E. W. 2001. Nutrition, physical activity, and quality of life in older adults: summary. *J Gerontol A Biol Sci Med Sci.,* 56**,** 89-94.

DRINKWATER, C. WILDMAN, J. MOFFAT, S. 2019. Social Prescribing. *BMJ*

EFFING, T., VAN DER PALEN, J. & FRITH, P. 2014. Education in COPD self-management: only part of the game. *Respirology (Carlton, Vic.),* 19**,** 151-152.

EFFING, T. M., EE. VAN DER VALK, PP. ZIELHUIS, GG. WALTERS, EH. VAN DER PALEN, JJ. ZWERINK, M. 2007. Self-management education for patients with chronic obstructive pulmonary disease. *Cochrane Database Syst Rev.*

EFFING, T. W., VERCOULEN, J. H., BOURBEAU, J., TRAPPENBURG, J., LENFERINK, A., CAFARELLA, P., COULTAS, D., MEEK, P., VAN DER VALK, P., BISCHOFF, E. W., BUCKNALL, C., DEWAN, N. A., EARLY, F., FAN, V., FRITH, P., JANSSEN, D. J., MITCHELL, K., MORGAN, M., NICI, L., PATEL, I., WALTERS, H., RICE, K. L., SINGH, S., ZUWALLACK, R., BENZO, R., GOLDSTEIN, R., PARTRIDGE, M. R. & VAN DER PALEN, J. 2016. Definition of a COPD self-management intervention: International Expert Group consensus. *Eur Respir J,* 48**,** 46-54.

EFIRD, J. 2011. Blocked randomization with randomly selected block sizes. *Int J Environ Res Public Health,* 8**,** 15-20.

ERWIN, E. BROTHERSON, M.J. SUMMERS, J.A. 2011. Understanding Qualitative Metasynthesis. Issues and opportunities in early childhood intervention research. . *Journal of early intervention,* 33.

FAN, V. C. J. G., M. LEW, R. BOURBEAU, J. ADAMS, S.G. LEATHERMAN, S.THWIN,S. HUANG, G.D. ROBBINS, R. SRIRAM, P.S. SHARAFKHANEH, MADOR, A.M.J. SAROSI,G. PANOS, R.J. RASTOGI, P. WAGNER, T.H. MAZZUCA, S.A. SHANNON, C. COLLING, C. LIANG, M.H. STOLLER, J.K. FIORE, L. NIEWOEHNER, D.E. 2012. A Comprehensive Care Management Program to Prevent Chronic Obstructive Pulmonary Disease Hospitalizations: A Randomized, Controlled Trial. *Annals of Internal Medicine* 156**,** 673-683.

FERREIRA, I. M., BROOKS, D., LACASSE, Y. & GOLDSTEIN, R. S. 2000. Nutritional support for individuals with COPD: a meta-analysis. *Chest,* 117**,** 672-8.

FOTOKIAN, Z., MOHAMMADI SHAHBOULAGHI, F., FALLAHI-KHOSHKNAB, M. & POURHABIB, A. 2017. The empowerment of elderly patients with chronic obstructive pulmonary disease: Managing life with the disease. *PLoS One,* 12**,** e0174028.

FOUNDATION, T. B. L. 2012. *COPD statistics UK* [Online]. Available: https://statistics.blf.org.uk/copd [Accessed Dec 2019 2019].

FRAMEWORK., Q. Q. A. O. 2010-11. *Quality and Outcomes Framework.* [Online]. Available: https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-data/quality-and-outcomes-framework-2010-11 [Accessed May 2018 2018].

FRANKLIN, M., LEWIS, S., WILLIS, K., BOURKE-TAYLOR, H. & SMITH, L. 2018. Patients' and healthcare professionals' perceptions of self-management support interactions: Systematic review and qualitative synthesis. *Chronic Illn,* 14**,** 79-103.

FRANKLIN, M. L., S. WILLIS, K. ROGERS, A. VENVILLE, A. SMITH, L. 2019. Controlled, constrained, or flexible? How Self-Management goals are shaped by patient-provider interactions. . *Qual Health Res,* 29**,** 557-567.

FRIEDMAN, E. M. 2014. Good friends, good food ... what more could we want? Assessing the links between social relationships and dietary behaviors. A commentary on Conklin et al. *Social Science & Medicine,* 100**,** 176-7.

FUND, T. K. 2014. *The NHS five year forward view* [Online]. The Kings Fund. Available: https://www.kingsfund.org.uk/projects/nhs-five-year-forward-view [Accessed Dec 2019 2019].

GALE, N., HEATH, G., CAMERON, E., RASHID, S. & REDWOOD, S. 2013. Using the frameowrk method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology,* 13.

GALLACHER, K., MORRISON, D., JANI, B., MACDONALD, S., MAY, C. R., MONTORI, V. M., ERWIN, P. J., BATTY, G. D., ETON, D. T., LANGHORNE, P. & MAIR, F. S. 2013b. Uncovering treatment burden as a key concept for stroke care: a systematic review of qualitative research. *PLoS Medicine,* 10**,** e1001473-e1001473.

GERTLER, P. M., S. PREMAND, P. RAWLINGS, L.B. VERMEERSCH, C.M.J. 2011. *Impact Evaluation in Practice,* Washington, The World Bank.

GOLD. 2018. Pocket guide to COPD diagnosis, management, and prevention - A guide for Health Care Professionals - 2018 report. *Global Initiative for Chronic Obstructive Lung Disease.* .

GRAHAM, H. 1987. Women's smoking and family health. *Soc Sci Med,* 25**,** 47-56.

GRANT, M. J. BOOTH, A. 2009. A typology of reviews: an analysis of 14 review types and assoicated methodologies. . *Health Information and Libraries Journal,* 26**,** 91-108.

GREGERSON, T. L. G., A. FRAUSING,E. RINGBAEK,T.BRONDUM, E. ULRIK, C.S. 2016. Do telemedical interventions improve quality of life in patients with COPD? A systematic review. . *International Journal Of Chronic Obstructive Pulmonary Disease,* 11**,** 809-822.

GUDMUNDSSON G, GISLASON T, JANSON C, LINDBERG E, HALLIN R, ULRIK CS, BRØNDUM E, NIEMINEN MM, AINE T & BAKKE P 2005. Risk factors for rehospitalisation in COPD: role of health status, anxiety and depression. *Eur Respir J,* 26**,** 414-9.

HALBERT, R. J., NATOLI, J. L., GANO, A., BADAMGARAV, E., BUIST, A. S. & MANNINO, D. M. 2006. Global burden of COPD: systematic review and meta-analysis. *The European Respiratory Journal,* 28**,** 523-532.

HALDING, A., WAHL, A. & HEGGDAL, K. 2010. 'Belonging'. 'Patients' experiences of social relationships during pulmonary rehabilitation. *Disability & Rehabilitation,* 32**,** 1272-1280 9p.

HALPIN, D. M. G. 2018. Palliative care for people with COPD: effective but underused. *European Respiratory Journal,* 51.

HANSON C, R. E., WOUTERS EFM, RENNARD S. 2014. Influence of diet and obesity on COPD development and outcomes. *International journal of chronic obstructive pulmonary disease.,* 9**,** 723-33.

HARDY, S., SMART, D., SCANLAN, M. & ROGERS, S. 2014. Integrating psychological screening into reviews of patients with COPD. *British Journal of Nursing,* 23**,** 832-836 5p.

HIBBARD, J. & GILBURT, H. 2014. *Supporting people to manage their health. An introduction to patient activation.,* London, The Kings Fund.

HIBBARD, J. S., J. MAHONEY, E.R. TUSLER, M. 2004. Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Services Research* 39**,** 1005-1026.

HOFFMAN, T. G., P.P. BOUTRON, I. MILNE, R. PERERA,R. MOHER, D. ALTMAN, D.G. BARBOUR, V. MACDONALD,H. JOHNSTON,M. LAMB, S.E. DIXON-WOODS, M. MCCULLOCH, P. WYATT,J.C. CHAN,A-W. MICHIE,S. 2014. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *British Medical Journal,* 348.

HOLT-LUNSTAD, J. SMITH, T.B. 2016. Loneliness and social isolation as risk factors for CVD: implications for evidence-based patient care and scientific inquiry. *Heart BMJ,* 102.

HOPKINS, R. M. R., G. PRATT, D.D. 2016. A framework for negotiating positionality in phenomenological research. *Medical Teacher,* 39**,** 20-25.

HUGHES, S. L., S. WILLIS, K. ROGERS, A. WYKE, S. SMITH, L. 2017. The experiences of facilitators and participants of long term condition self-management group programmes: A qualitative synthesis. *Patient Education and Counseling,* 100**,** 2244-2254.

INGADOTTIR, T. S. & JONSDOTTIR, H. 2010. Partnership-based nursing practice for people with chronic obstructive pulmonary disease and their families: influences on health-related quality of life and hospital admissions. *Journal of Clinical Nursing,* 19**,** 2795-2805.

IPAQ, G. 2005. Guidelines for Data Processing and Analysis of the International Physical Activity Questionnaire (IPAQ) – Short and Long Forms

IRZ X, F. L., KUOSMANEN N, MAZZOCCHI M, MODUGNO L, NOCELLA G, ET AL. 2014. Sociodemographic determinants of diet quality of the EU elderly: a comparative analysis in four countries. *Public Health Nutrition,* 17**,** 1177-89.

JAMES, E. K., A.VASSILEV, I. ELLIS, J.ROGERS, A. 2020. Mediating engagement in a social network intervention for people living with a long-term condition: A qualitative study of the role of facilitation. . *Health Expectations,* 23**,** 680-689.

JOGLEKAR, S., SASTRY, N., COULSON, N. S., TAYLOR, S. J., PATEL, A., DUSCHINSKY, R., ANAND, A., JAMESON EVANS, M., GRIFFITHS, C. J., SHEIKH, A., PANZARASA, P. & DE SIMONI, A. 2018. How Online Communities of People With Long-Term Conditions Function and Evolve: Network Analysis of the Structure and Dynamics of the Asthma UK and British Lung Foundation Online Communities. *J Med Internet Res,* 20**,** e238.

JOHNSTON, K. & GRIMMER-SOMERS, K. 2010. Pulmonary rehabilitation: overwhelming evidence but lost in translation? *Physiotherapy Canada,* 62**,** 368-373 6p.

JOLLY, K., SIDHU, M. S., BATES, E., MAJOTHI, S., SITCH, A., BAYLISS, S., KIM, H. J. S. & JORDAN, R. E. 2018. Systematic review of the effectiveness of community-based self-management interventions among primary care COPD patients. *NPJ Prim Care Respir Med,* 28**,** 44.

JONES, J. 2013. Association between Social Support and Self-Care Behaviors in Patients with COPD. *Communicating Nursing Research,* 46**,** 404-404.

JONES, P. W., HARDING, G., BERRY, P., WIKLUND, I., CHEN, W. H. & KLINE LEIDY, N. 2009. Development and first validation of the COPD Assessment Test. *Eur Respir J,* 34**,** 648-54.

JONKMAN, N. H., WESTLAND, H., TRAPPENBURG, J. C., GROENWOLD, R. H., BISCHOFF, E. W., BOURBEAU, J., BUCKNALL, C. E., COULTAS, D., EFFING, T. W., EPTON, M., GALLEFOSS, F., GARCIA-AYMERICH, J., LLOYD, S. M., MONNINKHOF, E. M., NGUYEN, H. Q., VAN DER PALEN, J., RICE, K. L., SEDENO, M., TAYLOR, S. J., TROOSTERS, T., ZWAR, N. A., HOES, A. W. & SCHUURMANS, M. J. 2016. Characteristics of effective self-management interventions in patients with COPD: individual patient data meta-analysis. *Eur Respir J,* 48**,** 55-68.

JONSDOTTIR, H. 2013. Self-management programmes for people living with chronic obstructive pulmonary disease: a call for a reconceptualisation. *Journal of Clinical Nursing,* 22**,** 621-637 17p.

KAPTEIN, A. A., FISCHER, M. J. & SCHARLOO, M. 2014. Self-management in patients with COPD: theoretical context, content, outcomes, and integration into clinical care. *International Journal Of Chronic Obstructive Pulmonary Disease,* 9**,** 907-917.

KAPTEIN, A. A. S., M. FISCHER, M.J. SNOEI, L. CAMERON, L.D. SONT, J.K. 2008. Illness perceptions and COPD, an emerging field for COPDpatient management. *Journal of asthma* 45**,** 625-629.

KENNEDY, A., VASSILEV, I., JAMES, E. & ROGERS, A. 2016. Implementing a social network intervention designed to enhance and diversify support for people with long-term conditions. A qualitative study. *Implement Sci,* 11**,** 27.

KENNEDY, A. B., P. REEVES, D. BLAKEMAN, T. BOWEN, R, CHEW-GRAHAM, C. ROGERS, A. 2013. Implementation of self management support for long term conditions in routine primary care settings: cluster randomised controlled trial. *British Medical Journal,* 346**,** 1-11.

KLIMEK, L., BERGMANN, K. C., BIEDERMANN, T., BOUSQUET, J., HELLINGS, P., JUNG, K., MERK, H., OLZE, H., SCHLENTER, W., STOCK, P., RING, J., WAGENMANN, M., WEHRMANN, W., MOSGES, R. & PFAAR, O. 2017. Visual analogue scales (VAS): Measuring instruments for the documentation of symptoms and therapy monitoring in cases of allergic rhinitis in everyday health care: Position Paper of the German Society of Allergology (AeDA) and the German Society of Allergy and Clinical Immunology (DGAKI), ENT Section, in collaboration with the working group on Clinical Immunology, Allergology and Environmental Medicine of the German Society of Otorhinolaryngology, Head and Neck Surgery (DGHNOKHC). *Allergo J Int,* 26**,** 16-24.

KROENKE, K., W. J., YU, Z. BAIR, M.J. KEAN, J. STUMP, T. MONAHAN, P.O. 2016. Patient Health Questionnaire Anxiety and Depression Scale: Initial Validation in Three Clinical Trials. . *Psychosomatic Medicine,* 78.

LENFERINK, A., VAN DER PALEN, J. & EFFING, T. 2018. The role of social support in improving chronic obstructive pulmonary disease self-management. *Expert Rev Respir Med,* 12**,** 623-626.

LEWIS, R. & CRAMP, F. 2010. Facilitators and barriers to exercise maintenance in chronic obstructive pulmonary disease: patient views. *Physiotherapy Ireland,* 31**,** 19-24.

LOZANO, R., NAGHAVI, M., FOREMAN, K., LIM, S., SHIBUYA, K., ABOYANS, V., ABRAHAM, J., ADAIR, T., AGGARWAL, R., AHN, S. Y., ALVARADO, M., ANDERSON, H. R., ANDERSON, L. M., ANDREWS, K. G., ATKINSON, C., BADDOUR, L. M., BARKER-COLLO, S., BARTELS, D. H., BELL, M. L., BENJAMIN, E. J., BENNETT, D., BHALLA, K., BIKBOV, B., BIN ABDULHAK, A., BIRBECK, G., BLYTH, F., BOLLIGER, I., BOUFOUS, S., BUCELLO, C., BURCH, M., BURNEY, P., CARAPETIS, J., CHEN, H., CHOU, D., CHUGH, S. S., COFFENG, L. E., COLAN, S. D., COLQUHOUN, S., COLSON, K. E., CONDON, J., CONNOR, M. D., COOPER, L. T., CORRIERE, M., CORTINOVIS, M., DE VACCARO, K. C., COUSER, W., COWIE, B. C., CRIQUI, M. H., CROSS, M., DABHADKAR, K. C., DAHODWALA, N., DE LEO, D., DEGENHARDT, L., DELOSSANTOS, A., DENENBERG, J., DES JARLAIS, D. C., DHARMARATNE, S. D., DORSEY, E. R., DRISCOLL, T., DUBER, H., EBEL, B., ERWIN, P. J., ESPINDOLA, P., EZZATI, M., FEIGIN, V., FLAXMAN, A. D., FOROUZANFAR, M. H., FOWKES, F. G. R., FRANKLIN, R., FRANSEN, M., FREEMAN, M. K., GABRIEL, S. E., GAKIDOU, E., GASPARI, F., GILLUM, R. F., GONZALEZ-MEDINA, D., HALASA, Y. A., HARING, D., HARRISON, J. E., HAVMOELLER, R., HAY, R. J., HOEN, B., HOTEZ, P. J., HOY, D., JACOBSEN, K. H., JAMES, S. L., JASRASARIA, R., JAYARAMAN, S., JOHNS, N., KARTHIKEYAN, G., KASSEBAUM, N., KEREN, A., KHOO, J.-P., KNOWLTON, L. M., KOBUSINGYE, O., KORANTENG, A., KRISHNAMURTHI, R., LIPNICK, M., LIPSHULTZ, S. E., OHNO, S. L., et al. 2012. Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet,* 380**,** 2095-2128.

MANNINO, D. M. 2002. COPD: epidemiology, prevalence, morbidity and mortality, and disease heterogeneity. *CHEST,* 121**,** 121S-6S 1p.

MAY, C. M., J. WELCH, L. HUNT, K. POPE, C. MYALL, M. GRIFFITHS, P. RODERICK, P. GLANVILLE, J. RICHARDSON, A. 2015. EXPERTS 1—experiences of long-term life-limiting conditions among patients and carers: protocol for a qualitative meta-synthesis and conceptual modelling study. *BMJ Open* 5.

MAY, C. R., ETON, D. T., BOEHMER, K., GALLACHER, K., HUNT, K., MACDONALD, S., MAIR, F. S., MAY, C. M., MONTORI, V. M., RICHARDSON, A., ROGERS, A. E. & SHIPPEE, N. 2014. Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness. *BMC Health Services Research,* 14**,** 281-281.

MAYER, S. KISS, N. LASZEWSKA, A. SIMON, J. 2017. Costing evidence for health care decision-making in Austria: A systematic review. *Plos One,* 12.

MAYNARD M, G. D., NESS AR, ABRAHAM L, BATES CJ, BLANE D. 2006. What influences diet in early old age? Prospective and cross-sectional analyses of the Boyd Orr cohort. *European Journal of public health,* 16**,** 316-24.

MCALLISTER, D.A. MORLING, J.R. FISCHBACHER,C.M. MACNEE, W. WILD,S. 2013.Socioeconomic deprivation increases the effect of winteron admissions to hospita with COPD: retrospective analysis of 10 years of national hospitalisation data. *Primiary Care Respiraotry Journal.* 22, 296-299.

MCMUNN, A. N., J. WAHRENDORF, M. BREEZE, E. ZANINOTTO, P. 2009. Participation in socially-productive activities, recriprocity and wellebing in later life: baseline results in Engaland. . *Ageing and society,* 29**,** 765-782.

MCNAUGHTON SA, BATES. C., MISHRA GD. 2012. Diet quality is associated with all-cause mortality in adults aged 65 years and older. . *The journal of nutrition. ,* 142**,** 320-5.

MERRIT, R. N., O. HASHAM, F. REES, T. . 2018. *The British Lung Foundation's integrated breathe easy voluntary group network. Findings from the outcome, impact and economic evaluation.* [Online]. [Accessed].

MEYER, K. A. W., R. 2019. Looking back and moving forward: The value of reflexive journaling for novice researchers. *Journal of Gerontological social work*

MICHIE, S. W., R. ROGERS, M.B. BONNELL, C. RUBIN, G.J. AMLOT, R. 2020. Reducing SARS-CoV-2 transmission in the UK: A behavioural science approach to identifying options for increasing adherence to social distancing and shielding vulnerable people. *British Journal of Health Psychology*

MILTE, C. M. & MCNAUGHTON, S. A. 2016. Dietary patterns and successful ageing: a systematic review. *Eur J Nutr,* 55**,** 423-450.

MOHER, D. L., A. TETZLAFF, J. DOUGLAS G. ALTMAN, DG. PRISMA GROUP 2009a. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *Annals of Internal Medicine,* 151.

MOHER, D. L., A. TETZLAFF, J. ALTMAN, D.G. THE PRISMA GROUP* 2009b. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *Annals of Internal Medicine* 151.

MOORE, G. F., AUDREY, S., BARKER, M., BOND, L., BONELL, C., HARDEMAN, W., MOORE, L., O'CATHAIN, A., TINATI, T., WIGHT, D. & BAIRD, J. 2015. Process evaluation of complex interventions: Medical Research Council guidance. *BMJ : British Medical Journal,* 350.

MOSEN, D. S., J. HIBBARD, J. SOBEL, D. REMMERS, C. BELLOWS, J. 2007. Is patient activation associated with outcomes of care for adults with chronic conditions? *Journal of Ambulatory Care Management,* 30**,** 21-29.

NICI, L., BONTLY, T. D., ZUWALLACK, R. & GROSS, N. 2014. Self-management in chronic obstructive pulmonary disease. Time for a paradigm shift? *Annals of the American Thoracic Society,* 11**,** 101-107 7p.

NICI, L. & ZUWALLACK, R. 2015. Chronic Obstructive Pulmonary Disease-Evolving Concepts in Treatment: Advances in Pulmonary Rehabilitation. *Seminars in Respiratory & Critical Care Medicine,* 36**,** 567-574 8p.

NIMROD G, SHIRA. A. 2014. The Paradox of Leisure in Later Life. *The journals of gerontology series B: Psychological Sciences and Social Sciences.* .

NOBLIT, G. HARE, RD. 1988. *Meta-Ethnography: synthesizing qualitative studies. ,* Newbury Park, Sage.

NOLAN, C. M., LONGWORTH, L., LORD, J., CANAVAN, J. L., JONES, S. E., KON, S. S. & MAN, W. D. 2016. The EQ-5D-5L health status questionnaire in COPD: validity, responsiveness and minimum important difference. *Thorax,* 71**,** 493-500.

OGUNBAYO, O. J. R., S. NEWHAM, J. HESLOP-MARSHALL, K. NETSS, P. HANRATTY ,B. KANER, E. 2017. Understanding the factors affecting self-management of COPD from the perspectives of healthcare practitioners: a qualitative study. . *Prim Care Respir J,* 27.

OSBORNE, R. H. ELSWORTH, G.R. WHITFIELD, K. 2007. The Health Education Impact Questionnaire (heiQ): an outcomes and evaluation measure for patient education and self-management intervention for people with chronic conditions. . *Patient Educ Couns,* 66**,** 192-201.

PESCOSOLIDO, B. A. 1991. Illness careers and network ties: a conceptual model of utilization and compliance. . *Advances in Medical Sociology,* Vol 2**,** 164-181.

PINNOCK, H., KENDALL, M., MURRAY, S. A., WORTH, A., LEVACK, P., PORTER, M., MACNEE, W. & SHEIKH, A. 2011. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *BMJ: British Medical Journal (Overseas & Retired Doctors Edition),* 342**,** d142-d142.

PINNOCK, H. P., H. L.PANAGIOTI, M.DAINES, L. PEARCE, G. EPIPHANIOU, E. BOWER, P. SHEIKH, A. GRIFFITHS, C. J. TAYLOR, S. J.PRISMS RECURSIVE GROUPS. 2017. Systematic meta-review of supported self-management for asthma: a healthcare perspective. *BMC Med,* 15**,** 64.

PINNOCK, H. S., L. JORDAN, R. 2016. Supported self-management for COPD: making progress, but there are still challenges. . *European Respiratory Journal,* 48**,** 6-9.

POUND, P. & CAMPBELL, R. 2015. Exploring the feasibility of theory synthesis: a worked example in the field of health related risk-taking. *Soc Sci Med,* 124**,** 57-65.

REEDY, J., KREBS-SMITH, S. M., MILLER, P. E., LIESE, A. D., KAHLE, L. L., PARK, Y. & SUBAR, A. F. 2014. Higher diet quality is associated with decreased risk of all-cause, cardiovascular disease, and cancer mortality among older adults. *J Nutr,* 144**,** 881-9.

REEVES, D., BLICKEM, C., VASSILEV, I., BROOKS, H., KENNEDY, A., RICHARDSON, G. & ROGERS, A. 2014. The Contribution of Social Networks to the Health and Self-Management of Patients with Long-Term Conditions: A Longitudinal Study. *PLOS ONE,* 9**,** e98340.

REIDY, C. FOSTER, C. ROGERS, A. 2020. A novel exploration of the support needs of people initiating insulin pump therapy using a social network approach: a longitudinal mixed-methods study. . *Diabetic Medicine*.

ROBINSON, K., LUCAS, E., VAN DEN DOLDER, P. & HALCOMB, E. 2018. Living with chronic obstructive pulmonary disease: The stories of frequent attenders to the Emergency Department. *J Clin Nurs,* 27**,** 48-56.

ROBINSON SM, J. K., BLOOM I, NTANI G, CROZIER SR, SYDDALL H, ET AL. 2017. Development of a short questionnaire to assess diet quality among older community-dwelling adults. *Journal Nutrition, Health and Aging,* 21**,** 247-53.

ROGERS, A., BROOKS, H., VASSILEV, I., KENNEDY, A., BLICKEM, C. & REEVES, D. 2014. Why less may be more: a mixed methods study of the work and relatedness of 'weak ties' in supporting long-term condition self-management. *Implementation Science,* 9**,** 19.

ROGERS, A., VASSILEV, I., SANDERS, C., KIRK, S., CHEW-GRAHAM, C., KENNEDY, A., PROTHEROE, J., BOWER, P., BLICKEM, C., REEVES, D., KAPADIA, D., BROOKS, H., FULLWOOD, C. & RICHARDSON, G. 2011. Social networks, work and network-based resources for the management of long-term conditions: a framework and study protocol for developing self-care support. *Implement Sci,* 6**,** 56.

ROGERS, A. B., H.VASSILEV, I.I.KENNEDY, A.BLICKEM, C.REEVES, D. 2014. Why less may be more: a mixed methods study of the work and relatedness of 'weak ties' in supporting long-termcondition self-management. . *Implement Science* 9.

ROGERS, A. G., C. KENNEDY, A. SANDERS, C. 2009. Are some more equal than others? Social comparison in self-managment skills training for long-term conditions. *Chronic Illness,* 5**,** 305-317.

ROGERS, P. J. 2008. Using programme theory to evaluate complicated and complex aspeacts if interventions. *Evaluation,* 14**,** 29-48.

RUSSELL, S., OGUNBAYO, O. J., NEWHAM, J. J., HESLOP-MARSHALL, K., NETTS, P., HANRATTY, B., BEYER, F. & KANER, E. 2018. Qualitative systematic review of barriers and facilitators to self-management of chronic obstructive pulmonary disease: views of patients and healthcare professionals. *NPJ Prim Care Respir Med,* 28**,** 2.

SADLER, E. WOLFE, C.D.A. MCKEVITT, C. 2014. Lay and health care professional understandings of self-management: A systematic review and narrative synthesis. *SAGE Open Medicine,* 2.

SAINI, M. and SHLONSKY, A. 2012. *Systematic synthesis of qualitative research. Pocket guides to social work methods.* , Oxford University Press. .

SCHOMERUS, G., MATSCHINGER, H. & ANGERMEYER, M. C. 2009. Attitudes that determine willingness to seek psychiatric help for depression: a representative population survey applying the Theory of Planned Behaviour. *Psychological Medicine,* 39**,** 1855-1865.

SCHROEDL, C. J., YOUNT, S. E., SZMUILOWICZ, E., HUTCHISON, P. J., ROSENBERG, S. R. & KALHAN, R. 2014. A qualitative study of unmet healthcare needs in chronic obstructive pulmonary disease. A potential role for specialist palliative care? *Annals of the American Thoracic Society,* 11**,** 1433-1438 6p.

SEDENO, M. F. NAULT, D. HAMD, D.H. BOURBEAU, J. 2009. A self-management education program including an action plan for acute COPD exacerbations. *Journal of Chronic Obstructive Pulmonary Disease* 6.

SEWELL, L. TAYLOR, A. STEILS, N. GELDER, C. 2018. Outcomes from an asset based community development approach to improve mental well-being in people with COPD: Is there a 'RIPPLE' effect? *Clin Rehabil,* 3.

SHAHEEN, S. O., JAMESON, K. A., SYDDALL, H. E., AIHIE SAYER, A., DENNISON, E. M., COOPER, C., ROBINSON, S. M. & HERTFORDSHIRE COHORT STUDY, G. 2010. The relationship of dietary patterns with adult lung function and COPD. *Eur Respir J,* 36**,** 277-84.

SHERIDAN, N., KENEALY, T., SALMON, E., REA, H., RAPHAEL, D. & SCHMIDT-BUSBY, J. 2011. Helplessness, self blame and faith may impact on self management in COPD: a qualitative study. *Primary Care Respiratory Journal,* 20**,** 307-314 8p.

SIAU, K. and LONG, Y. 2006. Synthesizing e-government stage models-a meta-synthesis based on a meta-ethnography approach. *Industrial Management and Data Systems,* 106**,** 443-458.

SILTANEN, H. A., T. HUHTAL, H. KAUNONEN, M. VASANKARI, T. PAAVILAINEN, E. 2020. Psychological issues need more attention in COPD self-management education. . *Scandinavian journal of Primary Health Care,* 38**,** 47-55.

SIMPSON, E. & JONES, M. 2013. An exploration of self-efficacy and self-management in COPD patients. *British Journal of Nursing,* 22**,** 1105-1109 5p.

SLEVIN, P., KESSIE, T., CULLEN, J., BUTLER, M. W., DONNELLY, S. C. & CAULFIELD, B. 2019. Exploring the potential benefits of digital health technology for the management of COPD: a qualitative study of patient perceptions. *ERJ Open Res,* 5.

SOICHER, J. E. 2009. *A longitudinal study of physical activity behaviour in chronic disease: the example of chronic obstructive pulmonary disease.* Ph.D., McGill University (Canada).

SPITZER, R. L. KROENKE, K, WILLIAMS, J.B.W. LOWE, B. 2006. A brief measure for assessing generalized anxiety disorder: the GAD-7. . *Archives of Internal Medicine,* 22.

SYDDALL HE, MARTIN. H., HARWOOD RH, COOPER C, SAYER AA 2009. The SF-36: a simple, effective measure of mobility-disability for epidemiological studies. *J Nutr Health Aging.,* 13**,** 57-62.

TAYLOR, S. J., SOHANPAL, R., BREMNER, S. A., DEVINE, A., MCDAID, D., FERNÁNDEZ, J. L., GRIFFITHS, C. J. & ELDRIDGE, S. 2012. Self-management support for moderate-to-severe chronic obstructive pulmonary disease: a pilot randomised controlled trial. *British Journal of General Practice,* 62**,** 687-695 9p.

TAYLOR, S. J. C., PINNOCK, H., EPIPHANIOU, E., PEARCE, G., PARKE, H. L., SCHWAPPACH, A., PURUSHOTHAM, N., JACOB, S., GRIFFITHS, C. J., GREENHALGH, T. & SHEIKH, A. 2014. A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – Practical systematic RevIew of Self-Management Support for long-term conditions. *Health Services and Delivery Research,* 2**,** 1-580.

TOMAKA, J., THOMPSON, S. & PALACIOS, R. 2006. The relation of social isolation, loneliness, and social support to disease outcomes among the elderly. *Journal of Aging & Health,* 18**,** 359-384 26p.

TRAPPENBURG, J. C. A., MONNINKHOF, E. M., BOURBEAU, J., TROOSTERS, T., SCHRIJVERS, A. J. P., VERHEIJ, T. J. M. & LAMMERS, J.-W. J. 2011. Effect of an action plan with ongoing support by a case manager on exacerbation-related outcome in patients with COPD: a multicentre randomised controlled trial. *Thorax,* 66**,** 977-984.

TRIVEDI, R., BRYSON, C., UDRIS, E. & AU, D. 2012. The influence of informal caregivers on adherence in COPD patients. *Ann Behav Med,* 44**,** 66-72.

VASSILEV, I., BAND, R., KENNEDY, A., JAMES, E., & ROGERS, A. 2019. The role of collective efficacy In long-term condition management: a metasynthesis. *Health and Social Care in the Community.*

VASSILEV. I, ROGERS. A, KENNEDY A, KOETSENRUIJER J. 2014. The influence of social networks on self-managment support: a metasynthesis. . *BMC Public Health,* 14.

VASSILEV, I., ROGERS, A., BLICKEM, C., BROOKS, H., KAPADIA, D., KENNEDY, A., SANDERS, C., KIRK, S. & REEVES, D. 2013. Social networks, the 'work' and work force of chronic illness self-management: a survey analysis of personal communities. *PLoS One,* 8**,** e59723.

VASSILEV , I. R., A. KENNEDY, A. OATLEY, C. JAMES, E. 2018. Identifying the processes of change and engagement from using a social network intervention for people with long-term conditions. A qualitative study. *Health Expectations,* 22**,** 173-182.

VASSILEV, I. R., A. KENNEDY,A. AND KOETSENRUIJTER,J. 2014. The influence of social networks on self-management support: a metasynthesis. . *BMC Public Health,* 14.

VENTEGODT S., K. I., ERVIN D.A., MERRICK J 2016. Concepts of Holistic Care. Health Care for People with Intellectual and Developmental Disabilities across the Lifespan.: Springer International Publishing.

WALKER S, KENNEDY. A., VASSILEV I, ROGERS A. 2018. How do people with long-term mental health problems negotiate relationships with network members at times of crisis? *Health Expectations,* 21**,** 336-46.

WALTERS, J. A., TURNOCK, A. C., WALTERS, E. H. & WOOD-BAKER, R. 2010. Action plans with limited patient education only for exacerbations of chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews***,** N.PAG-N.PAG 1p.

WEDZICHA, J. A. & DONALDSON, G. C. 2003. Exacerbations of chronic obstructive pulmonary disease. *Respiratory Care,* 48**,** 1204-1215 12p.

WEDZICHA, J. A. & SEEMUNGAL, T. A. 2007. COPD exacerbations: defining their cause and prevention. *Lancet,* 370 North American Edition**,** 786-796 11p.

WELLS, J. M. 2016. Depression Is Associated with Readmission for Acute Exacerbation of Chronic Obstructive Pulmonary Disease. *Annals of the American Thoracic Society,* 13**,** 197-203 10p.

WIGAL, J. K. CREER, T.L. KOTSES, H. 1991. The COPD Self-Efficacy Scale. *Chest* 99**,** 1193-1196.

WILKINSON, T. M. A., DONALDSON, G. C., HURST, J. R., SEEMUNGAL, T. A. R. & WEDZICHA, J. A. 2004. Early therapy improves outcomes of exacerbations of chronic obstructive pulmonary disease. *American Journal Of Respiratory And Critical Care Medicine,* 169**,** 1298-1303.

WILSON M-MG, T. D., RUBENSTEIN LZ, CHIBNALL JT, ANDERSON S, BAXI A, ET AL. 2005. Appetite assessment: simple appetite questionnaire predicts weight loss in community-dwelling adults and nursing home residents. *American Journal of Clinical Nutrition,* 82**,** 1074-81.

WOOD. 2018. Supporting self-management. Understanding its impact on the system. . Available from: https://www.health.org.uk/news-and-comment/blogs/supporting-self-management.

WUST, R. C. I. DEGENS, H. 2007. Factors contributing to muscle wasting and dysfunction in COPD patients. *International Journal Of Chronic Obstructive Pulmonary Disease,* 2**,** 289-300.

YARDLEY, L. AINSWORTH, B. ARDEN-CLOSE, E. MULLER, I. 2015. The person based approach to enhancing the acceptability and feasibility of interventions. . *Pilot and Feasibility studies,* 1**,** 37.

ZAUSZNIEWSKI, J. A. BEKHET, T A. HERBELL, K. 2018. Comprehensive evaluation of interventions: eight vital parameters. *Nurse Researcher,* 26**,** 20-25.

ZHOU X, P.-C. J., SANTOS DQ, MONTELEONE E, GIBOREAU A, APPLETON MK, ET AL. 2018. A Systematic Review of Behavioural Interventions Promoting Healthy Eating among Older People. Nutrients. *Nutrients,* 10.