How do older adults self-manage distress and what role does the internet have? A qualitative study

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Abstract

Although anxiety and depression are common in older adults, the medical terms may not be acceptable to them. Older people are more likely to perceive themselves as experiencing distress, and may also feel responsible for managing their own mood problems. To self-manage distress, older people could potentially engage with the internet to access health information or social support. This study aims to explore how older adults self-manage distress, with a particular focus on the role of the internet.

This study is underpinned by social constructionism and takes a qualitative approach towards data collection and analysis. Eighteen older adults (11 females, aged 65 – 91 years) who self-identified as experiencing distress were recruited from community groups in North Staffordshire, England. To generate data, 'think-aloud' methods (including storyboards and an extract from an online forum) were embedded within semi-structured interviews. Data were analysed thematically utilising constant comparison methods. A public and patient involvement and engagement group contributed to development of the research questions and methods, offered their perspectives on the findings and helped to create a dissemination plan.

Findings focus on participants' experiences of distress and actions taken, which included: pursuing independent activities, seeking social support and attending community groups and church. Five participants consulted a GP when distressed but reported being offered a lack of acceptable treatments. The internet was not considered a source of information about distress or mood problems and participants did not use the internet as a means of accessing social support.

Implications for older adults, healthcare services and policy makers are discussed. When presented with a distressed older adult, GPs should begin by exploring the older person's own understanding of their distress and its causes, provide information about different

management options and consider directing older people to local third sector services. GPs may also need to take into consideration that sign-posting older people to online support might not be acceptable.

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List of abbreviations

APA	American Psychiatric Association
CBT	Cognitive Behavioural Therapy
COPD	Chronic Obstructive Pulmonary Disease
DSM IV	The Diagnostic and Statistical Manual of Mental Disorders, Fourth Addition
DSM V	The Diagnostic and Statistical Manual of Mental Disorders, Fifth Addition
GAD	Generalised Anxiety Disorder
GHQ	General Health Questionnaire
GP	General Practitioner
GRIPP 2	Guidance for Reporting the Involvement of Patients and the Public, version 2
IAPT	Improving Access to Psychological Therapies
ICD-10	International Classification of Diseases, 10th revision
IPT	Interpersonal Therapy
MDD	Major Depressive Disorder
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
OFCOM	The Office of Communications
ONS	Office of National Statistics
PC	Personalised Computer
PPI	Patient and Public Involvement
PPIE	Patient and Public Involvement and Engagement
RCGP	Royal College of General Practitioners
REF	The Research Excellence Framework
RI	Research Institute for Primary Care and Health Sciences
RUG	Research User Group
SSRIs	Selective Serotonin Reuptake Inhibitors
UK	United Kingdom
USW	User Support Worker
WHO	World Health Organisation

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Chapter One: Introduction

Introduction

This study explores how older adults self-manage distress, with a particular focus on the role of the internet. I begin this introductory chapter by providing a context to older people, mental health and the National Health Service (NHS) in the United Kingdom (UK). I then provide a rationale for my study; this will set the scene for the following chapter which examines the broader field of literature. Next, I discuss my personal reasons for undertaking this research, and describe how Patient and Public Involvement and Engagement (PPIE) informed the study. I then discuss the structure and style of the thesis.

1.1 The context of the thesis

I will briefly discuss the ageing population, mental health policies that include older adults and the structure of the NHS. I then highlight the role primary and secondary care has in the treatment of people with mental health problems. Following this, I explain the diagnostic criteria for assessing depression and anxiety, and discuss the stepped care approach to the management of such problems. Next, I describe the support provided by social care and third sector services for mental health problems and discuss how this may impact older adults.

1.1.1   An ageing population

The World Health Organisation (WHO; 2017) suggest that an older adult is any individual aged 60 or above. The global population aged 60 years and over was estimated to be 962 million in 2017, more than twice as large as in 1980 when there were 382 million older people worldwide (United Nations, 2017). The Office of National Statistics (ONS; 2017) reported that 18% of the UK's population were aged 65 and over in 2017. As people age, they are progressively more likely to live with complex comorbidities, disability and frailty (Rechel et al, 2013). The prevalence of physical health problems such as cardiovascular disease,

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diabetes, osteoarthritis, hypertension and musculoskeletal pain all increase with age (Mortimer & Green, 2015; Jaul et al, 2017; Cimas et al, 2017). Older adults with physical health problems are the highest users of healthcare services, particularly primary care as these services provide the first point of contact in the healthcare system and include: general practice, community pharmacy, dental and optometry services (Zayas et al, 2016; Elliott, Stolee, Boscart, Giangregorio & Heckman, 2018). Along with physical health problems, anxiety and depression are prevalent within older people. Between 4.6% and 9.5% of older adults experience depression, whilst between 3.2% and 14.2% of older people suffer from anxiety (Meeks, Vahia, Lavretsky, Kulkarni & Jeste, 2011; Gum, King-Kallimanis, & Kohn, 2009). Research has also demonstrated an association between mental health problems, such as anxiety and depression, and physical health problems, which include: cardiovascular disease, diabetes, chronic obstructive pulmonary disease (COPD) and musculoskeletal disorders (McDaid et al, 2012; Lee et al, 2018; Lloyd et al, 2018). Healthcare services need to be organised to provide care for older adults with comorbid mood and physical health problems.

1.1.2 Mental health policy and older adults

The mental health of older adults is a public health concern, this is reflected in the policies and guidelines that have been produced by the UK government. The 'National Service Framework for Older People' (NSFOP; Department of Health, 2001) suggested that older adults, who experience mental health problems, should have access to specialist older peoples' mental health services to ensure effective diagnosis and treatment. Following the development of the 'NSFOP', the Department of Health (2005) developed a guide for mental health services for older adults entitled 'Everybody's Business'. The guide aimed to ensure age equality in the development of mental health services, with access to services based on need, not age. In February 2011, the Department of Health published 'No health without

mental health', within this policy the Department of Health (2011a) announced a fiscal commitment of £400 million to expand the Improving Access to Psychological therapies (IAPT) programme (National Collaborating Centre for Mental Health, 2018). IAPT services provide evidence- based treatments for people with depression and anxiety based on the guidelines provided by the National Institute for Health and Care Excellence (NICE; 2009a; 2011a respectively). Accompanying the 'No health without mental health' policy, the Department of Health also published 'Talking Therapies: A Four Year Plan of Action' (Department of Health, 2011b) and set policy priorities within this area. One priority was to improve older people's access to IAPT programmes, the Department of Health (2011b) set a target of 12% of referrals through IAPT programmes to be people aged 65 and over. Two years later, the Department of Health produced the guideline 'How to make IAPT more accessible to older people' (Department of Health, 2013a) as there was still significant under-representation of older adults accessing such services. Within this guideline the Department of Health (2013a) suggested that raising awareness of what IAPT can do for older people could inspire a range of health, social and voluntary sector staff to suggest talking treatments to older adults they work with. Engaging with older adults themselves was also suggested to be key in developing appropriate promotional campaigns, adapting self-management materials and monitoring how IAPT services respond to older people's needs. However, three years after the publication of 'How to make IAPT more accessible to older people', Age UK (2016a) reported that referral rates to IAPT services were 6.1% for older adults and, at the current growth rate, it would take fifteen years for the 12% target to be met.

NHS England (2016) published the 'Five year forward view for mental health' and proposed that all groups, from children and young people through to older adults, should have access to services which meet their needs. NHS England reported that the aim to improve mental health and well-being cannot be solely achieved by the NHS, but must be delivered in partnership

with other local organisations. Yet, within the 'Five year forward view for mental health',

NHS England did not set out a clear strategy that described how clinical commissioners could

work with local organisations to improve the mental health of older people.

1.1.3 The structure of the National Health Service

To set a context for the current study, which is based in the field of primary care and health

sciences, the current structure of the NHS will be discussed. The present structure of the NHS

was outlined in the paper: 'Equity and Excellence: Liberating the NHS' (Department of

Health, 2010a). The structure, which came into force in April 2013, aimed to reduce central

governmental control of the NHS and to give patients greater choice in their care. Within the

same year that the current structure of the NHS came into place, the Department of Health

(2013b) published the 'NHS Outcomes Framework'. The framework describes national

outcome goals that are used to monitor the progress of the NHS. A significant area for action

within the framework was helping all patients, not specifically older adults, to take charge of

their care and to self-manage both physical and mental health problems. Yet, similar to the

'Five year forward view for mental health' (NHS England, 2016), the framework did not

suggest any strategic ways in how this could be achieved.

Figure 1 indicates the post-April 2013 structure of the NHS in England (NHS England, 2014:

p17).

Figure 1 Post April 2013 NHS structure
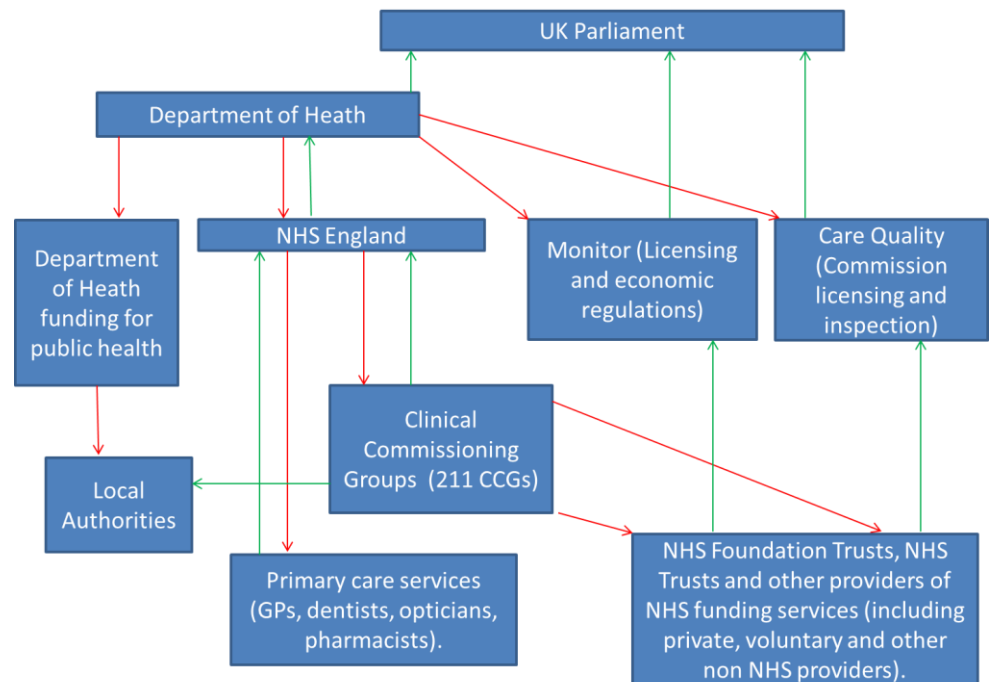
Figure notes: The red arrows indicate the direction of funding whilst the green arrows represent the direction of responsibility

1.1.4 The role of primary and secondary care in treating people with mental health problems

Over 59 million people in England, which is most of the population, were registered at a general practice on the 1st May, 2018 (NHS Digital, 2018). The Royal College of General Practitioners (RCGP; 2016) noted that 90% of individuals with a diagnosed mental health problem are managed in primary care settings. However, General Practitioners (GPs) could also act as gateways to specialist care as they may refer patients to secondary care, such as mental health services (Foot, Naylor & Imison, 2010). NHS England (2014) proposed that funding had been allocated to a range of mental health services, yet Gilburt's (2015) analyses found that 40% of mental health trusts experienced reductions in income in 2014. Gilburt reviewed different sources of information (e.g. literature reviews, national data-sets and national survey data), each of which provided a particular insight into the provision and

quality of the state of mental health services in England. Gilburt concluded that a rise in demand, and reduction in funding, is preventing mental health services from providing satisfactory care. However, services for older people were not included within Gilburt's review and, therefore, it remains unclear if mental health services for older adults are providing effective care and support.

1.1.5 Diagnostic criteria for depression and anxiety

The Diagnostic and Statistical Manual of Mental Disorders Fifth Addition (DSM V; American Psychiatric Association [APA], 2013) is used within NICE guidelines and clinicians in the UK to diagnose anxiety or depression. Other countries may use the International Classification of Diseases, 10th revision (ICD-10; World Health Organisation [WHO], 2016). Table 1 describes the symptoms which constitute a diagnosis of Major Depressive Disorder (MDD), according the DSM V (p184).

Table 1 DSM V criteria for assessing depression

A clinical diagnosis of depression requires five symptoms of depression to be present and at least one of these symptoms must be:

• Depressed mood or irritability most of the day, nearly every day, as indicated by either self-report or observation made by others

• Decreased interest or pleasure in most activities nearly every day

Other symptoms must include:

• Significant weight change or change in appetite

• Change in sleep, either insomnia or hypersomnia

• Change in activity, either psychomotor agitation or retardation

• Fatigue or loss of energy

• Feelings of guilt or worthlessness

• Diminished ability to think or concentrate

• Thoughts of death or suicide

Table notes: Symptoms of depression must be present for at least two weeks and be persuasive for a clinical diagnosis to be reached

If persistent, depressive symptoms that fall below the DSM V threshold criteria for a diagnosis of MDD can still be disabling (Andrews, Anderson, Slade & Sunderland, 2008). NICE (2009a) guidelines recognise subthreshold depression which is defined as at least one key symptom of depression, but with insufficient other symptoms and/or functional impairment to meet the criteria for MDD.

Table 2 describes the symptoms which constitute a label of Generalised Anxiety Disorder (GAD), according the DSM V (APA, 2013: p225).

Table 2 DSM V criteria for assessing Generalised Anxiety Disorder

A clinical diagnosis of Generalised Anxiety Disorder (GAD) requires the following core symptoms to be present:
•   Excessive anxiety and worry about a variety of events or activities •   A difficulty in controlling the worry or feelings of anxiety In addition to the core symptoms, at least three of the following six symptoms have to be present: •   A feeling of tension or restlessness •   A tendency to become fatigued •   Difficulty in concentrating or the mind going blank •   Irritability •   Significant muscle tension •   Difficulty sleeping
Table notes: To reach a clinical diagnosis, symptoms of GAD must be present for six months

If a clinician suspects that an individual is experiencing a mood problem such as MDD, subthreshold depression or GAD, NICE guidelines (2009a, 2011a) suggest offering treatment using a stepped care approach.

1.1.6 A stepped care approach

A stepped-care model is used to organise the provision of services and to help people with common mental health problems, such as anxiety and depression, within the UK (NICE, 2009a; 2011a). The model supports patients, carers and practitioners to identify and access the most effective interventions. The stepped-care approach for treating depression can be found in Table 3 (NICE, 2009a: p16).

Table 3 Stepped-care model for treating depression

Focus of intervention	Nature of intervention
Step one: All known and suspected presentations of depression	Assessment, support, psychoeducation, active monitoring and referral for further assessment and interventions
Step two: Persistent subthreshold depressive symptoms; mild to moderate depression	Low-intensity psychosocial interventions, psychological interventions, medication and referral for further assessment and interventions
Step three: Persistent subthreshold depressive symptoms or mild to moderate depression with inadequate response to initial interventions; moderate and severe depression	Medication, high-intensity psychological interventions, combined treatments, collaborative care and referral for further assessment and interventions
Step four: Severe and complex depression; risk to life; severe self-neglect	Medication, high-intensity psychological interventions, electroconvulsive therapy, crisis service, combined treatments, multi-professional and inpatient care

Table notes: Complex depression includes depression that shows an inadequate response to multiple treatments, is complicated by psychotic symptoms, and/or is associated with significant psychiatric comorbidity or psychosocial factors. Collaborative care is only for depression where the person also has a chronic physical health problem and associated functional impairment (NICE, 2009b)

According to the NICE guidelines (2009a) mild depression is when an individual has a small number of symptoms which have limited effect on their everyday life. Moderate depression is when an individual has a modest number of symptoms that make their life more difficult than usual. Severe depression is when a person has many symptoms that profoundly affect their everyday life. Severe depression is often called MDD within academic literature (Meeks, Vahia, Lavretsky, Kulkarni & Jeste, 2011).

The stepped care model for guiding management of people with anxiety is illustrated in Table 4 (NICE, 2011a: p11).

Table 4 Stepped-care model for treating anxiety

Focus of intervention	Nature of intervention
Step one: All known and suspected presentations of GAD	Identification and assessment; education about GAD and treatment options; active monitoring
Step two: Diagnosed GAD that has not improved after education and active monitoring in primary care	Low-intensity psychological interventions: individual non-facilitated self-help*, individual guided self-help and psychoeducational groups
Step three: GAD with an inadequate response to step 2 interventions or marked functional impairment	Choice of a high-intensity psychological intervention or a drug treatment
Step four: Complex treatment-refractory GAD and very marked functional impairment, such as self-neglect or a high risk of self-harm	Highly specialist treatment, such as complex drug and/or psychological treatment regimens; input from multi-agency teams, crisis services, day hospitals or inpatient care

Table notes: *A self-administered intervention intended to treat GAD involving written or electronic self-help materials (usually a book or workbook). It is similar to individual guided self-help but usually with minimal therapist contact, for example an occasional short telephone call of no more than 5 minutes

A stepped-care model presents patients with the least intrusive intervention and proceeds to more intense treatment approaches, if necessary. The model aims to standardise treatment procedures and improve the efficiency of managing common mental health problems (Scogin et al, 2003; NICE, 2009a; 2011a).

1.1.7 Social care and third sector services

Based on assessment of need, adult social care services offer help, care and support to people with a wide range of problems arising from disability, illness or other life situations (Humphries, Hall, Charles, Thorlby & Holder, 2016). Humphries et al suggest that social care services help people to live independently, protect vulnerable people from harm and offer essential help in times of crisis. Local authorities are responsible for providing social care services for eligible older adults who require support with daily living activities (Ismail, Thorlby & Holder, 2014). However, Hall and Holder (2016) interviewed several older adults about their personal experiences of using social care services and concluded that such services are struggling to meet the needs of older people. During the last five years there has been a £160 million governmental spending cut on older peoples' social care (Age UK, 2017). Humphries et al suggest that the financial and mental health costs to older adults, and those who care for them, are mounting.

Third sector organisations are commissioned to deliver specific health services to complement those offered by the NHS and social care services (Joint Commissioning Panel for Mental Health, 2013). The 'Health and Social Care Act' (Department of Health, 2012a) set out a clear aspiration for the voluntary and community sector to become providers of health services. Within the UK, third sector services can be commissioned through public bodies such as local authorities and the NHS (Sands, Chadborn, Craig & Gladman, 2016). NICE (2018) also produces evidence-based guidelines which influence commissioning of such services. The statutory sector spends around £3.39 billion per year on health services provided by third

sector organisations (Curry, Mundle, Sheil & Weaks, 2011). Health policies have aimed to improve the care for older adults experiencing mental health problems. Yet, as funding for social care services has reduced and mental health services are failing to keep up with demand (see Section 1.1.4), it could be argued that third sector services are going to evolve to play a bigger role in managing older peoples' mental health problems.

1.2 Rationale for the study

This thesis spans distress, self-management and the internet. I will now provide a rationale for the inclusion of these topics in relation to older adults. I critically explore these topics in more depth within the literature review described in Chapter Two.

1.2.1 Why research distress?

Distress as a highly subjective experience (Cromby, Harper & Reavey, 2009) and is related to depression and anxiety, but also distinct (Geraghty et al, 2015). The concepts are distinct as distress is not a diagnostic label, instead it is an individual's lived experience of a mood problem. Depression, anxiety and distress are related as the constructs potentially share an overlap in feelings; Geraghty et al suggested that an individual reaching the diagnostic criteria for depression is likely to have expressed feelings of distress. I further discuss the concept of distress in Section 2.5.

Whilst depression and anxiety in older adults have been linked to a reduced quality of life and an increase risk of suicide (Unützer & Bruce, 2002), the Mental Health Foundation (2016) reported that 85% of older people experiencing such mental health problems do not seek help from healthcare services. Mental health policies such as 'No health without mental health' (Department of Health, 2011a) suggest that individuals should have access to services based on need, not age. However, the findings from the Mental Health Foundation suggest that older adults with mental health problems could have hidden needs. Older adults' perceptions of

mental health problems could prevent older people from seeking help from healthcare services. Chew-Graham et al (2012) reported that older adults were reluctant to recognise symptoms of depression as reasons to consult a GP. Older peoples' reluctance to seek help from GPs may stem from stigmatised attitudes towards mental health problems (Cornford, Hill, & Reilly, 2007; Connor et al, 2010). Rather than perceiving themselves as experiencing anxiety or depression, older adults are more likely to self-identify with the less stigmatising term distress (Wetherell et al, 2010).

1.2.2 Why research self-management?

Fuller, Edwards, Proctor and Moss (2000) found that younger adults experiencing distress hold stoic attitudes towards managing their mood problems. Fuller et al did not sample older adults, a sense of stoicism may be increased within older people due to their stigmatised attitudes towards mood problems (Cornford, Hill, & Reilly, 2007; Connor et al, 2010). To the best of my knowledge, there is little research which has explored how older adults self-manage distress.

I explore the definitions surrounding self-management in Section 2.6.1 and propose that the Department of Health's (2005) definition is appropriate for the current study. The Department of Health defined self-management as:

> 'The actions taken by individuals towards their own health and well-being, it comprises of the ability to meet their social, emotional and psychological needs, to care for conditions and to prevent further illness.'

> (Department of Health, 2005:p2)

The Department of Health's (2005) definition of self-management suggests that individuals take increased accountability for their health and well-being. Lorig et al (2008) suggested that individuals should take responsibility and self-manage their health problems as they are the

'expert patient' (p247). Whilst Lorig et al failed to acknowledge that people apply individualised notions of self-management within their own, unique, social contexts, Miller, Lasiter, Ellis & Buelow (2015) suggested that the self-management of a health problem is affected by the larger society in which an individual lives. An individual's social context may contribute to experiences of distress, or influence how distress is managed. Furthermore, the improvement and maintenance of health have become important goals for large numbers of people and the self-management of health problems has rapidly become a prominent feature of modern society (Crawford, 2006). Identifying the self-management strategies distressed older people employ could be useful information as services within society could promote and support these strategies.

1.2.3 Why research use of the internet?

Use of the internet is becoming a societal norm. The Office of National Statistics (ONS; 2018) reported that 90% of households in the UK have access to the internet, this has increased from 57% in 2006. The ONS also found that although the number of older adults reporting to use the Internet has more than doubled from 20% in 2011 to 44% in 2018, older people are less likely to be online than any other age group and are more likely to be digitally excluded. Digital exclusion involves the unequal access and capacity to use technology such as computers or the internet (Schejter, Harush, Rivka & Tirosh, 2015).

The Department of Health (2018) produced a report entitled 'The future of healthcare: our vision for digital, data and technology in health and care'. The report highlights the potential benefits of digital services (e.g. accessing NHS websites and online forums for information). Depressed younger adults use the internet as a source of health information and as a means of accessing social support through engaging in social media platforms, particularly online forums (Webb, Burns & Colins, 2008; Gowen et al, 2012; Ramirez & Badger, 2014; Van Grieken et al, 2015; Villaggi et al, 2015; Aref-Adib, 2016). Distressed older adults could

potentially manage their mood problems by using the internet as a source of health information, or to access social support. However, I noted a lack of research which explored the role of the internet in how older adults self-manage distress. This information could be important for healthcare professionals when directing distressed older adults to certain self-management strategies. I provide a critical discussion regarding the role of the internet in the self-management of health and illness in Section 2.7.

1.3 Personal reasons for undertaking this thesis

I have always had aspirations for a career in academia because of my interest in both research and teaching. As I was about to complete my Masters in Health Psychology I found a PhD studentship advertised at Keele University in early 2015. The studentship focused on depressed older adults' use of online forums; an area that I had an interest in, particularly as I grew up in a small town which was heavily populated by older people. The PhD proposal described the research as a qualitative study. Although I appreciate quantitative methods, I have an affinity towards qualitative methods due to their exploratory nature. Older people may have subjective experiences of using online forums when experiencing mood problems; qualitative methods would give me the opportunity to explore this topic in-depth.

1.4 Public and patient involvement and engagement

PPIE involves developing, conducting and disseminating research 'with' the public, not 'for the public (INVOLVE, 2010: p3). The UK government has established PPIE in healthcare policy and is committed to empowering the public to have a greater role in influencing healthcare services (Department of Health, 2010a). The National Institute for Health Research (NIHR) created a national advisory group, called INVOLVE, which aimed to support public involvement in healthcare research (INVOLVE, 2012). Reported positive effects of PPIE include: developing appropriate research questions, clarifying language for public facing

documents and providing a wider perspective upon data analysis (Brett et al, 2014; Domecq et al, 2014).

I integrated PPIE activities at key stages throughout the research process. The Research Institute for Primary Care and Health Sciences (RI) at Keele University has established a Research User Group (RUG) to support the use of PPIE in research. I used the RUG to access older adults who were currently, or had previously, experienced mood problems. I believed that these individuals would identify factors that would be relevant to the study's target sample population. I ran three PPIE workshops and gathered feedback from PPIE members on the development of the research questions and methods, the interpretation of the findings and when creating a dissemination plan. I discuss the impact of PPIE upon the current study within Chapter Seven.

1.5 Structure of the thesis

Including the current chapter, I divided this thesis into eight separate chapters. Within Chapter Two, I review the existing literature. I separate the literature according to topics and present the research questions.

Chapter Three describes the methodology which underpins the approach taken to study how older adults self-manage distress. I discuss social constructionism and provide a rationale for qualitative data collection, I also discuss why I integrated 'think aloud' methods within semi-structured interviews. The process of analysis and strategies to increase quality in qualitative studies are also discussed in Chapter Three. This leads me into Chapter Four where I document the methods I used for the study. I describe participant recruitment and sampling, how the field was accessed and how data was collected. I also reflect upon ethical considerations, report how I conducted data analysis and describe how I tried to ensure this study was of a high quality.

The findings are presented in Chapter Five and Six. Within Chapter Five I report how participants identified and managed distress. In Chapter Six I describe the role of the internet in how participants managed distress. Following this, Chapter Seven documents the impact of PPIE upon the current study.

Chapter Eight discusses the findings in line with the research questions and wider literature. I also describe the strengths, limitations and challenges of the study. Following this, I provide a reflection on the study and discuss the implications of the findings for older adults, healthcare services, third sector services and policy-makers. I end the thesis by suggesting future areas of research.

1.6 Style of the thesis

I conclude this chapter with a justification of the writing style I have adopted for the thesis. The traditional style of reporting empirical research is in the third person, it is objective and does not acknowledge that the researcher is part of the research process (Gilgun, 2005; Gillet, Hammond & Martala-Lockett, 2009). Holliday (2002) argued that writing in the first person is acceptable in qualitative research where the researcher may directly influence the data collected. Failure to recognise how I contributed to the research goes against my epistemological beliefs, which are strongly aligned to a social constructionist approach to knowledge formulation. Social constructionists recognise that researchers and participants co-construct data together (Mojtahed et al, 2014), using the first person acknowledges a researcher's involvement within a study (Charmaz, 2014).

I have used a middle-ground approach when writing this thesis. I used first person where appropriate so that the reader can be knowledgeable of my part within the research process. However, the use of the first person was not appropriate for the entire thesis, particularly

when drawing on evidence from other academics within the literature review and discussion. I use the third person when I was not directly influencing the research process.

Summary

Within the current chapter I have discussed the context and rationale for the current study. I have also stated my personal reasons for undertaking this study, emphasised the role of PPIE and described the structure of the thesis. I concluded the chapter by discussing the writing style I have adopted throughout this thesis. The next chapter critically examines the literature which has informed this study and states the research questions.

Chapter Two: Literature review

Introduction

I now provide a review of the literature to critically examine the current state of knowledge regarding older adults, distress, self-management and the internet. I will begin by describing the approach taken towards the literature review, and then discuss the research which has informed this study. I conclude the chapter by presenting the research questions.

2.1 Approach to literature review

The two main approaches to reviewing published research are systematic or narrative literature reviews. Systematic reviews are based upon pre-defined eligibility criteria and conducted according to a pre-defined protocol (Moher et al, 2015). Higgens and Green (2011) reported that systematic reviews are usually based upon narrowly defined research questions and, therefore, provide specific answers to specific questions. In contrast, narrative literature reviews are general and cover several aspects of a topic (Robinson & Lowe, 2015). Keary, Byrne and Lawton (2012) proposed that a narrative literature review can capture a vast amount of research whilst also providing a basis for an evidence-based argument; this was important for the current study which spanned older adults, distress, self-management and the internet. I conducted a narrative literature review as it enabled me to capture a broad range of studies that may have been missed if I had conducted a narrowly defined systematic review.

I referred to Keary, Byrne and Lawton's (2012) recommendations when conducting the narrative literature review. I first began by identifying subjects and key words that were relevant to the study, I utilised these terms to scope the literature to identify key authors and sources. I searched electronic databases which included: Web of Science, PubMed, Medline, PsycINFO, Psycarticle and CINAHL. I identified abstracts and full-text articles and screened their reference lists to ensure key literature was not overlooked. I also engaged with grey

literature, such as policy documents, to contextualise the topic. I then critically analysed the literature by looking for strengths and weaknesses of the studies, assessing how each study fits in line with the existing literature and identifying opposing arguments or debates between the research studies. This enabled me to offer a critical perspective on the topic areas throughout my narrative review.

Conducting this literature review was an evolving process which began in October 2015. To give me a sense of the prevalence of common mental health problems in older people, I started reading the literature around anxiety and depression in older adults. A clear message became apparent from the studies I engaged with at this point: although anxiety and depression are prevalent in older adults, older people face a range of barriers to care when experiencing mental health problems. To explore this further I refined my search terms to focus on barriers to care, stigma and treatments for mental health problems (see Figure 2). The research reported conflicting findings in regards to older peoples' adherence to medication and also described that older adults are less likely to access talking therapies. Due to stigma, older people are more likely to self-identify as distressed. Taking this into account, I searched the literature in regards to distress. I found studies which proposed that the management of distress needs to point towards self-management strategies. I than began to explore the literature surrounding self-management, most studies focused on how people self-manage physical health conditions. I expanded my search terms to include younger adults and found studies which focused on the self-management of mental health problems. The literature suggested that one of the self-management strategies younger people employed was using the internet. I then specifically searched the databases to explore internet use as a self-management strategy when experiencing mental health problems and distress. Research proposed that the internet could be a source of health information or social support, however,

these studies mostly sampled younger adults. This gap in the literature led to the formulation

of my research questions. Figure 2 details the development of my search strategies

Figure 2 Development of search strategies

Web of Science, PubMed, Medline, PsycINFO, Psycarticle and CINAHL	Key messages from literature
'anxiety' or 'depression' or older adults' or 'aging' or 'ageing' or 'geriatrics' or 'elderly' 'mental health'	High prevalence rates, barriers to care
'anxiety' or 'depression' or 'older adults' or 'aging' or 'ageing' or 'geriatrics' or 'elderly' or 'mental health' or 'barriers to care' or 'stigma' or 'treatments' or 'medication' or 'anti-depressants' or 'talking therapies'	Lack of acceptable treatments, perceptions of mental health problems, more likely to self-identify as distressed
'distress' or 'older adults' or 'aging' or 'ageing' or 'geriatrics' or 'elderly'	Management of distress needs to point to self-management strategies
'self-management' or 'self-help' or 'self-care' or 'coping' or 'self-management strategies' or 'physical health' or 'mental health' or 'anxiety' or 'depression' or 'distress' or 'older adults' or 'geriatrics' or 'elderly' or 'aging' or 'ageing'	Most literature focuses on management of physical health conditions. Younger adults, internet could be a self-management strategy
'older adults' or 'elderly' or 'geriatrics' or 'aging' or 'ageing' or 'younger adults' or 'internet' or 'online forums' or 'e-health' or 'social media' or 'online forums' 'self-management' or 'self-management strategies'	Younger adults use the internet as source of health information or social support when experiencing mental health problems. A lack of research focusing on distressed older adults use of the internet as a self-management strategy
Identified gaps in the literature, development of research questions	

Within the following sections the division of literature is presented based upon key areas identified by the search strategies. 2.2 Depression and anxiety in older adults A comprehensive meta-analysis extracted data from 181 studies published between 1980 and 2010 and found that the prevalence of Major Depressive Disorder (MDD), in people over the age of 75 years old, ranged from 4.6% to 9.3% (Meeks, Vahia, Lavretsky, Kulkarni & Jeste, 2011). Meeks et al also found that the rate of sub-threshold depression (symptoms of depression that do not meet the full diagnostic criteria set for MDD) ranged from 4.5% to 37.4% in individuals aged 75 and above. Although the meta-analysis failed to capture any literature published after 2010, Meeks et al's findings imply that older adults' symptoms of depression may fall anywhere on the spectrum ranging from sub-threshold to MDD, with the former being more prevalent than the latter. Although conducted in America, meaning that the findings may not be generalisable to the UK's population of older adults, Laborde-Lahoz et al (2015) found that the prevalence of subthreshold depression in older people aged 65 and above was 13.8%. In addition to being highly prevalent, Laborde-Lahoz et al found that subthreshold depression was associated with elevated risks of experiencing Generalised Anxiety Disorder (GAD).

The prevalence of GAD in community dwelling older adults reportedly ranges between 3.2% and 14.2% (Trollor, Anderson, Sachdev, Brodaty & Andrews, 2007; Gum, King-Kallimanis & Kohn, 2009; Byers, Yaffe, Covinsky, Friedman & Bruce, 2010), a rate that increases to 23.5% in older adults aged 55 years and over who are caregivers (Mahoney, Regan, Katona & Livingston, 2005). Prevalence rates of GAD in clinical populations of older people range between 18% and 24% (Tolin, Robinson, Gaztambide & Blank, 2005; Yohannes, Willgoss, Baldwin & Connolly, 2010).

Prevalence rates of anxiety and depression in older adults vary within the epidemiological literature, this could be because studies which have investigated such issues used arbitrary

definitions of what constituted being an older person. For example, Meeks et al (2011) defined an older adult as a person aged 75 years and over whereas Mahoney et al (2005) used the age of 55 years and above to define being an older adult. However, the age of 65 has been used within a number of research studies to differentiate between older and middle-aged adults (Osmanovic-Thunström, Mossello, Åkerstedt, Fratiglioni & Wang, 2015; Chatterji, Byles, Cutler, Seeman & Verdes, 2015).

2.3 Management of common mental health problems in older adults in primary care

The National Institute for Health and Care Excellence (NICE) clinical guidelines (NICE, 2009a, 2011a, 2011b) recommend a stepped care approach when helping people experiencing common mental health problem, such as anxiety or depression (see Table 3, p8 and Table 4, p9). The first step is initiated when a General Practitioner (GP) suspects that an individual is presenting with symptoms of anxiety or depression. Within the first step, NICE (2009a; 2011a) guidelines for both anxiety and depression suggest that GPs should actively monitor the individual and their symptoms. Active monitoring is the process of GPs assessing and discussing a problem, providing information about the nature and course of the problem, arranging a further assessment, and making contact if the individual does not attend follow-up appointments (NICE, 2009a; 2011a).

If an individual is thought to have subthreshold or mild to moderate depression (NICE, 2009a), or GAD that has not improved after education or active monitoring in primary care (NICE, 2011a), the second step within the stepped-care approach may be instigated. For depression, the second step suggests treatments such as low-intensity psychosocial interventions, psychological interventions and medication (NICE, 2009a). In relation to GAD, the second step advises GPs to encourage the individual to engage in physical activity, group-based activities, self-help groups or to attend psychological therapies (NICE, 2011a). Psychological therapies, also known as 'talking therapies', are interpersonal interventions

delivered by trained therapists which aim to improve the mental health of individual patients or groups (Lees, 2016). If the patient experiencing GAD has an inadequate response to treatments in step two, or marked functional impairment, they may progress to step three and be offered high intensity psychological interventions or medication (NICE, 2011a). Step three will be initiated for depression if subthreshold depressive symptoms, or mild to moderate depression, have inadequate responses to treatments recommended in step two, or if an individual presents with moderate or severe depression (NICE, 2009a). Treatments may include medication, high-intensity psychological interventions and combined interventions.

To manage depression, the final step is initiated if an individual presents with severe depression, risk to life and/or severe self-neglect (NICE, 2009a). Medication, high-intensity psychological interventions, electroconvulsive therapy, crisis service, combined treatments, multi-professional and inpatient care may be offered as treatments. For anxiety, the fourth step would be triggered if the GAD did not respond to previous treatments and had marked functional impairment, such as self-neglect or high risk of self-harm (NICE, 2011a). Treatments would include medication and/or psychological treatments, input from multi-agency teams, crisis services, day hospitals or inpatient care.

Research has shown the effectiveness of psychological therapies as treatments for mood problems (Craig et al, 2008; Richards et al, 2016), this research has informed the development of NICE (2009a; 2011a) guidelines for anxiety and depression. There are many psychological therapies such as: Cognitive Behavioural Therapy (CBT), Interpersonal Therapy (IPT), counselling, family therapy, group therapy and behavioural activation (Hanley & Gilhooly, 2018: p21). Table 5 provides a brief description of these psychological therapies.

Table 5 Psychological therapies

Therapy	Description of therapy

Cognitive Behavioural Therapy	Helps the patient to make sense of problems by breaking them down into smaller parts. Based on the concept that situations, thoughts, emotions, physical feelings and actions are interconnected and affect each other
Interpersonal Therapy	The central idea is that psychological symptoms can be understood as a response to current difficulties in relations and affect the quality of such relationships
Counselling	Involves a trained therapist listening to you and helping you to find ways to manage problems
Family therapy (or counselling)	A treatment which aims to address specific issues (such as a major transition) which affect the health and functioning of a family
Group therapy	Where one or more therapists treat a small number of patients as a group
Behavioural activation	A therapist aims to increase the amount of positive reinforcement a person experiences, and reduce negative behaviour patterns

A meta-analysis and meta-regression of randomised controlled trials found that brief psychological therapies, which lasted between 6 to 8 weeks, reduced symptoms of anxiety and depression in adults (Cape, Whittington, Buszewicz, Wallace & Underwood, 2010). Cape et al's research only included studies which focused on CBT, psychodynamic therapy and supportive therapy. The findings may not be applicable to other forms of therapies such as IPT or behavioural activation, which are both suggested as treatments for mood problems within the NICE (2011b) guidelines for common mental health problems. Gilbody et al (2017) conducted a randomised control trial to establish a collaborative care intervention for older adults with sub-threshold depression. Collaborative care in this study involved organising and delivering a psychological intervention in the form of behavioural activation and medication management (Overend et al, 2015; Taylor et al, 2018). The intervention was reported to be patient-centred, meaning that participants' values guided clinical decisions, and

delivered by a case manager who worked to a defined protocol (Gunn, Diggens, Hegarty, Blashki, 2006) and liaised with the participants' GPs to manage antidepressant medication. Gilbody et al found that, at a 4 month follow up, participants who had received the intervention reported a reduction in depressive symptoms and valued having the opportunity to talk outside of the primary care consultation.

Although Cape et al (2010) and Gilbody et al (2017) reported the positive effects of psychological therapies for people experiencing symptoms of depression and anxiety, the Department of Health (2011b) reported that older adults were less likely to access psychological therapies in comparison to younger adults. Prina et al (2014) found that GPs were more likely to refer younger, rather than older, adults to psychological treatments. Pettit et al (2017) assessed referral, access and engagement rates to the Improving Access to Psychological Therapies (IAPT) services by age and found that the proportion of the population being referred, accessing and engaging with psychological therapies peaks in individuals aged between 25 and 29 years old, and declines after this age. The lowest numbers of individuals being referred and accessing psychological treatments were aged between 70 and 74 years old. Pettit et al's study failed to explain why the differences in referral, access and engagement rates existed between participants from different age groups.

Corresponding with the stepped-care approach (NICE, 2009a; 2011a), older adults experiencing depression could be offered antidepressant medication in steps two, three and four, whilst older people experiencing anxiety could be offered antidepressant treatment in steps three and four. Cipriani et al (2018) reported a systematic review and network analysis which aimed to compare the use of antidepressant medication against a placebo and found that antidepressants were effective in treating people with severe depression. However, Marston and colleagues (2014) found that 58.7% of older adults experiencing moderate depression were offered antidepressants by a clinician. Blazer and Hybels (2005) suggested

that clinicians' rates of offering antidepressant treatment among older adults has increased with the availability of selective serotonin reuptake inhibitors (SSRIs).

Among older adults who begin taking antidepressants, non-adherence rates have been reported to range between 40% and 75% (Salzman, 1995; Fawzi et al, 2012). Contrasting Salzman's and Fawzi's findings, Gum et al (2006) found that older adults with depression intended to adhere to long-term antidepressant treatment, but also appreciated accessing psychological interventions. Within Gum et al's study the views and experiences of older adults adhering to antidepressant medication for longer than 12 months were not captured.

2.4 Barriers to care for older adults with mood problems

Byers, Arean and Yaffe (2012) report that only 30% of community dwelling older adults aged 55 and above, who scored positively for anxiety or depression, sought help from healthcare services for their mental health problems. Barriers to help-seeking from healthcare services could be due to a number of reasons, one being the perceived relationship an older adult has with a GP. In a qualitative study which included interviews with 31 older adults aged 65 and above, Mellor, Davison, McCabe, George, Moore and Ski (2006) found that depressed older people believe that GPs are too busy to be concerned about their mental health problems, have a lack of knowledge about mood problems and report a lack of trust between themselves and clinicians. Data in Mellor et al's study was recorded, by the interviewer, at the time of the interview therefore important details may have been missed.

A lack of continuity with the same GP could also prevent some older adults from seeking help from healthcare services when experiencing mood problems. Relationship continuity is the relationship between a patient and a GP that spans over episodes of care and provides consistency through the GP's developing knowledge of the patient (Haggerty et al, 2003). Within the UK there has been a trend towards larger general practices where expansive

clinical teams manage an increasing patient population (Baird, Charles, Honeyman, Maguire & Das, 2016). Patients in larger practices have reported lower satisfaction with several aspects of care, including continuity with GPs (Baird, Charles, Honeyman, Maguire & Das, 2016). Haggerty, Roberge, Freeman and Beaulieu (2013) conducted a metasummary of qualitative studies which explored patients' experiences of care. A metasummary is a quantitatively oriented aggregation of themes which emerge within a number of sets of qualitative data (Sandelowsi, Barroso & Voils, 2007). Haggerty et al found that relational continuity with a trusted GP encouraged patients to be more open about their problems. Haggerty et al's meta-summary was limited to findings considered important by the authors of the included studies and, therefore, may have missed findings that were considered minor in the original studies, but would have emerged as important across several studies. However, Haggerty's findings suggest that a lack of relationship continuity could prevent individuals from disclosing their symptoms of mental health problems to a GP; this would impede these individuals from receiving a diagnosis and accessing treatments.

Older adults' perception of mental health problems could also prevent them from seeking help from healthcare services when experiencing mood problems. Chew-Graham et al (2012) conducted a secondary analysis of qualitative data and found that older adults were reluctant to recognise and name symptoms of depression as reasons to consult a GP. Although the data generated in the primary study did not address the exact research questions formulated by Chew-Graham et al, the secondary analysis did contribute to the understanding of why older people with depression may not present to primary care settings. From Chew-Graham et al's findings it could be argued that older adults with depression did not perceive themselves as candidates for care. Candidacy refers to how a person's eligibility for healthcare and treatment is determined between themselves, their social contexts and healthcare services (Dixon-woods et al, 2006).

Corrigan (2004) suggested that people experiencing symptoms of depression want to avoid being labelled as mentally ill by GPs as society views this as negative. Further research has also indicated that some older people, who score positively for anxiety or depression, do not intend to seek help from healthcare services due to their stigmatised attitudes towards mood problems (Cornford, Hill & Reilly, 2007; Connor et al, 2010). Research exploring stigma only captured participants who were willing to participate within these studies. Individuals who did not participate in such studies may have held stronger stigmatised attitudes towards mental health problems, which could have led to their reluctance to participate.

Wetherell et al (2010) examined age differences in the discrimination between anxiety and depressive symptoms in a community sample of 374 American adults aged between 18 and 93 years old. Older participants were significantly less likely than younger participants to classify feelings such as sadness, worthlessness/guilt, worry, and fear as symptoms of anxiety or depression; perhaps perceiving these symptoms as 'distress'. Wetherell et al's sample was predominantly well-educated, a factor might be expected to increase knowledge about mental health problems. The results from Wetherell et al's study may only represent older people with a higher level of mental health literacy. Health literacy is an individual's cognitive and social skills which determine their ability to access, understand and use information in ways which promote healthy behaviours (Nutbeam, 2000). The Patient and Public Involvement and Engagement (PPIE) group which advised this study suggested that older people would not self-identify with a mental health problem due to stigma, but would identify as experiencing distress (see Section 7.2.3.1).

2.5 The concept of Distress

Within the next section I discuss the literature surrounding the concept of distress. Horwitz (2007) proposed that distress is a reaction to a stressful situation. Pollock (1988) suggested that lay people's understanding of stress was a 'manufactured concept created by society' (p381).

According to Pollock, lay people's understanding of stress gives the concept a broad meaning as they describe: causes of stress, the way stress is experienced and the consequences of stress. Breznitz and Goldberger (1993) defined stress as 'any external events or conditions that affect the organism' (p3). Breznitz and Goldberger suggest that stress is a natural response that supports adaptation to an individual's environment, but the authors do not take into account the meaning stress may have to a lay person. According to Horwitz the transition of stress to distress depends on the duration and intensity of the stressful situation. Either a longer duration, or a higher perceived intensity of stress, is likely to produce feelings of distress. Terluin et al (2006) suggest that distress is often triggered by a range of life events such as bereavement or receiving a diagnosis of a physical health problem.

Distress has been described as a non-specific mood problem (Strine et al, 2005), yet according to Wheaton (2007) this lack of specificity should be disregarded as distress is characterised by symptoms of depression and anxiety. Terluin et al (2006) developed the Four-Dimensional Symptom Questionnaire (4DSQ), a tool for distinguishing between distress, depression and anxiety. Terluin et al found that distress is comprised of symptoms including: feeling low, worrying, irritability, poor concentration and sleep problems. Terluin et al suggested that MDD includes all of the symptoms which indicate distress, but is identified by additional symptoms such as anhedonia, thoughts of self-harm, suicidal ideation and pervasive negative thoughts about the self. In terms of GAD, distinguishing symptoms from distress are irrational fears and avoidance behaviours (Terluin et al, 2014).

Terluin et al's (2006; 2014) conceptualisation between distress, depression and anxiety is symptomatic based. Pilgrim and Bentall (1999) suggested that descriptions of distress, made by the individuals experiencing the mood problem, may differ from symptomatic criteria. For example, not all individuals who describe themselves as distressed may experience all of the symptoms of distress proposed by Terluin et al. This is because distress is highly subjective

(Cromby, Harper & Reavey, 2009), and using symptomatic criteria assumes historical and cultural consistencies which aim to gain universal validity of the representation of distress. Cromby et al advocate that experiences of distress are bound in social conditions, life events and relationships and, therefore, have specific meanings to each individual. The use of symptomatic criteria to identify distress may result in researchers or clinicians missing the complexity and fluidity of people's actual experiences of mood problems.

I consider distress to be a subjective experience. I view distress as both related to depression and anxiety, but also distinct. I believe the concepts are distinct as distress is not a diagnosable mental health problem; it is the individual's subjective, lived experience of a mood problem which is often triggered by a stressful situation (Dowrick & Frances, 2013; Geraghty et al, 2017). An individual who does, or does not, reach the diagnostic criteria for anxiety or depression may report feelings of distress (Geraghty et al, 2015). Therefore, depression, anxiety and distress may be related as the concepts could potentially share an overlap in feelings. However, the reverse may not be the case, an individual experiencing distress may not meet the diagnostic criteria which would infer a diagnosis of depression or anxiety.

2.5.1 Physical health problems, life events and distress

Distress has been linked to a range of physical health problems. Adults experiencing distress were twice as likely to be diagnosed with heart disease, lung disease, arthritis or stroke when compared to adults who are not experiencing distress (Pratt, Dey & Cohen, 2007). Chittleborough, Winefield, Gill, Koster and Taylor (2011) examined associations between distress and chronic health conditions among different age groups. Chittleborough et al used the Kessler 10 scale (Kessler, 2002) to measure distress, the scale assesses symptoms of depression and anxiety. Arthritis and distress were significantly associated with distress for all age groups, cardiovascular disease was significantly associated with distress for those aged 35 and over, asthma and osteoporosis were associated with distress in adults aged 50 and over.

Both Pratt et al and Chittleborough et al's studies employed a cross-sectional design, therefore, the direction of the relationship between distress and physical health problems could not be inferred.

Distress has been linked to certain life events such as: having a reduction in income, becoming unemployed, going through a divorce or being isolated from family and friends (Shih & Simon, 2008; Taylor, Taylor, Nguyen & Chatters, 2018). Perissinotto et al (2012) conducted a population-based longitudinal study examining the relationships between health changes as people age. The authors found that loneliness, defined as the 'subjective feeling of isolation, not belonging, or lacking companionship' (p1080), was associated with feelings of distress. Data from a population-wide survey in Australia has also found that retirement increased the prevalence of distress in older adults (Phongsavan et al, 2006). Although the results may not be applicable to retired older adults who reside in the UK, Phongsavan et al found that being in employment fostered psychological well-being as working provided financial resources and was a valued social role within society.

In a qualitative study reporting interviews with 19 older adults, Kingstone et al (2017) found that participants viewed various forms of losses as justifiable causes of low mood or stress (which are perhaps characteristics of distress). Forms of loss included: a loss of significant relationships (e.g. spouses or friends), changes in physical health and mobility (e.g. joint replacement or osteoarthritis), changes in capabilities (e.g. driving) and a loss of control of daily life (e.g. burden of providing caregiving). Kingstone et al's sample consisted of 18 females and only 1 male, therefore, male older people's perspective on the causes of low mood or stress were absent.

2.5.2 Help-seeking when experiencing distress

An Australian study conducted by Clover, Mitchell, Britton and Carter (2015) asked oncology outpatients to complete a questionnaire assessing if they were distressed and if they intended to seek help for their mood problems. Distress was measured using the Distress Thermometer which has been widely validated in oncology settings (Ma et al, 2014). Clover et al reported that only one-third of distressed patients with cancer wished to be referred for help from the healthcare system when distressed. Similarly, an Australian study conducted by Baker-Glenn, Park, Granger, Symonds and Mitchell (2011) found that only 36% of distressed patients with cancer expressed a desire to seek help from healthcare services for their mood problems. Baker-Glenn et al found that patients with cancer preferred to manage their experiences of distress on their own, healthcare services were perceived to treat only the physical health problem. As both Baker-Glenn et al and Clover et al sampled distressed cancer patients, the findings may not be applicable to patients suffering from other physical illnesses, or people who do not suffer from any physical health problems.

Lay perspectives about help-seeking when experiencing distress has been explored by Walters, Buszewicz, Weich and King (2008). A total of 1 357 individuals, who attended seven general practices within inner-city London, completed a waiting room questionnaire which consisted of the 12-item General Health Questionnaire (GHQ 12; Goldberg et al, 1997) and questions on help-seeking preferences. The GHQ 12 measures distress and common mental health problems. The maximum score on the GHQ is 12. A score of three or over indicates that an individual is distressed, a score of 9 or more could suggest that an individual is experiencing a mental health problem (Ozdemir & Rezaki, 2007; Baksheev, Robinson, Cosgrave, Baker & Yung, 2011). Of those participants who scored as distressed in Walters et al's study, 53% reported that they did not wish to consult a GP and preferred to self-manage their distress. Participants self-managed their mood problems by seeking help from friends

and family, engaging in relaxation activities or exercising. Participants who scored higher on the GHQ 12 questionnaire, and who could have possibly received a diagnosis of a mental health problem, particularly valued self-management strategies which permitted social contact. Walters et al's findings may not reflect the views of individuals who do not attend their general practices, these individuals might have a higher preference to self-manage their mood.

One Australian qualitative study, reporting interviews with 22 adults who lived in rural areas, suggested that individuals may wish to self-manage their experiences of distress due to a sense of stoicism (Fuller, Edwards, Proctor & Moss, 2000). The concept of stoicism has been defined as 'a lack of emotional expression and exercising emotional control or endurance' (Wagstaff & Rowledge, 1995: p181). Fuller et al found that individuals who held stoic attitudes assumed greater responsibility for managing their distress, this created a reluctance to seek help from healthcare services. A limitation of Fuller et al's study is that they did not define how they categorised a rural area. The authors reported that the study setting was the Northern and Western regions of Southern Australia, which are largely populated by remote communities. Fuller et al also did not solely sample older adults, a sense of stoicism may be increased within this population due to the range of barriers to care described in Section 2.4.

The literature I have presented within this section suggests that some individuals experiencing distress do not seek help from healthcare services and may hold stoic attitudes towards managing their mood problems. However, some studies have focused on the management of distress within primary care, I explore these studies within the next section.

2.5.3 Managing distress in primary care

When studying 'hard to reach' groups, which were defined as groups of people who were less likely to seek care for mental health problems (e.g. older adults), Bristow et al (2011) found

that distress was not recognised as a biomedical problem and that a biomedical treatment was deemed inappropriate. Geraghty et al (2017) explored lay perspectives on the solutions offered by GPs when experiencing distress. Interviews were conducted with 20 patients whose GPs had identified them as experiencing distress. Patients reported that GPs primarily offered reassurance, time off work or medication to help them to sleep. Geraghty et al reported that GPs sometimes labelled patients as 'depressed' to access a wider range of treatments such as antidepressants or psychological therapies. Geraghty et al argued that interventions are needed which de-medicalise distress and point towards self-management strategies. The participants within Geraghty et al's research were predominantly older adults, making the findings important for the current study.

2.6 Self-management, health and older adults

I will now explore the literature surrounding self-management. As described in Section 2.1, I found literature by first identifying subjects and key words. I utilised these terms to scope the literature, which included searching electronic databases such as: Web of Sciences, PubMed, Medline, PsycINFO, Psycarticle and CINAHL. Search criteria included: 'self-management' or 'self-help' or 'self-care' or 'coping' or 'self-management strategies', and 'physical health' or 'mental health' or 'anxiety' or 'depression' or 'distress', and 'older adults' or 'geriatrics' or 'elderly' or 'aging' or 'ageing'. The literature was broad and selected on the basis on which it could inform the study. I also include relevant policy documents to contextualise the topic.

2.6.1 Definitions

Several terms such as self-care, self-help, coping and self-management are used interchangeably depending on the content and focus of the research. However, an understanding of the differences between the terms is needed for conceptual clarity (Wilkinson & Whitehead, 2009). Miller, Lasiter, Ellis and Buelow (2015) proposed that self-

management is a term used mainly within the context of healthcare and should be understood as:

> 'A fluid, iterative process during which patients incorporate multidimensional strategies that meet their self-identified needs to cope with a chronic disease within the context of their daily living.'

(Miller et al, 2015: p154)

Coventry, Fisher, Kenning, Bee and Bower (2014), along with Kennedy et al (2014), have used the Department of Health's (2005) definition of self-management within their research, which is as follows:

> 'The actions taken by individuals towards their own health and well-being, it comprises of the ability to meet their social, emotional and psychological needs, to care for conditions and to prevent further illness.'

(Department of Health, 2005: p2)

The Department of Health's definition of the construct places emphasis on how individuals, themselves, can shape their health and well-being.

Although the terms self-management and self-care are often used interchangeably, the terms allude to slightly different concepts. Self-care is not a term commonly used within the mental health field (Gao et al, 2013). Gao et al suggested that self-care is the actions that an individual takes to care for minor ailments, usually without contact from healthcare professionals. Gao et al's definition of self-care ignores the possibility that seeking help from a healthcare professional may be a strategy to manage an individual's health. The National Health Service (NHS) developed a designated online forum to promote self-care. The Self-care forum (2018) provides information about various acute physical illnesses (e.g. the

common cold), but provides no information in relation to mental health problems. A definition purely centred on acute physical ailments is not appropriate for the current study which focuses on distress.

Similar to self-care, the term self-help has been used interchangeably with self-management throughout the literature. In the context of mental health, Williams and Whitfield (2001) conceptualise self-help as any action where people use resources to improve their mood. Self-help can be unguided or guided. Unguided self-help involves no input from healthcare professionals, guided self-help involves minimal input from healthcare professionals (Hof, Cuijpers & Stein, 2009). Cuijpers and Schuurmans (2007) define guided self-help in the following way:

'A psychological treatment in which the patient takes home a standardised psychological treatment protocol and works through it mostly independently.'

(Cuijpers & Schuurmans, 2007: p284)

Guided self-help interventions are a NICE (2009a; 2011a) recommended treatment for depression or anxiety and are commonly delivered in the UK within IAPT services (The National Collaborating Centre for Mental Health, 2010). Richards, Dowling, O'Brien, Viganò and Timulak (2017) found that self-help interventions are being increasingly delivered through the internet. As described in Section 2.3, older adults are unlikely to access psychological therapies, therefore, guided self-help was an inappropriate focus for the current study. Un-guided self-help and self-management are broad terms which both allude to actions an individual does to improve their health. However, self-management is a term used more often in health research and, therefore, is more appropriate for the current study which is situated within the field of primary care and health sciences.

The concept of 'coping' overlaps with self-management. The seminal work of Lazarus and Folkman (1984) defined coping as a 'constantly changing cognitive effort to manage specific demands that are appraised as taxing or exceeding the resources of the person' (p 141). Within Miller et al's (2015) definition of self-management, the authors recognise that individuals employ self-management strategies to cope with their disease. In a concept review based on health literature, Audulv, Packer, Hutchinson, Roger and Kephart (2016) analysed the differences and similarities between the constructs coping and self-management. Audulv and colleagues suggest that the aim of coping is to gain a sense of internal control (e.g. by thinking positively or by trying to regulate emotions). The researchers found that between 60 and 80% of coping strategies were internally focused. Internal strategies were defined as mental or cognitive strategies used to manage or overcome a demand or challenge. However self-management research tends to focus on situation management (e.g. resource utilisation), together with management of internal processes (e.g. thinking and emotional regulation).

To aid conceptual clarity, the current study will employ the term self-management in connotation to the Department of Health's (2005) definition of the construct:

> 'Self-management is the actions taken by individuals towards their own health and well-being, it comprises of the ability to meet their social, emotional and psychological needs, to care for conditions and to prevent further illness.'

> (Department of Health, 2005: p2)

This definition recognises the broader social, emotional and psychological dimensions of managing health and retains relevance in contemporary health literature (Coventry, Fisher, Kenning, Bee & Bower, 2014; Kennedy et al, 2014). The current research will also recognise that self-management includes multi-dimensional strategies in the context of the individual's everyday life, as proposed by Miller et al (2015).

2.6.2 Self-management, policy and primary care

Self-management represents a core concept in healthcare policy within the UK. Involving patients in managing their own health is one of six underlying objectives within the report 'Improving General Practice – A Call to Action' (NHS England, 2013). The 'NHS Mandate' (Department of Health, 2012b) called for the support of patients with chronic conditions to enable them to stay independent for longer and the NHS 'Five Year Forward View' (NHS England, 2014) set out a central ambition for the NHS to become better at supporting people to manage their own health.

Self-management is key throughout health polices, however, there may be a gap between policy aspirations and the implementation of self-management support within primary care. Self-management support is when healthcare professionals and services work to ensure that people have the knowledge, skills and confidence they need to self-manage their health problems effectively (De Longh, Fagan, Fenner & Kidd, 2015). Kennedy et al (2013) conducted a randomised control trial to assess the implementation of self-management support for physical conditions within primary care settings. The intervention to enhance self-management support did not add noticeable value to existing care. Kennedy et al targeted 44 practices and had a response rate of 43%, this could mean the sample was not representative of the practice populations. In a qualitative study which explored the results of the randomised control trial, Kennedy et al (2014) found that patients self-managed their health problems in orientation with their everyday lives and the availability of social contacts who linked the patients to wider community resources. Blakeman et al (2014) aimed to determine the effectiveness of an intervention which provided information and telephone-guided access to community support, versus usual care, for patients with chronic kidney disease. Lay health workers helped participants to access community support. Blakeman et al found that the intervention had significant effects on health-related quality of life and blood pressure control.

Both Blakeman et al and Kennedy et al's studies infer that self-management requires resources which extend beyond primary care practices, implicating the need for links to broader networks of care within the community.

2.6.3 The 'self' in self-management

Central to self-management is the notion of a 'self'. In order to self-manage a health condition, the 'self' is suggested to be an individual who has actively taken responsibility for their health (Rose & Keigher, 1996). Dowrick (2009) described a sense of 'self' as:

> 'Our desire and curiosity, our understanding of our position in time and (social) spaces, our sources of engagement, our practices, our ability as storytellers, our conversations combine to give us a coherent sense of self, an awareness or purpose and value and a sense of meaning.'

(Dowrick, 2009: p177)

Numerous factors can influence one's perceived sense of 'self' including their social interactions, physical characteristics and societal views.

Social identity theory pays specific attention to the sense of 'self' that individuals derive from group membership; that is their social identity (Tajfel, 1979). In order to understand behaviours in various social contexts, Tajfel suggested that it is necessary to recognise that individuals can define their sense of 'self' in social not just personal terms (e.g. 'us' and 'we' not just 'I' and 'me'). The social identity theory assumes that individuals strive to achieve, or maintain, a positive sense of 'self' and that in many social contexts an individual's self-concept will derive from group memberships and be defined in terms of social identity (Tajfel & Turner, 1986).

The social contexts in which a sense of 'self' is developed is rarely taken into account within health research. Interventions which aim to manage stress are often individualistic, they focus

on changing an individual's behaviours or thoughts (Friedman & Rosenman, 1974; Edwards, Baglioni & Cooper, 1990; Brammer, 1992). The role of group membership and shared social identity is often left unexplored throughout individualistic interventions as it is ultimately the individual who engages in health-related behaviours. However, Jetten, Haslam and Haslam (2012) proposed that people engage in health behaviours in groups (e.g. attending specific groups focusing on health issues), and different groups may engage in different types of health behaviours. Whilst health and self-management is personal, it also has a social dimension.

2.6.4 Self-management of health

Self-management research has particularly focused on long-term physical conditions such as cancer, epilepsy and diabetes (Hoff & Sawka-Miller, 2010). The 'Year of Care programme' (NHS England, 2011) set out to deliver self-management support for people with physical conditions, using diabetes as an exemplar. Working with a healthcare professional, the aim of this model is that patients are involved in deciding and agreeing how their diabetes would be managed. Although the outcomes of this intervention may not be generalisable to individuals suffering from health problems other than diabetes, participants reported improved experiences of care and positive changes in self-management behaviours.

Self-management is not only applicable to those experiencing physical health problems, but also those with mental health problems. Lawn et al (2007) proposed that self-management interventions often only included mental health problems as factors that accompany physical health problems. This is apparent within the Identifying Depression and Empowering Activities for Seniors (IDEAS; Quijano et al, 2007) study which aimed to detect and reduce depressive symptoms among older adults with physical health problems. Healthcare professionals were encouraged to case-find for symptoms of depression in older adults with physical health problems and educated these individuals on how to potentially manage their

mood problems (e.g. exercising, adopting a healthy lifestyle, socialising with friends). Participants increased their knowledge of how to self- manage depressive symptoms that accompanied physical health problems. I noted a lack of self-management research which explored how older adults, who do not necessarily have physical health problems, manage mental health problems.

2.6.5 Self-management strategies

Key to the self-management of any health problem is the development of self-management strategies. A self-management strategy is an activity an individual does to manage their own health (Barlow, 2002). Research has suggested that individuals manage physical health problems by deploying strategies to continue everyday activities (Grime, Richardson & Ong, 2010). When researching the self-management of osteoarthritis in a sample of adults aged 50 and over, Mordon, Jinks and Ong (2011) described the initiation of self-management strategies in the following way:

> 'Strategies were often self-discovered or initiated through lived experience of the condition, drawn from biographical experiences, or opportunistically developed.'

(Mordon et al, 2011: p185)

Morgan and Jorm (2009) used a Delphi method to obtain consensus on helpful and feasible self-management strategies for sub-threshold depression. A sample of 63 patients with sub-threshold depression and 34 healthcare professionals participated. A total of 282 distinct strategies were reported, 48 of these strategies were endorsed by 80% of both patients and professionals. Patients endorsed more strategies than healthcare professionals, the authors did not explore reasons for this within their study. Van Grieken, Kirkenier, Koeter, Nabitz and Schene (2015) conducted a qualitative study with 20 depressed adults and found that

participants self-managed their mood problems by engaging in hobbies or voluntary work, socialising with friends and by setting a daily routine.

To self-manage their mood, individuals could employ self-management strategies that may be detrimental to their health. Meta-ethnographic studies, albeit which only sampled younger men, found that individuals with a label of depression expressed feelings of anger towards their diagnosis of a mental health problem and self-managed their mood by using drugs, alcohol or over-work as a distraction (Addis, 2008; Hoy, 2012). Addis and Hoy did not sample male older adults, so the findings may not be relevant to the broader population of older adults.

Individuals utilise self-management strategies within their unique social context which may change overtime (Vassilev et al, 2011). Social connections are part of an individual's social context. An individual's social network, which is a system of social connections, influences how individuals self-manage an illness as they provide access to social support (Griffiths et al, 2012; Vassilev, Rogers, Kennedy & Koetsenruijter, 2014). To self-manage distress, older adults could seek social support from their social connections. Although there is no precise definition of social support, a widely used definition is:

> 'The communication between recipients and providers that reduces uncertainty about the situation, the self, relationships and functions to enhance a perception of personal control over one's life experience.'

> (Albrecht and Adelman,1987: p19)

According to this definition social support is any type of communication that helps an individual feel more certain about a situation and, therefore, feel as if they have control over the said situation. This definition is limited as it suggests that supportive communication must reduce uncertainty, this leaves out communication that would be supportive but does not

reduce uncertainty. For example, after suffering a bereavement a friend may offer an older adult advice on how to manage, this is a form of support even if the advice does not lessen the sense of uncertainty about the future.

Martínez-Hernáez, Carceller-Maicas, DiGiacomo and Ariste (2016) found that women self-reported having more frequent contact and receiving more social support from friends than men. Individuals with social connections which extended beyond family members, and incorporated friends, reported better health and well-being scores in comparison to individuals who only had family members as social connections (Rogers et al, 2011). Fiori et al (2006) examined depressed older adults' social networks using data from the first wave of the Americans Changing Lives study (ACL; House, 1995). The ACL study longitudinally investigated the role of a broad range of social, psychological and behavioural factors in health, and the way health changes with age over the adult life course. Fiori et al (2006) found that the absence of family, in the context of friends, is less detrimental for depressed older adults than the absence of friends in the context of familial support. This could be because older adults may value friendships as they are voluntary by nature; family relationships are generally viewed as compulsory (Shiovitz-Ezra & Leitsch, 2010). Fiori et al utilised a cross-sectional design by analysing the first wave of data collected by the ACL study in 1986, therefore, this data may be outdated.

Attending community groups (such as exercise or computer groups) has been shown to improve an individual's effort to manage a health condition (Chen, 2008; Reeves et al, 2014; Vassilev et al, 2014; Schulman Green et al, 2012; Koetsenruijter et al, 2015). A community group may be organised by a third sector organisation, they are groups of individuals that meet on a regular basis to carry out particular activities (Carr & Halvorsen, 2001; Voluntary Action, 2018). In a study which specifically investigated the benefits of attending community groups for retired older adults, Steffens et al (2016) found that participants had a better quality

of life, and a reduced likelihood of mortality, than people who did not attend groups. Steffens et al used the English Longitudinal Study of Ageing (ELSA) data set, which is a source of information on the health, social, well-being and economic circumstances of the English population aged 50 and over (Marmot, 2003). Attending community groups was determined by participants' responses to the question: "Are you a member of any of the following organizations, clubs or societies?" (p3). Participants could tick any, or all, of eight response options (such as social, exercise or religious groups). Participants could also indicate if they did not attend community groups. As participants indicated which community groups they attended from a pre-selected list, the selection of groups from the list may not have included all groups that participants attended.

Koenig, Larson and Larson (2001) reviewed the literature which explored the role that religion plays in helping individuals to manage health problems. Koenig et al found that in times of stress having a belief in God provided participants with a sense of personal strength. In a cross-sectional study of over 1 000 community dwelling individuals, Kidwai, Mancha, Brown and Eaton (2014) found that an increased frequency in attending church correlated with a reduction in feelings of distress after a negative life event, which included: divorce, retirement and loss of a spouse or family member. Attending church may reduce feelings of distress as it is a source of social contact. Cummings and Pargament (2010) suggested that individuals who attended church on a regular basis reported having a larger social network, and having more sources of social support, compared to individuals who did not attend church. Cummings and Pargament, Kidwai et al and Koenig et al's studies only captured individuals who identified as Christians or Catholics, the results may not be applicable to people who identify with other faiths, or to those who have no religious faith.

2.7 The role of the internet in the self-management of health and illness

I will now critique the literature which focuses on the role of the internet in the self-management of health and illness. As described in Section 2.1, I identified literature by searching electronic databases using key terms. The search criteria used for the electronic searches included: 'older adults' or 'elderly' or 'geriatrics' or 'aging' or 'ageing', and 'internet' or 'online forums' or 'e-health' or 'social media', and 'self-management' or 'self-management strategies'. From the literature review, the key identified areas to critique were: older adults' use of the internet, potential self-management strategies via the internet and online forums.

2.7.1 Older adults' use of the internet

There are now more older adults using the internet than ever before. The Office of National Statistics (ONS; 2018) reported internet use of individuals stratified by age, sex, disability and geographical location. The ONS found that since 2011 the percentage of adults, aged 65 years and over, who had never used the internet had declined by 27%; this suggests that Internet use is increasing in older people. Despite these increases, the ONS also reported that 4.2 million people over the age of 55 had never been online and that there remains a core set of older adults who had no intention of using the internet. Age UK (2016b) produced the report 'The internet and Older People in the UK – Key Statistics' which suggested that older people remain the section of the population that are least likely to use the internet. A survey conducted by the Office of Communications (OFCOM; 2018) asked people over the age of 65 what would prompt them to use the internet, 74% of participants reported that nothing would encourage them to use the resource. Some older adults may not wish to engage with the internet and, therefore, may be digitally excluded.

Other older adults may face a 'digital divide' in terms of accessing the internet and this may prevent them from being digitally included. A 'digital divide' is the gap between those who

do, and those who do not, have access to digital technology and the internet (Van Dijk, 2006).

The Digital Inclusion Panel (DIP) highlighted the importance of bridging the 'digital divide'

as:

> 'Digital inclusion is not about computers, the internet or even technology. It is about
>
> using technology as a channel to improve skills, to enhance quality of life, to drive
>
> education and to promote economic well-being across all elements of society. Digital
>
> inclusion is really about social inclusion.'

(DIP, 2004: p12)

Within the 2017 'Digital Skills and Inclusion Policy', digital inclusion was defined as:

'having the skills and motivation to confidently go online to access the opportunities of the

internet' (Department for Digital, Culture, Media & Sport, 2017: p3). The Department of

Health (Cracknell, 2010; Dilnot, 2011) identified that enhancing older adults' digital inclusion

is crucial as society is becoming increasingly internet-based. Olphert, Damodaran and May

(2005) argued that the internet offers some older adults the potential to improve their quality

of life by providing a means to access information, or resources, that otherwise would have

been inaccessible due to a lack of mobility or transport. As the internet offers access to an

increasing range of goods and services, this provides older people with the opportunity to live

more independently (Milligan & Passey, 2011; Cotten, Anderson & McCullough, 2013).

Although some older adults may use the internet, potential barriers to older people using the

resource include: attitudes towards technology, limited experience of using the internet, a lack

of confidence or knowledge about how to use the resource, and an absence of help in learning

how to engage with the internet (Morris, Goodman, & Brading, 2007; Gatto & Tak, 2008;

Helsper & Reisdorf, 2013). In a qualitative study which explored older adults' attitudes

towards internet use, Harley, Howland, Harris and Redlich (2014) recruited older people from

community groups in the South of England. They found that participants perceived that younger adults constantly engaged with the internet and expressed concerns in relation to what they described as a 'digital imperative' within society. A 'digital imperative' was the perception that individuals had to go online to communicate and access information, services and goods. Participants in Harley et al's study valued in-person contact as a basis for communication. Harley et al's recruitment strategy could have resulted in an implicit bias towards more community-orientated older adults, the views of older people who did not attend community groups were not represented.

Whilst some older adults may face barriers to using the internet, others may engage with the internet as a leisure activity. McKenna, Broome and Liddle (2007) investigated how older adults used their leisure time and compared this with their life satisfaction. Older adults mainly occupied their time by engaging in personal care and hobbies, the latter being a significant factor in increasing life satisfaction. Each of the 195 participants in McKenna et al's sample suffered from, on average, two physical health problems. McKenna et al failed to explore if physical health problems affected participants' abilities to access and engage in hobbies. This is important as older adults who suffer from physical health problems are likely to engage in leisure activities which demand less physical effort, this corresponds with a shift from older adults engaging in outdoor activities to indoor activities, such as using a computer and the internet within their own homes (Nimrod, 2007). In a review of the literature, Nimrod suggested that older adults could engage with leisure activities on the internet such as: researching family trees, creating photo albums and playing games. Older adults may also use the internet as a source of information about current affairs, to conduct online shopping, manage financial accounts or to plan trips (Iyer & Eastman, 2006; Nimrod, 2009).

2.7.2 Potential self-management strategies via the internet

Cotten, Ford, Ford and Hale (2012) examined whether internet use reduced the likelihood of a reaching a depression categorisation, as measured by the Center for Epidemiologic Studies Depression Scale (CES-DS; Radloff, 1977), among retired Americans aged 50 years and over. The findings suggested that internet use reduced the probability of a depression categorisation by 28%. Cotton, Ford, Ford and Hale employed a basic measure of internet use, one closed question which required a 'yes' or 'no' answer, this did not reveal specific ways in which internet use affected participants' mood problems. Gunn et al (2018) found that internet use was one of several self-management strategies that individuals experiencing symptoms of depression used, other self-management strategies included reading and attending self-help groups. Gunn et al's sample did not include adults aged over 75 years old, the findings may not represent individuals within this age group.

One way the internet may have a role in the self-management of distress is by being a source of health information. A study conducted by Ybarra and Suman (2006) found that access to health information online was linked to a reduction in symptoms of anxiety in patients managing various physical health problems. The mean age of participants in Ybarra and Suman's study was 48 years old, more research is needed which solely samples older adults to establish if people within this age group use the internet as a source of health information. Gunn et al (2018) found that 36% of adults experiencing severe depression used the internet as a source of health information. In comparison to adults experiencing mild depression, Gunn and colleagues reported that adults with severe depression were more likely to seek health information from the internet; the authors did not suggest why this might be.

The internet could potentially provide harmful information to older adults about how to manage mood problems. Luxton et al (2012) conducted a literature review which focused on how using the internet as a source of health information influenced suicidal behaviour. Luxton

identified that although the internet provided anti-suicide information and prevention possibilities, there was a considerable amount of pro-suicide information and other content that may have enhanced suicide risk. However, due to the various websites which provided health information, and other influences on suicidal behaviours, it was difficult for the studies within Luxton's review to test if health information, provided through the internet, predicted suicidal behaviour.

Older adults could use the internet to self-manage distress as engaging with the resource could provide a means of communicating with other individuals. One way of communicating online is via social media platforms, these are websites or applications that allow users to create, share content and participate in conversations with other people (Fuchs, 2017). Engagement with social media platforms can range from passive behaviours, such as reading posts and online discussions, to active participation by posting, blogging or uploading content (Hawn, 2009). OFCOM (2017) found that 76% of all internet users had a social media account, Facebook being the most dominant platform. Between July and August 2012, Leist (2012) reviewed the literature on older adults' social media use. Although the review was conducted quickly and literature may have been overlooked, Leist found that engaging with social media sites permitted older adults, with a lack of physical mobility, to communicate with other individuals regardless of geographical location or time.

Using the internet as a means of communicating with friends and family has been associated with reduced feelings of loneliness linked to social isolation (Findlay, 2003; Fokkema & Knipscheer, 2007; Bartels & Naslund, 2013; Cotten, Anderson & McCullough, 2013). Social isolation has been defined as an objective assessment of the size and frequency of the social connections an individual has, whereas loneliness is seen as a subjective experience (Grenade & Boldy, 2008). Sum, Mathews, Hughes and Campbell (2008) used an online questionnaire to survey 222 Australian older adults and found that engaging with social media platforms

increased their perceived levels of social support, and decreased feelings of loneliness. Sum et al's study failed to capture if participants lived in urban or rural areas, this is important as urban internet users are significantly more likely than rural internet users to use social networking sites (Duggan & Brenner, 2013).

Some individuals may not communicate within social media platforms due to the potential for abusive responses (OFCOM, 2017). Within a comprehensive literature review, Harris and McCabe (2017) found that the potential for abusive responses was more likely to deter women from engaging with social media platforms rather than men. OFCOM also found that 25% of adults did not trust the information they read on social media platforms, this had increased from 18% in 2015.

Engaging with social media platforms could also impact how individuals use resources such as community groups. A higher engagement within social media platforms (e.g. Facebook) was related to lower levels of younger adults' participation within community activities, such as attending community groups (Hampton, Sessions & Her, 2011; Theocharis & Lowe, 2016) As Hampton et al and Theocharis and Lowe did not sample older adults, data may not be representative of older people.

2.7.3 Online forums

An online forum is a discussion site, often focused on a narrow topic or theme, where people can hold conversations in the form of posted messages (Morzy, 2013; Weslowski, 2014). Engaging within online forums provides people with opportunities to establish new social connections (Jorm, 2005). Within online forums conversations between users can be archived and organized which creates a repository of past information whereby exchanges can be looked back and reflected upon (Beer & Burrows, 2007). Individuals often use a pseudonym when engaging within online forums, this offers a level of anonymity which is unavailable

when communicating in-person (Seraj, 2012). Seraj suggested that the anonymity afforded by online forums provides individuals with an opportunity to openly discuss their mood problems without the fear of being judged.

Previous research has explored the impact of engaging within online forums upon people experiencing physical health conditions including: primary biliary cirrhosis (Lasker, Sogolow & Sharim, 2005), cancer (Gooden & Winefield, 2007), Huntington's disease (Coulson, Buchanan & Aubeeluck, 2007) and chronic fatigue syndrome (Brady, Segar & Sanders, 2016). Heisler et al (2010) conducted a randomised control trial which compared peer support, provided by engaging within online forums, with in-person support from nurses within primary care settings, and examined how the support affected patients' self-management of diabetes. Participants reported a preference for seeking peer support within online forums, this support improved participants' self-management of diabetes as they reciprocally shared their experiences of managing the health problem. Heisler et al's conclusions are consistent with Kennedy et al's (2014) study which found that self-management support needs to extend beyond primary care settings. However, Heisler et al's intervention only lasted six months and there is limited research on the impacts of online peer support over longer periods of time.

Using qualitative methods, Greidanus and Everall (2010) explored how online forums could provide support for distressed adolescents. Trained crisis intervention moderators over-saw the online forums and encouraged participants to engage in the platforms. The moderators also referred a few participants to offline services such as GPs and third sector charities; highlighting that there is still a need for in-person services. Over a number of months, participants began to provide social support to other participants. As younger adults are more likely to engage with the internet (ONS, 2018), the results are likely to have been different if the sample had consisted of distressed older adults.

'Senior online communities' are online forums which aim to purely consist of older people (Berdychevsky & Nimrod, 2015). Nimrod (2010) used content analysis to explore the characteristics of online forums populated by older adults. Nimrod demonstrated that older people use online forums to discuss general matters as well as topics exclusive to aging, such as retirement. A limitation of Nimrod's study is that content analysis is a purely descriptive method, Nimrod did not reveal the underlying motives which encouraged older adults to engage with such forums. Several studies have also explored the benefits of participation in 'senior online communities' and demonstrated the communities' ability to provide social support (Wright, 2000; Pfeil, 2007; Pfeil & Zaphiris, 2009), and companionship (Kanayama, 2003; Nimrod, 2014). However, I found no studies reporting how older adults' might use online forums to manage their mood problems.

2.8 Research questions

The literature review has highlighted that there is a lack of research which specifically explores how older adults self-manage experiences of distress. I also noted an absence of research which explores the role of the internet in how older adults self-manage distress and, to the best of my knowledge, no studies have specifically explored distressed older adults' use of online forums. The identified gaps in current knowledge helped me to formulate the research questions for this study. The main aims of the current study are to explore the self-management strategies older adults use to manage distress, and to examine the role of the internet, including online forums, in how older adults self-manage distress.

The research questions are:

1) How do older adults self-manage experiences of distress?

2) What is the role of the internet, particularly online forums, in how older adults self-manage experiences of distress?

The research questions are broad and exploratory to reflect the current gaps within the literature.

Summary

Within this chapter I have documented the approach taken towards reviewing the literature and provided a critique of the current state of knowledge regarding older adults, distress, self-management and the internet. I have also presented the research questions. Within the next chapter I will discuss the methodology which underpinned the study.

Chapter Three: Methodology

Introduction

In this chapter I discuss the methodological framework which underpins this study. Firstly, I explain my philosophical stance, which is strongly aligned to social constructionism. I then provide a rationale for taking a qualitative approach to this study and critically discuss 'think aloud' methods. Next, I justify the methods used for data collection and analysis. I conclude the chapter by exploring strategies used to maintain quality in qualitative research.

3.1 A social constructionist approach

I now describe my philosophical stance, which fits within a social constructionist approach to knowledge formulation, and discuss the literature which has informed this. The roots of social constructionism lie within phenomenology developed by Edward Husserl (1859-1938), and social phenomenology developed by Alfred Schutz (1899-1959). Husserl's (1931) theory of phenomenology suggest that individuals give meaning to phenomena in their everyday lives. Husserl reasoned that the existence of other people, values, norms and physical objects is always mediated by experiences as they register on people's conscious awareness. In that sense, individuals do no not directly have contact with reality, contact is always indirect and mediated through the processes of the human mind. As a method of inquiry, phenomenology aims to provide accounts that offer an insight into the subjective experiences of individuals (Schutz, 1967). Schutz builds upon Husserl's work and particularly focuses on inter-subjectivity which indicates that an individual's actions, behaviours and experiences gain meaning through social interactions and cannot be separated from them (Di Paolo & De Jaegher, 2015).

A social constructionist approach to research also draws upon principles from the field of symbolic interactionism, which began with the work of Mead (1891–1929). Central to

symbolic interactionism is the view that people participate in the construction of their social worlds, including the construction of their own and others' identities via on-going social interaction. According to Mead (1934), language and social interaction are crucial for the development of the mind, consciousness and the self; it is language that allows individuals to internalise social interactions, to represent ourselves and to think about and reflect upon experiences. Mead suggests that the self does not pre-exist society, but develops from it. Unlike positivist frameworks which accept the belief that there is an objective reality, both phenomenology and symbolic interactionism question the existence of objective knowledge. Berger and Luckmann (1967) drew on the principles of phenomenology and symbolic interactionalism within their book 'The Social Construction of Reality.' Berger and Luckmann proposed that knowledge is seen to be continually constructed, interpreted and experienced by people through their interactions with others.

Whilst a social constructionist framework is broad, Gergen (1985) and Burr (2015) proposed that such an approach to research accepts one or more of the following assumptions: a critical stance towards taken for granted knowledge, historical and cultural specificity, and knowledge being sustained by social processes. I will now explore each of these assumptions and discuss them in relevance to my approach towards the phenomena under study.

3.1.1 A critical stance towards knowledge

A social constructionist approach opposes positivism, which assumes that researchers can take methods to study the natural world (e.g. physics or biology) and apply these to social dimensions (Berger & Luckmann, 1966). Advocates of the realist paradigm, the basis for natural sciences and positivism in social sciences, claim that truth is unitary in nature and knowledge is objective and separate from the individual (Weaver & Olsen, 2006). Kuhn (1962) criticised the positivist approach and proposed that the truth only remains so until the discovery of anomalies. According to Kuhn researchers try to explain these anomalies which

result in 'scientific revolutions' and new paradigms of truth. The post-positivism paradigm

recognises that all observations are 'fallible' and all theories revisable (Ryan, 2006). Similar

to the positivist perspective, post-positivists perceive that truth is objective (Bhasker, 1989).

In contrast, social constructionism argues that knowledge is not an objective truth waiting to

be discovered, but constructed between individuals within society (Hacking & Hacking,

1999). Burr (2015) described the need to question the formulation of knowledge in the

following way:

> 'Social constructionists are encouraged to be suspicious of society's assumptions
>
> about how the world appears to be, categories which humans apprehend to the world
>
> do not necessarily refer to 'real' divisions, they are divisions that have been
>
> constructed by society.'

(Burr, 2015: p2)

The Diagnostic and Statistical Manual of Mental Disorders Fifth Addition (DSM V;

American Psychiatric Association [APA] 2013), and the International Classification of

Disease Related Health Problems (ICD-10) 10th Revision (World Health Organisation

[WHO], 2016) both outline labels to attach to constellations of symptoms and thus contend

what are deemed as mental health problems worldwide. A critical stance needs to be adopted

when exploring how mental health problems are defined as diagnostic criteria has changed

over time due to the shifting values of what symptoms constitute certain mental health

problems. For example, what was referred to as 'dysthymia' within the Diagnostic and

Statistical Manual of Mental Disorders Fourth Addition (DSM IV; APA, 1994), now falls

under the category of 'Persistent depressive disorder', which included both 'Major depressive

disorder' (MDD) and the previous 'Dysthymic disorder'. The committee which oversaw the

development of the DSM IV did not identify a meaningful difference between the two

conditions which led to their combination. This example shows how the DSM IV committee constructed what constituted a category of depression; it was not an objective truth but a social construction of medical knowledge and definitions. DSM IV criteria for depression and anxiety require the presence of either functional impairment or 'clinically significant distress'. However, the DSM IV does not give a clear definition of distress. The meaning of the distress may differ between healthcare professionals, who are influenced by diagnostic criteria and may perceive distress as a marker of a mental health problem, and other individuals within society (e.g. older adults).

I have taken a critical approach to the concepts of distress and self-management. I believe such concepts are not an objective truth waiting to be discovered, but are constructions created by individuals within a society.

3.1.2 Historical and cultural specificity

Under a social constructionist framework, knowledge is a product of culture and history. To describe something as being socially constructed means the phenomena has gone through a period of development and, therefore, has a history in which social processes have shaped the phenomena into what society thinks of it today (Hacking & Hacking, 1999). Gergen (2009) argued that truth is our current accepted way of understanding the world, which potentially varies over time and across different cultures. For example, a study that explored lay concepts of depression from Anglo-Australian, Ethiopian and Somali communities residing in Australia found that conceptualisations of depression varied cross-culturally (Kokanovic, Dowrick, Butler, Herrman & Gunn, 2008). I recognise that the present study, and therefore the phenomena under study, is being conducted at a particular time in history and within a specific, Western, culture.

Much of an individual's judgement and experience of an illness is influenced by cultural norms and values. Radley (1994) gave the example of common ailments such as a 'cold' and 'flu'. Individuals may suffer from a variety of symptoms such as a headache, sore throat or temperature, but Radley asked "is the individual suffering from a bad 'cold' or is it 'flu'?" (p65). In Western cultures Radley argued that individuals see themselves as responsible for catching a 'cold'. By comparison, individuals think the 'flu' is something that they are unfortunate enough to catch, even though they share a number of common symptoms. Radley's example illustrated how constructs which share similar symptoms are socially constructed into different concepts by society. Therefore, defining a health problem is a social matter involving the interpretation of symptoms within a particular cultural context of norms and values. In relation to the current study, distress may share an overlap of symptoms with depression and anxiety (Geraghty et al, 2015). However, studies have shown that older adults hold stigmatised views of mental health problems (Cornford, Hill & Reilly, 2007; Connor et al, 2010). Wetherall et al's (2010) study proposed that older adults may be more likely to self-identify as distressed, rather than experiencing anxiety and depression. The Public and Patient Involvement and Engagement (PPIE) group which advised this study agreed with Wetherall et al's (2010) conclusions and reinforced that older people hold stigmatised attitudes towards anxiety and depression (see Section 7.2.3.1). This shows that although distress could potentially share an overlap of symptoms with depression and anxiety, the concept has been socially constructed to represent a less stigmatised concept. As the concept is less stigmatised, older adults may be more comfortable self-identifying as distressed.

3.1.3 Knowledge being sustained through social processes

Social interaction is the process in which an individual acts and reacts to those around them (Goffman, 1967). Social interactions are important to social constructionists as knowledge is not seen to be innate within each individual, but formed through interaction with others

(Gergen, 1985). Social constructionists believe that language and thought are inseparable as language provides the basis for all thought (Burr, 2015). Concepts are seen to be mental representations that make up the fundamental building blocks of thoughts and beliefs (Prinz, 2004). Individuals are born into a world where conceptual frameworks already exist. The way a person thinks, and the concepts used, are sustained through language which provides a framework of meaning for all individuals (Berger & Luckmann, 1991). I believe that concepts such as self-management and distress come to exist in the form that they do due to language and social interactions.

Underpinned by social constructionism, the Social Construction Of Technology (SCOT) theory (Pinch & Bijker, 1987) advocates that technology is a product of the social, political, economic, and cultural environment in which it is situated. The SCOT theory suggests that without an understanding of the social context, technology cannot be understood (Burr, 2015). As a research method, the SCOT is mainly used to develop and design technologies (Kline & Pinch, 1996). According to Pinch and Bijker, the SCOT has three underlying methodological assumptions:

1) Interpretive flexibility; this refers to the way in which various groups of people involved in the development of a technology have different understandings of that technology and its technical characteristics.

2) Relevant social group; the development of technology involves different groups of which the individuals of the group have their own meanings and views as to what a certain piece of technology should look like, and so have to come together to negotiate its design. The development process continues until every individual in the group is satisfied with the design.

3) Closure and stabilisation; the design process which includes more than one social group will have disagreements because of the diverse understanding and interpretation of a piece of

technology. Therefore, the design process continues until every member of the different social groups comes to a common agreement.

Whilst the SCOT theory encourages researchers to explore the social context in which a piece of technology is situated, the use of the SCOT theory as a method is inappropriate for this study as the focus is not to design a piece of technology, but to explore older adults' use of the internet to self-manage distress.

3.1.4 Discourse and reality

Ontology refers to the nature and structure of reality and being (Runes, 1984). Ontological questions could be problematic for researchers who identify as social constructionists. Berger and Luckmann (1967) argue that:

> 'Knowledge constitutes the fabric of meanings without which no society could exist. The sociology of knowledge, therefore, must concern itself with the social construction of reality.'

(Berger & Luckmann, 1967: p27)

Some social constructionists claim that nothing exists beyond language. This position is called a 'radical' social constructionist approach and denies any material basis to reality (Elder-Vass, 2012). In contrast, Edley (2001), drawing on Edwards (1997), proposed that when a social constructionist researcher suggests there is 'nothing beyond discourse', they are not making ontological claims. When used ontologically, Edley proposed that social constructionists believe the way in which phenomena takes on a particular form is due to language. I take this ontological view, I do not deny that there may be scientific or objective structures which naturally occur outside the context of language, but such structures are known as they are *because* of discourse. For example, I believe that the internet is a scientific structure but has become known as the 'internet' through language and that an older adult's

perception, and use of the internet, is impacted by social processes and discourse. My ontological views align with a subtle realist approach which assumes that subjective perceptions and experiences do not preclude the existence of independent phenomena (Kirk, Miller & Miller, 1986). Subtle realists assume that there is a real word, an objective reality, but individuals can only know reality from their own personal perspectives of it (Hammersley, 1992).

A social constructionist approach to research overlaps with a critical realist framework (Bhasker, 1989). Similar to a social constructionist approach, critical realism views that an individual's knowledge is historically and culturally situated (Archer, 1998). However, critical realists emphasise the objective nature of reality, they argue that reality is distinct from an individual's conception of it. This contrasts a social constructionist approach which suggests that structures within society are known as they are because of language. As reality is seen as objective by critical realists, Bhasker proposed that researchers who work under this framework distance themselves from qualitative data collection methods. Archer (1998) further proposed that critical realists 'do not uncover real structures by interviewing people in-depth about them' (p1999). As critical realism decreases the importance of language in favour of an exploration of what they believe to be objective structures, I aligned this study with a social constructionist approach.

The terms constructivism and constructionist tend to be used interchangeably and subsumed under the generic term 'constructivism', particularly in Charmaz's (2006) work. Constructivism proposes that every person mentally constructs their world of experiences through cognitive processes (Young & Collin, 2004). In contrast, a social constructionist approach has a social rather than individual focus. I believe that concepts such as distress and self-management are shaped by society and cultural traditions, this aligns with a social constructionist framework, rather than a constructivist approach.

3.2 A qualitative approach

Framed by the research questions, the methods used in the present study needed to be exploratory, therefore, a qualitative approach to data collection was necessary. Under a social constructionist framework, Gergen (1996) emphasized the importance of language and strongly advocated the use of qualitative methods. A qualitative approach to data collection is concerned with understanding meaning and experiences within society, aiming for depth rather than breadth of study (Silverman, 2010). The importance of qualitative data collection methods to explore the complexities which are inherit within social contexts was suggested by Sofaer (1999) who proposed such methods were:

> '…valuable in providing rich descriptions of complex phenomena, tracking unique or unexpected events, along with illuminating the experience and interpretations of participants from various socio-demographic backgrounds.'

(Sofaer, 1999: p1101)

I employed a qualitative approach to data collection as it provided an opportunity for me to explore in-depth how older adults self-manage distress.

3.2.1 Semi-structured Interviews

There are various qualitative data collection methods which could have been used to respond to the research questions, for example: interviews, focus groups or ethnographic approaches such as participant observation. Focus groups are time-efficient as more participants are involved in a single session, however, social pressures could influence individual responses (Gill, Stewart, Treasure & Chadwick, 2008). Some older adults may lack the confidence to speak out against the majority view within focus groups, to prevent this from occurring, interviews would be a more appropriate method for the current study. Older adults could also find discussing their experiences of distress in a group situation uncomfortable, this reinforces

that interviews are a more suitable method for this study. Participant observation is a process which enables researchers to learn about activities that participants engage in within their natural environment, researchers do this through observing and participating in those activities (Spradley, 2016). Although participant observation can yield rich data, conducting several interviews would allow me to gather a range of older adults' experiences of self-managing distress within an achievable time frame.

There are three distinct interview approaches: structured, semi-structured and unstructured (Knox & Burkard, 2009). Knox and Burkard suggested that qualitative researchers should be transparent about the reasons for using interviews, as well as the decisions regarding the nature of the interview. To allow for an in-depth exploration, researchers must be open to new and unexpected phenomena, rather than having ready-made categories and schemes of interpretation (Kvale, 2007). Semi-structured interviews are sufficiently structured to address dimensions of the research questions, but also leave space for participants to offer new meanings to the topic of study (Galletta, 2013). Therefore, semi-structured interviews are the appropriate data collection method for the current exploratory study.

Cachia and Millward (2011) noted that telephone interviews have been widely used to conduct quantitative research, generally for survey methods, but are also being increasingly used in qualitative research. However, face-to-face interviews have long been the dominant interview technique when collecting qualitative data (Vogl, 2013). Face-to-face interviews are characterised by synchronous in-person communication in time and place. Interviews primarily focus on discourse between the researcher and participant, but also permit researchers to read the body language of a participant (Oltmann, 2016). As the current study explores a potentially sensitive topic, seeing the participants' body language could be an

indicator if they feel uncomfortable due to the interview, therefore, it was important that face-to-face interviews were conducted.

Rapport means creating a safe and comfortable environment for participants to share their personal experiences (DiCicco-Bloom & Crabtree, 2006). Researchers could conduct multiple interviews with individual participants which, arguably, would enable them to build up a better sense of rapport. I felt it was more appropriate to conduct a single in-depth interview with an array of participants, this reduces the burden placed upon participants as they are not expected to contribute to the study after the single interview is complete.

3.2.2 Topic guide

Creating an effective topic guide is crucial when conducting semi-structured interviews. The topic guide for the current study needed to be grounded within relevant literature; this ensures researchers develop questions that will generate meaningful data that differs from previous research and answers the specific gaps in knowledge (Jacobs & Furgerson, 2012). For the current study, I devised the questions within the topic guide in line with Turner's (2010) recommendations for creating effective interview questions. Turner suggested that the questions should be open ended, worded clearly and neutral. A PPIE group also provided feedback on the topic guide, as described in Section 7.2.3.2. The topic guide can be found in Appendix 6.

3.2.3 'Think aloud' methods

'Think aloud' methods are used to study how participants understand and respond to materials (e.g. questionnaires, images or videos) presented by researchers (Ericsson & Simon, 1993; Beatty & Willis, 2007). 'Think aloud' methods are typically oriented around a set task and focus on the participants' use of language to talk the interviewer through their thoughts i.e. to think aloud when completing the task (Frøkjær & Hornbæk, 2005). As thoughts are cognitive

processes, some scholars may argue that 'think aloud' methods sit under a constructivist approach to research. However, a social constructionist approach to research asserts that language gives meaning to phenomena and provides the basis for all thought (Berger & Luckmann, 1991). I believe that how we interpret thoughts is influenced by language, society and cultural traditions.

There are two types of 'think aloud' methods, concurrent and retrospective. The former entails that participants 'think aloud' whilst completing a task, the latter requires the participant to complete a task and then reflect upon their thoughts. Wildenbos and Peute (2015) aimed to compare General Practitioners' (GPs) performance when completing concurrent or retrospective 'think aloud' activities. Participants were asked to either concurrently or retrospectively 'think aloud' when reading a new physician data query tool. Wildenbos and Peute found that participants reflected more richly on their thoughts of using the data query tool when retrospectively 'thinking aloud'. In a review of the literature, which mainly included studies which sampled younger adults, Jääskeläinen (2010) found that asking participants to concurrently 'think aloud' could potentially hinder verbalisation. As both Jääskeläinen and Wildenbos and Peute did not specifically sample older adults, the findings are unlikely to be transferable to older people.

Think aloud' methods have become increasingly used in research contexts such as; chronic illnesses, self-management and internet use. Voncken-Brewster et al (2013) aimed to evaluate and improve the usability of an online intervention. Eight people with chronic obstructive pulmonary disease, aged between 51 – 70 years old, were asked to retrospectively 'think aloud' after completing an online intervention. The usability study identified several areas for improvement, confirming the need for usability evaluations during the development of online interventions. Or and Tao (2012) evaluated a new computer-based self-management system

interface for older adults with chronic diseases, using a paper prototype approach. Fifty older

adults were asked to concurrently 'think aloud' when reading the self-management interface.

This study verified the usability of the self-management system developed for older adults

with chronic diseases. Although Voncken – Brewster and Or and Tao's research only focused

on physical chronic conditions, the studies identified that 'think aloud' methods can be used

to explore people's opinions on new, unfamiliar, phenomena. Older adults may not be as

familiar in using the internet when compared to younger generations (Office of National

Statistics [ONS], 2018). 'Think aloud' methods would be useful when exploring the role of

the internet, particularly online forums, in how older adults self-manage distress. Yet, to the

best of my knowledge, no previous studies have used such methods when exploring this topic.

The 'think aloud' activities incorporated within this study included reading a transcript from

an online forum and two storyboards (described below in Sections 3.2.4 and 3.2.5). The 'think

aloud' activities needed to be appropriate for the target sample, therefore, they were created

through discussion with a PPIE group (more details provided in Section 7.2.3.2). Due to the

conflicting views around whether to use 'think aloud' methods concurrently or retrospectively

(Jääskeläinen, 2010; Or & Tao, 2012; Wildenbos & Peute, 2015). I gave participants the

choice of whether to speak whilst completing the activities (concurrent 'think aloud'), or to

speak after they had completed the tasks (retrospective 'think aloud').

3.2.4 Transcript from an online forum

As described in Section 2.7.3, online forums are web-based platforms in which people can

read, post messages and share their views on a particular topic with other individuals, at their

own convenience (Izuka, Alexander, Balasooriya-Smeekens, Mant & De Simoni, 2017). The

increase in internet use within society has permitted online forums to become an important

means of communication (Im & Chee, 2006). An important aspect of online forums is that

messages between users can be archived (Morzy, 2013). Researchers have made use of the

archival capacity through studies employing data mining and analysis of user-created content stored within online forum archives (Weslowski, 2014). In a commentary of the literature, Jowett (2015) found that open-access online forums were seen as useful sources of data for researchers. Open-access online forums refer to such forums whereby conversations are publicly available, Jowett failed to acknowledge the ethical implications of researchers using open-access forums for research purposes. However, open-access online forums did allow researchers to explore everyday conversations about topics for which data might otherwise be difficult to obtain (e.g. stigmatised health problems).

One of the biggest ethical concerns about using online forums in the data collection process is whether the conversations within such forums should be considered public or private. According to Townsend, Wallace, Smart and Norman (2016) queries of whether online postings are public or private are determined by the online setting itself, and whether there is a reasonable expectation of privacy on behalf of the online forum user. A password protected online forum is considered private, whereas an open-access online forum is considered public (British Psychological Society [BPS] 2017).

The Office of Communications (OFCOM; 2018) suggested that there remains a core set of older adults who do not use the internet, therefore it is not anticipated that every older adult may use an online forum to support the management of distress. Instead of using the content within online forums as data, I believed showing a transcript from an online forum in the form of a 'think aloud' activity would encourage participants to discuss why they do, or do not, use such platforms when experiencing distress; the PPIE group agreed (see Section 7.2.3.2). For ethical reasons, I only searched open-access online forums to provide the transcript for the 'think aloud' activity; the postings within these forums where deemed publicly available. I provide a description of how I searched for the transcript within Section 4.2.

3.2.5 Storyboards

Storyboards are materials that describe and explain a story through a series of stills, sketches and animations (Gubrium, 2009). The origin of storyboarding is in the film and animation industry where they are typically used to visualise scenes; the same approach to visualising a story can be used in research. Asking participants to create a storyboard as a data collection method could elicit subjective experiences in an innovative way (Horrocks & Johnson, 2012). Although not in the context of healthcare, Sawhney (2009) conducted a study in which young people living in Palestinian refugee camps developed storyboards to tell their stories. Sawhney proposed that asking participants to create storyboards tapped into a more unique understanding of the participants' lives than what would be discovered by using traditional qualitative methods. Asking participants to create their own storyboards could be viewed as a narrative research method. Narrative methods systematically gather, analyse, and represent people's stories as told by them (Miller & Salkhind, 2002).

Unlike Sawhney's (2009) research, Colucci (2007) contended that showing participants pre-created storyboards, developed by the researcher, triggered people to provide an in-depth account of personal experiences. Colucci argued that asking participants to create their own storyboards may make participants feel uneasy and deter them from taking part in the study. Cross and Warwick-Booth (2016) echoed this argument and synthesised that the main purpose of using storyboards was to create a less threatening, more engaging, atmosphere for participants that supported reflection and confidence to share their thoughts or experiences. The PPIE group which advised this study suggested that distressed older adults may not feel comfortable in creating their own storyboards (See Section, 7.2.3.2). In addition, the Office of National Statistics (ONS; 2018) suggested that older adults may not engage with the internet, asking older people who do not use the internet to generate storyboards on this topic may limit the stories and data produced by such methods. Thus, the current study did not ask

participants to create their own storyboards but used pre-created storyboards as 'think aloud' methods.

Researchers must ensure that pre-created storyboards are suitable for the study and participants. Walsh, Petrie and Zhang (2015) conducted a survey in China to gather feedback on the user needs and requirements related to storyboard scenarios of socialising on social networking sites. Storyboards were chosen as a method because Walsh et al argued that a visual presentation of scenarios helped respondents to identify themselves within a novel situation. Walsh et al found that if the storyboards contained unfamiliar or irritating situations, it caused misunderstandings which distracted participants from the intended meaning of the storyboard. The mean age of the participants within Walsh et al's study was 23 years old, the researchers did not seek advice from people of this age to ensure the storyboards were appropriate for the target sample. The current study used two storyboards as 'think aloud' activities, one which depicted a positive encounter with an online forum, and another which depicted a negative encounter. The storyboards were developed through discussion with a PPIE group, made up of older adults with mood problems. This enhanced the likelihood that the storyboards would be appropriate for the target sample population. More information regarding the development of the storyboards are given within Section 7.2.3.2.

3.3 Data Collection

Within the next section I justify the methods I employed for recruitment and fieldwork.

3.3.1 Sampling strategy

Stigma and attributing symptoms of mental health problems to the aging process, or physical illnesses, may prevent older adults from seeking help from healthcare services for their mood problems (Burroughs et al, 2006; Kovandžić et al, 2011; Chew-Graham et al, 2012; Alderson et al, 2014). Recruiting from the third sector enables access to older adults who may not

present their experiences of distress to their GP. A similar recruitment strategy was used by Steinman, Hammerback and Snowden (2013), and Kingstone et al (2017), to access older adults reporting experiences of depression and low mood.

It is important to select appropriate participants to address the research questions. A purposive sampling technique is the deliberate choice of a participant due to the characteristics of the said participant (Etikan, Musa, & Alkassim, 2016). Whilst purposive sampling is strategic and necessitates an attempt to establish a good correspondence between research questions and sampling (Bryman, 2004; Creswell et al, 2013), iterative sampling involves a process whereby researchers move back and forth between recruiting participants for data collection, and engaging in analysis of the data that has already been generated (Ravitch & Carl, 2015). When employing an iterative approach to sampling, the emerging analysis is intended to shape subsequent sampling decisions (Petty, Thomson & Stew, 2012). In order to locate 'hidden' populations, researchers may also use snowball sampling, this method of recruitment relies on referrals from initial participants to other individuals that fit within the inclusion criteria of a study (Johnson, 2014). I used a purposive and iterative approach to sampling (as described in Section 4.1). I also aimed to encourage snowball sampling to capture older adults who did not attend community groups.

3.3.2 Accessing the field

Gaining access to research sites and participants is unique to each study. Researchers must learn the social structure of a research site to successfully negotiate entry (Seidman, 2013), which in this study was the community groups I recruited from. Feldman, Bell and Berger (2003) suggested that access to research sites is gained by building positive relationships with gate-keepers. A gatekeeper is described as an individual who controls access to an institution or an organisation, they make the decision whether to allow a researcher to undertake the research within that institution or organisation (Jupp, 2006). As part of my preparatory work

prior to the commencement of my fieldwork, I made contact with one gate-keeper who granted me access to community groups which she oversaw, as described in Section 4.1.

When first visiting community groups, Seidman (2013) suggested that researchers should take the time to make an initial contact visit whereby they introduce themselves, and the research, before collecting any data. By making an initial contact visit Seidman proposed researchers are implicitly showing potential participants respect, which aids recruitment and helps to build up a sense of rapport. Rapport has been defined in Section 3.2.1. I made an initial contact visit to each community group I recruited from, more details can be found in Section 4.1.

3.4 Choosing an analysis method

I now justify the methods I selected for data analysis, which was an inductive and iterative process. There are various methods available when analysing qualitative data, a few being: thematic analysis, content analysis or framework analysis; such methods are often driven by either induction, deduction, abduction or retroduction (Blaikie, 2000). Braun and Clarke (2006) described an inductive approach to data analysis as the process of coding data without trying to fit it into a pre-existing coding frame. An inductive approach is used for generating new ideas and concepts, which is suited to exploring phenomenon that have been under-considered (e.g. there is no theory on which to base a deductive analysis). Villaggi et al (2015) conducted the only qualitative study I found which explored the self-management strategies individuals used to manage anxiety. Villaggi et al used deductive framework analysis methods as emerging codes from the data were categorised into Whitley and Drake's (2010) model of self-management. Villaggi et al suggested that the data reflected the importance of the subjective nature of self-management, this is refutable as they imposed Whitley and Drake's model of self-management onto the data which could have limited the exploration of self-management strategies used when experiencing anxiety. It was important

that I used inductive analysis methods, this ensured the findings were strongly linked to the data and offered an authentic reflection of the self-management strategies participants used when experiencing distress.

The research questions in this study were exploratory and the findings needed to be guided by the data. Berkowitz (1997) suggested an iterative analysis consisted of revisiting the data as additional questions emerge, discovering new connections between the data and developing increasingly complex formulations due to a deepening in understanding of the data. The role of iteration is not a repetitive task, but a reflexive process key to sparking insight and developing the meaning of the data (Srivastava & Hopwood, 2009). An iterative approach to data analysis is evident in grounded theory whereby researchers are encouraged to compare and contrast data using the constant comparison technique (Lincoln & Guba, 1985; Charmaz, 2006; Kolb, 2012). The constant comparison technique requires researchers to simultaneously code and analyse the data to develop themes, by continuously comparing codes the researcher refines these themes and explores the relationships between the codes and themes (Taylor & Bogdan, 1984). Elliott and Jordan (2010) suggested that constant comparison begins by comparing code to code. But, as the method progresses, it is an increasingly abstract process of comparing themes to codes and themes to themes. Through the process of comparing themes to codes, a researcher can check to see if further codes fit within the developed theme, and, in doing so, ensure that the themes are capable of accounting for all related codes within the data. By using this method research begins with raw data; through constant comparisons patterns are discovered within the data-set and a substantive representation of the data will emerge (Glaser & Strauss, 1967).

Braun and Clarke (2006) argue that a number of qualitative analysis methods are essentially thematic as they involve searching for themes within the data, but are claimed as other

methods such as discourse analysis or qualitative content analysis (Starks, Brown & Trinidad, 2007; Gee, 2014). Rather than to develop themes which span across participants, the goal of narrative analysis is to understand the meaning of an individual's experience and to keep that individual's story intact by analysing from their story (Riessman, 2008). The 'think aloud' activities used in this study could elicit participant narratives about their own experiences of using the internet to self-manage distress. However, as the ONS (2018) suggested that not all older adults may use the internet, this may limit the stories some older adults would be able to share within the data collection process. Thematic analysis is an over-arching, flexible approach to analysis, which is why I believe it is the most appropriate analysis method for this study.

Methods of analysis should be applied rigorously to the data (Watkins, 2017) and researchers need to be clear and explicit about how they conducted the analysis. I followed Braun and Clarke's (2006) six step guideline on how to conduct thematic analysis, whilst also describing how I incorporated constant comparison methods (Glaser and Strauss, 1967; Lincoln & Guba, 1985). A description of data analysis can be found in Section 4.5.

3.4.1 Saturation

Saturation is a commonly used criterion for when data collection should cease in qualitative studies and can be influenced by data analysis methods. Although the concept of theoretical saturation was first introduced within Glaser and Strauss' (1967) grounded theory methodology, it is now more widely used as a fundamental concept in interview based research (Rowlands, Waddell & McKenna, 2015). Saunders et al (2018) identified four separate approaches to saturation as described in Table 6 (p1900).

Table 6 Approaches to data saturation (Saunders et al, 2018)

Approach	Description

Theoretical saturation	Rooted in traditional grounded theory methodology, uses the development of categories and emerging theory in the analysis process as the criteria for additional data collection
Inductive thematic saturation	Similar to theoretical saturation, but focuses on the identification of new codes or themes and is based on the number of such codes or themes rather than the completeness of existing theory
A priori thematic saturation	Data is collected to demonstrate a theme rather than to develop or refine a theory
Data saturation	Saturation is a matter of identifying redundancy in the data with no reference to the theory. Saturation is distinct from data analysis

I describe my approach to participant recruitment and saturation in Section 4.1.

3.5 Quality in qualitative studies

Numerous methods can be employed to ensure qualitative studies are of a high quality. The traditional methodological criteria for ensuring quality in quantitative research (validity, reliability and generalisability) are generally not applied to qualitative studies due to the different philosophical frameworks, sampling approaches, size of the samples and general aims of qualitative research (Kitto, Chesters & Grbich, 2008). Instead, concepts such as credibility, consistency and transferability are used to judge the quality or 'trustworthiness' of a qualitative study (Henwood & Pidgeon, 1992; Merriam, 2009). I will now explore these three aspects and describe how I will support the quality of my research.

Credibility refers to the conscious effort to establish confidence in the accurate interpretation of the data (Patton, 1999). According to Charmaz and Bryant (2011) ensuring credibility begins by being informed by the literature that studies are asking appropriate research questions, and continues through to the development of appropriate methods for data collection and analysis. Bergman and Coxen (2005) suggested that to enhance the credibility of findings, accurate and clear audio-recordings of interviews must be obtained, this will help

researchers when transcribing and interpreting the meaning of the data. I endeavoured to ensure the data I collected was of a high quality, as described in Section 4.6.

Investigator triangulation, which is the use of multiple researchers within a single study (Carter et al, 2014), could also enhance the credibility of findings. Discussing emerging interpretations of the data with other researchers, or a PPIE group, could widen the vision of a researcher as each individual brings their own experiences and perceptions about the research topic into the analysis process (Shenton, 2004). Carter et al also suggested that an alternative perspective on the data may also challenge assumptions and interpretations made by a researcher whose familiarity with the data may inhibit their ability to view the study with any detachment. I employed investigator triangulation when interpreting the data, this included discussing the findings with both my supervisory team, who were from a range of different academic backgrounds, and a PPIE group who offered a lay perspective on the data.

To enhance the credibility of qualitative findings, researchers should also seek to evaluate the data collection and analysis processes through reflexive practices (Guba & Lincoln, 1989). A reflexive commentary on data collection and analysis monitors the researcher's emerging interpretations, this is critical in establishing credibility as emerging patterns inform overall findings (Berger, 2015). I provide more detail about my stance towards reflexive practices in Section 3.5.1.

In terms of reliability, a positivist researcher employs techniques to show that if the study were to be repeated in the same context, with the same methods and participants, similar results would be obtained (Litwin & Fink, 1995). The acceptance of socially constructed knowledge, and the subjective nature of the phenomena studied by qualitative researchers, renders the concept of reliability as problematic (Marshall & Rossman, 1999). Instead of searching for reliability, qualitative researchers should ensure the findings are consistent with

the data presented (Seale, 1999; Tobin & Begley, 2004). To address the issue of consistency, qualitative researchers should describe the research methods and data analysis process, use investigator triangulation and provide a reflexive commentary which focuses on data collection and analysis (Shenton, 2004). I endeavoured to use these strategies to ensure the consistency of the findings in the current study (see Section 4.6.2).

Transferability refers to 'how well a study's findings inform contexts that differ from that in which the original study was conducted' (Green & Thorogood, 2004: p95). Under a positivist framework, researchers aim to demonstrate that the results of their research can be applied to a wider population (Merriam, 2009). Erlandson, Harris, Skipper and Allen (1993) suggested that as qualitative studies are specific to a small number of participants within particular contexts, the findings and conclusions cannot be applied to other situations or populations. In contrast, Denscombe (2014), proposed that although each participant within a qualitative study may be distinctive, they are also part of a broader group and the prospect of transferability could be applied. Bassey (1981) proposed that if researchers believe situations to be similar to those described within qualitative studies, they may relate the findings to other situations. Lincoln and Guba (1989) proposed:

> 'It is, in summary, not the naturalist's task to provide an index of transferability, it is his or her responsibility to provide the data base that makes transferability judgements possible on the part of potential appliers.'

(Lincoln & Guba, 1989: p319)

Lincoln and Guba suggested that researchers should provide a thick, rich description about data collection processes to enable the prospect of transferability. A thick rich description includes: providing information about the organisations taking part in the study and where they are based, the inclusion and exclusion criteria of participants, the number of participants

involved in the study, the data collection methods employed, the number and estimated length of data collection sessions and the time period over which the data was collected (Shenton, 2004).

Table 7 reports the strategies I used to support the quality of this study (see Section 4.6 for a detailed description).

Table 7 Strategies used to maintain quality

Quality criterion	Methods used
Credibility	Ensuring good quality data was collected, investigator triangulation and reflexive practices
Consistency	Providing a detailed description of methods used, investigator triangulation and reflexive practices
Transferability	A rich, thick description of the study's context

3.5.1 Reflexive practices

Under a social constructionist approach, being reflexive is particularly important as the researcher is seen to directly affect the research process, particularly when collecting and analysing the data. Denzin and Lincoln (1994) proposed:

'Representation … is always self-presentation … the Other's presence is directly connected to the writer's self-presence in the text.'

(Denzin & Lincoln, 1994: p503)

The researcher and their values cannot be disentangled from the research process. Finlay and Gough (2008) suggested that reflexive practices involve self-questioning, self-understanding, laying open pre-conceptions and becoming aware of situational dynamics in which the researcher and participant are jointly involved in.

Social constructionists believe that the data produced within an interview is a product of emergent processes that occur through interactions between the participant and researcher (Charmaz, 2006). This approach is in line with the notion of intersubjectivity which acknowledges the shared experience between researchers and participants (Schwandt, 2001). Charmaz also suggested that researchers cannot maintain a detached objective position when analysing interview data as such data is a product of interactions between the researcher and participant.

Reflexive practices provide an opportunity for revising and re-framing the findings as they unfold (Ibrahim & Edgely, 2015). As an iterative process between data collection and analysis was utilised, reflexive practices enabled me to modify certain data collection methods (e.g. the topic guide) in light of emerging findings. As described in Section 3.5, being reflexive is also a way to indicate quality in data collection and analysis as researchers seek to make sense of their influence over the research process (Jootun, McGhee & Marland, 2009). I believe reflexive practices are necessary to unpick how I affected the data collection and analysis. I completed a reflexive diary after each interview, examples of these can be found in Appendices 10a and 10b.

Summary

In conclusion, this methodology chapter has set the scene between theory and methods. I described my philosophical beliefs, which are closely aligned to a social constructionist approach to knowledge formulation. I justified why I adopted a qualitative approach and explained why I selected semi-structured interviews incorporating 'think aloud' methods. I also justified my approach towards data collection and analysis. I then explored strategies to maintain quality throughout qualitative studies. The next chapter will report how I applied the methods.

Chapter Four: Methods

Introduction

In this chapter I describe how I applied the methods discussed in Chapter Three and how I used these to address the research questions, which are:

1) How do older adults self-manage experiences of distress?

2) What is the role of the internet, particularly online forums, in how older adults self-manage experiences of distress?

As described in Section 3.2, a qualitative approach to data collection and analysis was adopted due to the exploratory nature of the research questions. I begin this chapter by describing participant recruitment and then report how I found a transcript from an online forum to use as a 'think aloud' activity. Next, I describe data generation and discuss ethical considerations. Following this, I report how I analysed the data and conclude the chapter by describing the strategies used to maintain quality throughout the study.

4.1 Participant recruitment

I recruited distressed older adults from community groups as older people may not seek help from healthcare services when experiencing mood problems. I obtained ethical approval from Keele University's Ethics Review Panel in September 2016 (ERP1279, see Appendices 1a and 1b). I commenced recruitment in the same month. I stated in my ethics application that I would be recruiting from community groups around North Staffordshire, as opposed to National Health Service (NHS) sites, so NHS research ethics committee approval was not required.

My study adopted an iterative approach between data collection, analysis and recruitment; this allowed me to alter these methods in response to the data being collected and enabled me to

search for heterogeneity in terms of the participants' demographic profiles. I now describe the

process of recruitment, beginning with an explanation of the inclusion and exclusion criteria.

It was necessary that the sample consisted of older adults who self-identified as experiencing

distress, the inclusion criteria were:

- Sixty-five years of age or over

- Self-identified as currently experiencing distress (e.g. feeling low or stressed), or had

  experienced distress within the previous twelve months

The exclusion criteria were:

- Did not have the capacity to give informed consent

- Did not speak English

The ethics documents (e.g. consent form and information leaflet) were in English, therefore

knowledge of the English language was required for informed consent to be obtained. In order

for participants to be interviewed, they also had to speak English as I did not have access to

funds for use of interpreters to translate the interviews.

I discussed potential recruitment sources with my supervisory team, a Public and Patient

Involvement and Engagement (PPIE) group and searched the internet for local community

groups. I identified groups in North Staffordshire which I felt would provide access to older

adults. As previous research had recruited older people experiencing depression and low

mood through community groups (Steinman, Hammerback & Snowden, 2013; Kingstone et al

2017), I anticipated some older adults attending community groups could be experiencing

distress, or had experienced distress within the previous twelve months.

All of the community groups I targeted were organised by the same third sector charity, Age

UK, and overseen by one gate-keeper (see Section 3.3.2 for definition of a gate-keeper). I

contacted the gate-keeper of the charity via email, I attached a letter explaining why I had

contacted her and an information leaflet about the study (See Appendices 2 and 3). The gate-keeper contacted me by telephone and, following discussion, granted access to the community groups overseen by the third sector charity. During the telephone call the gate-keeper directed me to certain community groups which were attended by older adults she thought would most likely participate in the study. Together we devised a schedule of when I would attend three community groups. The gate-keeper accompanied me to the first 'contact visit' of each community group, these visits took place between September 2016 and January 2017. The gate-keeper also introduced me to 'intermediate' gate-keepers and members of the community groups. Wanat (2008) described intermediate gate-keepers as individuals who do not have the power to grant access to research sites, but who do hold positions of responsibility in the said research sites. In this study, intermediate gate-keepers were volunteers who oversaw each community group on a weekly basis when the gate-keeper could not attend. Intermediate gate-keepers were in a unique position in that they were responsible for leading group activities, but also had informal relationships with potential participants. Intermediate gate-keepers introduced me to potential participants and showed me the activities participated in by community group members (e.g. knitting, art and crafts, low mobility exercises and computer activities).

Within the contact visits I introduced myself and the research and then distributed information leaflets to community group members. Once I had distributed information leaflets, I participated in the community groups' activities to build rapport with potential participants. After engaging in the group activity, I collectively asked group members if they would be interested in taking part in the study. Due to the sensitive nature of the study potential participants may not have wished to self-identify as experiencing distress, or having experienced distress in the previous twelve months, in front of their peers. I provided my contact details on the information sheet (see Appendix 3), and told group members that they

could contact me if they wished to participate in the study and subsequent interview arrangements could be made. All participants expressed the wish to participate in the study within my contact visits or during subsequent visits to the community groups. After each contact visit, I attended the community groups on a weekly basis for between six to eight weeks, even when no interview was scheduled, this aided recruitment as I became increasingly familiar to group members.

I used a purposive and iterative sampling strategy to recruit a range of participants from different demographic backgrounds as literature proposed that individuals self-manage within their own, unique, social context (Miller, Lasiter, Ellis & Buelow, 2015). I recruited participants with a range of ages, this was important as older adults may self-manage differently as their age increases (Nicholas et al, 2016). I also recruited participants who lived in both urban and rural areas. Individuals who live in rural areas are less likely to have access to internet services, specifically broadband (Office of Communications [OFCOM], 2016), this is especially pertinent to the current study as rural communities have an older age profile than urban communities (Department of Environment, Food and Rural Affairs, 2018). Older adults who live in rural areas may have different experiences and perceptions of using the internet as a self-management strategy of distress. Defining what constitutes an urban or rural area is complex. Bibby and Brindley (2013) described large towns, with a population of over 10 000 people, and cities as urban areas; rural comprises the areas outside of those described as urban (e.g. small towns [fewer than 10,000 people], villages or hamlets, and all the spaces between). Although some researchers recognise urban and rural areas are at either ends of a continuum, for clarity I used Bibby and Brindley's boundary of a population of 10 000 people to distinguish between an urban or rural area within the present study.

I sought to include both retired and employed older adults within the study. Older adults who are retired, compared with those who are employed, may self-manage distress differently due

to financial resources. Age UK (2018) reported that 1.13 million older adults aged 65 and over were still in employment. Cremer and Pestieau (2003) found that retirement resulted in a lower income and increased the likelihood of older adults falling below the poverty line. Osberg (2001) proposed that living below the poverty line is when an individual cannot afford the necessities in life (e.g. food, clothing and housing), this may contribute to an older adult's experience of distress. Despite most of the community groups being attended by retired older adults, as data collection progressed I specifically targeted employed older adults and two participants who worked part-time were recruited (see Table 9, Section 5.1).

I also recruited a mixture of both male and female older adults. Addis (2008) and Hoy (2012) identified that men self-managed their mood problems by over-working or drinking alcohol to distract them from their problems, females may not self-manage in this way. At the start of this study's recruitment phase, only female older adults agreed to participate. As recruitment continued I made a concerted effort to sample male older adults to increase the diversity of the sample. After discussion with the gate-keeper, I made a further two contact visits to community groups which taught computer and internet use; these groups had the most male attendees. I recruited seven male older adults to the study (see Table 9, Section 5.1).

I tried to encourage snowball sampling (Johnson, 2014) to capture older adults who did not attend community groups. I asked community group members to give information leaflets to their friends who may be interested in taking part, however this was not fruitful. By the end of March 2017, eighteen participants had been recruited and I felt that saturation had been reached. As I used thematic analysis with constant comparison techniques (see Section 4.5), the approach I took towards saturation aligns with inductive thematic saturation (see Table 6, Section 3.4.1). I ceased recruitment when I believed no new codes or themes were being generated within the interviews. Although no new codes were identified when saturation was reached, there is always the possibility that additional participants might have contributed

different data than the older adults who were recruited, this is discussed as a limitation in

Section 8.3.2. However, the sample was diverse in terms of sex, age, marital status, retirement

and living location (e.g. urban or rural areas). The participants' demographic information can

be found in Table 9 (see Section 5.1). A diagram of the process of recruitment can be found in

Figure 3.

Figure 3 Process of recruitment

Set inclusion criteria
1) Sixty-five years old or over
2) Self-identified as currently experiencing distress, or had done within the previous twelve months

Identify sources of recruitment
Supervisory team, PPIE group, Internet searches

Community groups ran by third sector charity
Made contact with gate-keeper and developed a plan of when to attend five community groups

Recruitment
Gate-keeper accompanied me to a contact visit at each of the community groups. I continuously returned to each community group to sample participants and to build up rapport

Data Collection
Conducting semi-structured interviews following ethical procedures

Data Analysis
Taking emerging analysis into account and turning to different community groups to seek a range of demographic backgrounds and experiences

End of recruitment
Saturation had been reached

4.2 Finding a transcript from an online forum

'Think aloud' activities were incorporated into semi-structured interviews to collect the data.

To find a suitable transcript from an online forum to be used as a 'think aloud' activity, I

searched the internet to find open access online forums in which older adults experiencing

distress may have participated. I searched Google by using terms such as: 'distress', 'older

adults', 'online forums' and 'discussion sites'. I found no online forums which focused on

older adults experiencing distress. I changed my search strategy to include terms such as

'depression' and 'anxiety'. I found one open-access online forum in which an individual self-

reported that they were 63 years old and experiencing depression (Sixty-three years old and

depressed, 2011, http://www.cure-your-depression.com/63-years-old-and-depressed.html).

The individual received advice from several other users within the online forum. I took a

transcript from this online forum and anonymised any identifiable information (e.g. names or

place names). I then showed this transcript to a PPIE group. The PPIE group suggested that

within the interviews using the transcript as a 'think aloud' activity would elicit discussion on

using the internet, and online forums, as a self-management strategy of distress. The transcript

can be seen in Appendix 8.

4.3. Data generation

I now describe the process of the interviews, including the use of a topic guide and 'think

aloud' methods.

I conducted all interviews between September 2016 and March 2017. Semi-structured

interviews were used to generate data, being sufficiently structured to address dimensions of

the research questions whilst allowing participants to offer new meanings to the topics under

study. Although participants were given a choice of preferred venue in which to be

interviewed (within the community group building or at home), all participants chose to be

interviewed within a private room at the building where the community groups were held.

Permission was obtained from the organisations which owned each of the buildings. Although I anticipated that each interview would last one hour, I ensured each private room was available for two hours to allow for plenty of time.

I wanted to be certain that participants knew what to expect within the interview and how the data would be subsequently used. Throughout the information leaflet, contact visits and following visits to community groups, I explained what the interview would entail. Before each interview commenced I restated the purpose of the interview, addressed terms of confidentiality, described the format of the interview, indicated how long the interview would approximately take, informed participants on how to contact myself at a later date (which was again highlighted at the end of the interview), asked participants if they had any questions and then obtained written informed consent.

To aid the interview I used a topic guide, which was a list of questions and prompts to be covered within the interview. The order of the prompts, and the time spent on each question, was dictated by the participants. Within the topic guide there was time allocated for the introduction of the 'think aloud' activities, which aimed to elicit discussion about the role of the internet as a self-management strategy when experiencing distress. The 'think aloud' activities particularly focussed on online forums. A description of an online forum was provided along with an example of an online forum via a laptop. The example of an online forum was taken from the Talk Mental Health forum which is run by the Talk Health partnership (2016, https://www.talkhealthpartnership.com/forum/viewforum.php?f=111), this ensured that participants were aware of what an online forum was. Participants were asked to read and comment upon a transcript from an online forum and two storyboards. I liaised with a PPIE team to develop the storyboards, see Section 7.2.3.2, and provide a description of how I found a transcript from an online forum in Section 4.2. Participants were given the choice to

concurrently discuss the 'think aloud' activities whilst they were reading the material, or to retrospectively discuss the 'think aloud' activities after they have read the material.

After each interview finished, I transcribed the audio-recordings and read the transcript before conducting anymore subsequent interviews. I also reflected on the topic guide and 'think aloud' activities. As data collection and analysis was iterative, I integrated supplementary prompts or questions into the topic guide to allow for emerging areas or themes to be explored in more detail. I also regularly liaised with my supervisory team to discuss the emergent data, the 'think aloud' activities and any modifications to the topic guide.

4.4 Ethical considerations

As the research explored a potentially sensitive topic area, ethical considerations were of the upmost importance. Participants could have been emotionally vulnerable, one way of safe-guarding them was the method of recruitment; participants were known to a recognised third sector charity and the gate-keeper was aware of my contact with members of the community groups. I invited participants to share information about the study with a relative or friend before deciding whether to participate. I also gave each participant the choice to choose when and where they wished to be interviewed to ensure they felt comfortable.

The contact visit was particularly important for ethical reasons as it arguably initiated the process of informed consent. Although I did not show the consent form within the contact visit, I did describe aspects of the form. I explained that the interview would be confidential, the data gathered would be pseudo-anonymised (e.g. their names and any names or locations mentioned within the interview would be changed) and I also stated that participants had the right to withdraw the data up to three months after being interviewed. The contact visit also allowed me to become familiar with the research setting and to ensure a private room was available for the interviews to take place within.

To meet ethical requirements participants had to be given at least 24 hours to decide if they wished to participate in the study. Each community group was held on a weekly basis meaning that every interview was at least one week after the participant had registered an interest to participate and an interview was scheduled. This gave participants time to re-read the information sheet, to decide if they wished to take part in the study, to discuss the study with family and friends, or to contact me if they had any questions.

Gaining fully informed consent was a vital ethical consideration. I did not interview anyone who did not have the capacity to consent (e.g. an older adult with cognitive impairment). The gate-keeper who ran the community groups told me about two older adults suffering from dementia, however these older people did not seem interested in participating in the study. Cognitive capacity was presumed in accordance with the Mental Health Act (2005). I asked participants to tell me details of the study before the interview commenced to ensure information had been retained. Participants were asked to provide consent for the study, and for the use of quotations within outputs of the study, in written form. Participants were made aware of the burden being placed upon them through participating in this research (such as time involved) and were not only encouraged to ask questions at key moments in the research (such as before giving consent), but also generally throughout the whole process. I ensured each participant knew that they were free to agree or refuse to participate and could stop the interview at any time. I also took the contact details of Healthy Minds, a service which provides a range of treatments and support options for people struggling to manage distress. I was also prepared to encourage participants to make an appointment with their GP should the participants have needed or wanted further information, advice or support. I debriefed each participant after each interview highlighting again how the data was going to be used and that they had three months to withdraw their data after the interview, if they wished to do so. I also

adhered to the Research Institute for Primary Care and Health Sciences' (RI's) lone worker policy when conducting the interviews (see Appendix 9).

Exiting the field was also an ethical consideration. As I attended the same community groups weekly for between six to eight weeks, I had established rapport with participants and other members of the community groups. It was important that community group members were made aware of when I was going to stop attending the community groups. I told the members of each group, the gate-keeper and intermediate gate-keepers my expected time-frame and number of meetings I would be attending.

Data from the interviews were pseudo-anonymised by removing each participant's name and replacing it with a unique participant number to protect their identity. When participants identified other individuals or places during interviews, these were also changed. I first replaced the participants' name with a participant number, the interview data was stored under these numbers for each participant. During the analysis process the participant number was replaced by pseudonyms, I selected names alphabetically to keep the chronological order (e.g. participant One was replaced with a name beginning with A). I selected the names by searching a name database for the most popular names at the time that participants were born and through discussion with my supervisors. Names were chosen to be culturally appropriate, I did not include a name beginning with the letter Q as no names beginning with this letter were thought to represent participants.

To meet ethical requirements the Keele Clinical Trial Unit's data security policy and procedures were incorporated into the process of data management. Paper-based field notes and consent forms were stored in a locked filing cabinet. The audio-recordings were transferred and stored securely in a password protected folder on the RI's networked server at Keele University and deleted from the audio-recorder. I converted the audio-recordings into

electronic formats through transcription, this enabled me to use NVivo 10 to organise and analyse the data. The NVivo 10 file was password-protected.

4.5 Data analysis

Thematic analysis (Braun & Clarke, 2006), incorporating constant comparison techniques (Lincoln & Guba, 1985), were used to analyse the data. The data generated by the 'think aloud' activities was not treated as a separate data set. The analysis was not a linear process where I simply moved from one step to the next. It was a recursive process whereby I moved back and forth as needed, particularly when developing codes and themes. The process of data analysis commenced when I began data collection, I started to code and search for potential patterns within the data. Data analysis ended when I wrote up and reported the content and meaning of themes that emerged from the data set. Analysis involved a constant comparison between each interview transcript, the data set, the coded extracts of the data and the analysis of the data that I was producing. Table 8 explains how I utilised Braun and Clarke's guidelines (p35), whilst also incorporating constant comparison methods.

Table 8 Process of data analysis

	Description of analysis
Step One	The first step was to immerse myself within the data, I did this through transcription. Transcription was an important part of the analysis as it transformed the audio-recordings to textual format. According to Braun and Clarke (2006) transcription involves a rigorous and thorough 'verbatim' account of all the verbal and sometimes non-verbal utterances (e.g coughs and laughing). This was the method I followed. I transcribed the audio-recordings of each interview, by doing this I started to identify links, connections and patterns both within and between the interviews. Transcribing the interviews myself also allowed me to control the quality of the transcription produced. Subsequent to transcribing the data, Braun and Clarke (2006) argued that researchers should immerse themselves within their data so that they are familiar with the breadth and depth of the content, this includes repeated 'active' reading of the data. I 'actively' read the transcripts by searching for meanings and patterns inherent within the data. I read each interview transcript at least once before I began any coding, my ideas and identification of possible patterns were shaped as I read the whole interview transcript. I also made notes about any hunches I had about the data. This step was time consuming, however, I needed to be fully immersed within the data for further analysis.
Step Two	The second step began when I started to produce initial codes. A code identified a feature of the data that appeared to be interesting to me in relation to the research questions. Braun and Clarke (2006) described codes as a basic element of the raw data. I coded the transcripts on a line by line basis and used Nvivo 10 to assist this process, I was able to create a node for each code devised. I coded for as many patterns as possible and kept some of the surrounding data to ensure context was not lost. I drew upon constant comparison techniques as any newly collected data was compared with previous data. This process was iterative, codes and developing themes were later formed, enhanced, confirmed or discounted as a result of any new data which emerged from the study.
Step Three	Once I had a number of transcripts and a substantial list of codes, the third step began and I started to focus the analysis on broader levels of themes. I began to consider how various codes combined to form an overarching theme. I used a thematic map to start thinking about relationships between the codes and themes. Many initial codes went onto form themes, others were placed to one side for later consideration or consolidation. I also had codes that did not fit into any main themes. At the end of this step I had a collection of themes, sub-themes and extracts of the data that had been coded in relation to the themes and sub-themes. I liaised with my supervisory teams to discuss the codes and emerging themes.

Table 8 Description of analysis continued

Step Four	Next, I began to refine the themes. There were two levels of reviewing and refining the themes. The first level involved reviewing the coded extracts for each theme by reading the collated extracts and considering if they formed a coherent pattern. If the collated extracts did form a clear pattern, they were integrated into the second level of reviewing. If the codes did not present a coherent pattern within the theme, I considered whether the theme itself was problematic or if the code simply did not fit into the theme, in which case I either re-worked the theme, created a new theme or discarded the theme from analysis. I then created a new thematic map of the overall data set. The next level of reviewing and refining the themes involved a process similar to the first level, but was relative to the entire data set. At this level I considered each theme in relation to the whole data set and deliberated if the thematic map accurately reflected the meanings within the data set. I discussed the thematic map with my supervisory team and a PPIE group (See Section 7.2.3.3). After this I re-read the entire data set, the reason for this was twofold; to reassert that the themes worked in relation to the data set and to code any additional data that had been missed at earlier coding stages. I also reviewed any codes that were not within a theme, I either integrated them into a refined theme or discarded the codes. I again refined the thematic map in line with the refined codes and themes. I also discussed the altered thematic map with my supervisory team. I stopped coding when my refinements were not modifying the themes. At this point I was fairly confident in the themes. I also created visual representations of the data to show the nuances in how individual participants self-managed their experiences of distress, examples of these can be seen in Figure 5 and 6.
Step Five	I then organised each theme into a coherent account, with accompanying narrative, thus creating a data analysis document. Within the narrative I identified the 'story' of each theme and considered how each theme integrated into the broader 'story' of the data set. At the end of this step I had clearly defined and wrote about each theme.
Step Six	The final step involved the final analysis and write-up of the results. This consisted of agreeing the name of each theme with my supervisory team. Chapter Five and Six document the write-up of the analysis.

4.6 Maintaining quality

The quality criterion I focused on to enhance the trustworthiness of the findings were:

credibility, consistency and transferability.

4.6.1 Credibility

To ensure the credibility of the findings, I ensured I collected high quality data, used investigator triangulation and was reflexive throughout the research process, particularly data collection and analysis.

4.6.1.1 Data quality

To collect high quality verbatim data, I ensured clear audio-recordings of the interviews were obtained. Each interview was conducted in a private room, the only people present were myself and the participant; this ensured the audio-recordings did not pick up any external noise irrelevant to the interview. I also carefully transcribed each of the audio-recordings and checked the written format against the recordings numerous times.

4.6.1.2 Investigator triangulation

I employed investigator triangulation as multiple researchers were involved in analysing the data. Throughout the analysis process I met with my supervisory team which included an academic GP with expertise in qualitative methods (CCG), an anthropologist (HB), and a research associate in the field of mental health (TK). After I had conducted the first interview I met with CCG and HB to discuss the interview transcript, any potential modifications to the topic guide and the participant's engagement with the 'think aloud' methods. I also received feedback on my interviewing technique. I then met with my supervisory team at least once a month and had interim meetings with HB to explore the data, modifications to the topic guide, data discrepancies and to discuss the developing thematic maps. My supervisory team had in-depth knowledge about the research process which was helpful in generating ideas for further coding and advancing my interpretations of the data. I also discussed the findings with a PPIE group (See Section 7.2.3.3). When my supervisory team and I thought that saturation had been reached, participant recruitment ceased.

4.6.1.3 Reflexive diaries

The importance of reflexive practices was described in Section 3.5.1. After each interview, I documented my experiences, opinions, thoughts and feelings on the interview in a reflexive diary. I tried to be critical of both myself and the methods. I continuously thought about how my own actions may have shaped the data, examples of these reflexive diaries can be found in Appendices 10a and 10b.

4.6.2 Consistency

To ensure the findings were consistent with the data, I have provided a detailed description of the methods used to conduct this study within this chapter, used investigator triangulation (See Section 4.6.1.2) and kept reflexive diaries (See Appendices 10 a and 10b).

4.6.3 Transferability

The findings from the current research may be transferable to other distressed older adults. In line with Shenton's (2004) definition of a thick, rich description (see Section 3.5), I provided a description of the organisation I recruited from and where this was based in Section 4.1, I also detailed the inclusion and exclusion criteria within this section. I reported the data collection methods, and the time period over which the data was collected, in Section 4.3. The number and length of interviews are described in Section 5.1.

Summary

This chapter states the methods I used to conduct the study. I described participant recruitment, how I found a transcript from an online forum to use as a 'think aloud' activity, data collection, ethical considerations and data analysis. I also discussed the strategies I used to maintain quality throughout the study. The next chapter will be the first of two chapters in which I report the study findings.

Introduction

This chapter responds to the first research question and explores how older adults understand and report managing distress. I begin the chapter with a description of the participants' demographic and self-reported health information. I then present the findings in detail with visual representations of the analysis to support the understanding of the data. I conclude the chapter with a philosophical reflection.

5.1 Participant characteristics

To contextualise the findings, Table 9 illustrates the participants' demographic background and provides details about their health information. Eighteen participants took part in interviews which lasted between 44 and 92 minutes (mean 63 minutes). All participants were White British, reflecting the composition of the community groups I recruited from.

Table 9 Participant demographic and health information

	Gender	Age	Retired	Marital status	Urban/ rural	Lives alone/ lives with	Self-reported physical health problems	Self-reported label of a mental health problem from a GP
Anne	Female	88	Yes	Widowed	Rural	Alone	Diabetes, osteoporosis, recovering from hip replacement	No
Barbara	Female	72	Yes	Married	Urban	Husband	Stroke	No
Carol	Female	77	Yes	Widowed	Urban	Alone	Breast cancer (in remission), recovering from hip replacement, broken wrist and rib, bladder problems	Depression
Diane	Female	87	Yes	Widowed	Urban	Alone	Recovering from hip replacement, actinic keratosis	Anxiety
Elizabeth	Female	79	Yes	Widowed	Rural	Alone	Arthritis, COPD, recovering from hip replacement	No
Frances	Female	65	Yes	Married	Urban	Husband	Arthritis, high blood pressure	Depression
Gill	Female	72	Yes	Married	Urban	Husband	Heart murmur, stroke	No
Helen	Female	87	Yes	Married	Urban	Husband	Sleep apnoea, benign brain tumour	Anxiety
Irene	Female	77	No	Married	Urban	Husband	None	No

Table 9 Participant demographic and health information continued

	Gender	Age	Retired	Marital Status	Urban/ rural	Lives alone/ Lives with	Self-reported Physical health problems	Self-reported mental health problem
Janet	Female	69	Yes	Married	Urban	Husband	Arthritis, COPD	No
Kathleen	Female	67	Yes	Married	Urban	Husband	Burst ear drum, awaiting small bowel resection	No
Leslie	Male	69	Yes	Married	Rural	Wife	Broken ankle, high cholesterol	No
Michael	Male	91	Yes	Married	Urban	Wife	Minor hearing loss, glaucoma	No
Nigel	Male	80	Yes	Married	Urban	Wife	Recovering from heart surgery	No
Owen	Male	68	Yes	Married	Urban	Wife	Diabetes, high cholesterol	Depression
Peter	Male	65	Yes	Widowed	Rural	Alone	None	No
Robert	Male	77	No	Divorced	Rural	Son and daughter-in-law	Arthritis, COPD, awaiting shoulder and spinal surgery	No
Stephen	Male	88	Yes	Married	Urban	Wife	COPD, recovering from heart operation	No

Table Notes: All ages reported at time of participation, participants self-reported receiving a label of a mental health problem from a General Practitioner (GP) within past 12 months, classification of urban and rural areas described in Section 4.1, COPD – Chronic Obstructive Pulmonary Disease

5.2 Findings

From the analysis described in Section 4.5, the following themes are reported in this chapter: the experience of distress, actions taken, help-seeking from healthcare services and perceptions of treatments offered in primary care. A table of the analysis and thematic maps can be found in Appendices 11c, 11d and 11e. Illustrative data are presented to support the interpretation and are identified by participant pseudonyms; it is also noted if data extracts were generated during the 'think aloud' activities. I sensitively edited some extracts of the data to ensure anonymity and readability, I took care to ensure the meaning of the data was not altered during this process.

5.3 The experience of distress

The inclusion criteria, as described in Section 4.1, insisted that participants must have self-reported as experiencing distress currently, or within the last 12 months. During each interview, I explored how each participant conceptualised their distress.

When describing their mood problems participants drew upon a variety of terms, including feeling "*low*", as described by Gill:

> *"I think what has made me low lately is erm … I've become very breathless and erm two years ago I had a mini-stroke and they put me on Warfarin and then six months ago at the hospital they took me off it."*

(Gill)

Participants often linked their experiences of distress with suffering from physical health problems, this was also illustrated by Carol when using the term "*stressed*" to describe her experiences of distress:

"I have had two hips done, breast cancer and I erm, problems with my bladder, I've

also broken a wrist and broken a rib so yes I could say I've been stressed out."

(Carol)

Six participants used the term "*stressed*" to describe their mood problems. Some participants

also used the term "*worry*" to describe their experiences:

"I worry, I tend to keep things back yeah … I do tend to keep things back but erm I

worry."

(Elizabeth)

Terms were often used in combination to describe distress, Leslie suggested that older adults

would view distress as feeling "*a bit run down*" and "*low*":

"I think that they'd think that they're just a bit run down and feeling a bit low and that

they'd just get on with it."

(Leslie)

A small number of participants also described their distress as temporary by using the term

"*off days*":

"I can only say how I feel and I do have my off days but then I just do something, I

think it was how you're brought up when you're young because I was brought up

through the war years."

(Elizabeth)

Elizabeth suggested that her experience of distress fluctuates from day-to-day.

When describing their experiences of distress two participants described feelings of anger in

relation to family situations. Irene reflected upon a recent time when she was told her son,

who suffered from Schizophrenia, should not live with her:

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"I found that very difficult to deal with and then one day, one of the doctors, when we had the meetings said 'it is the worst thing you could do, is having him living with you because he will never learn independence, not that you would do everything for him, but he needs to learn to live independently' and (sigh) I was just so cross, so angry, but the more I thought this is right, and erm, and then it was trying to get my son round to erm, to that, that was very stressful."

(Irene)

Irene suggested that determining the best way to care for her grown-up son contributed to her experience of distress.

When experiencing distress, three participants disclosed seeking help from a General Practitioner (GP) and reported receiving a label of depression, these participants used terms such as "*depressed*" to describe their mood problems:

"I went to the doctors and I said, 'I don't feel very well and I don't know why' and he said 'I think you're affected by stress, you're depressed' and I said why? And he just put me on these tablets."

(Owen)

Two participants consulted a GP who labelled their experiences of distress as anxiety, Helen described this in the following way:

"Fortunately when I went to the doctors and he said I was anxious, it was only short-term anxiety, it didn't go on and on and on."

(Helen)

Helen did not anticipate that her anxiety would persist long-term, instead her mood problem represented a temporary episode and a short-term state. After consulting a GP, participants

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who had received a label of a mental health problem conceptualised such problems as medical conditions:

> *"I mean depression is an illness and until you suffer with it you don't think it is, no, I mean years ago I wouldn't have thought it was an illness but it is, it is changing times."*

(Frances)

By using the phrase "*changing times*" Frances is suggesting that the conceptualisation of mental health problems is shifting, and that such problems were not perceived as medical condition in the past. Only participants who had received a label of depression or anxiety from a GP freely used terms such as "*anxious*" or "*depressed*" when discussing their own mood problems. Most participants, who did not consult a GP for their mood problems, suggested that they do not wish to be labelled as experiencing mental health problems due to stigma:

> *"Still some stigma, I wouldn't want to be seen as having a [mental health] problem like that, no, but erm, and people will say 'pull yourself together'."*

(Kathleen)

Although participants who did not consult a GP did not identify their own experiences of distress using terms such as "*anxious*" or "*depressed*", they did use these terms to describe other older adults' mood problems, as alluded to by Anne when reflecting upon her late husband, Alf's, mental health problems:

> *"Well one of [Alf's] friends, he used to come up because he had had problems, his wife had died and he used to come and talk it over with [Alf], who was depressed, and [Alf] felt as if he was helping him then so that helped [Alf], does that make sense?"*

(Anne)

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This section has identified that participants gave meaning to their distress through language and used a variety of terms to describe their experiences.. Participants with, or without, a label of a mental health problem drew upon a variety of other terms such as: "*low*", "*stressed*", "*worry*", "*run down*", "*off days*", and "*anger*" to describe their mood problems.When discussing their own mood problems, the terms "*depressed*" or "*anxious*" were only used by participants who had received a label of anxiety or depression from a GP. This shows that the meaning of these participants' distress where developed through communication between a GP and themselves, highlighting the importance of social processes in participants' understanding of mood problems. Participants without a label of anxiety and depression used these terms to describe other older adults' mood problems, which shows that these terms were in their vocabulary. However, these participants did not describe their own experiences of distress using these terms. This could be because these participants held stigmatised attitudes towards mental health problems.

In the next section I will describe how participants attributed their experiences of distress to various forms of loss.

5.3.1 Impact of loss

All participants reported attributing their experiences of distress to some form of loss, one being the loss of a job, through retirement, as described by Janet:

> *"You know you think retirement is going to be this wonderful thing but it really isn't unless you're prepared for it you see … I just decided to take early retirement, no preparation, I think if you prepare for it, it is so much better, so it was when I realised I had nothing to do and I was sitting at home."*

<div align="right">(Janet)</div>

Most retired participants reported being unprepared for the amount of free-time that retirement afforded. A few participants also described that their previous employment had given them a sense of enjoyment:

> *"After retirement and at first when I retired, because I enjoyed the job meeting them many people, it was hard, it was difficult, as I say you knew all the secretaries they knew you and they just let you get on with your job, and obviously you had to be certain places like when taking the meals to the wards and stuff and you had to be a certain places at certain times, but the rest of the time you were fetching and carrying people and it was a complete pleasure."*

(Leslie)

Most participants who were retired reflected positively on their previous employment as it often provided an opportunity for them to socialise with other employees and members of the public, retirement took this opportunity for social contact away.

Sixteen participants disclosed suffering from various physical health problems, as described in Table 9. Participants reported that physical health problems caused a loss of physical mobility:

> *"I've had my hips done, I've got arthritis in my back so that limits my walking."*

(Elizabeth)

A loss of physical mobility prevented participants from engaging in usual activities with their peers:

> *"Me and [Olive] have been friends twenty-odd years and we met at the shop I worked in in the market, she was the first person I worked with there, yeah and we've stayed friends ever since and before I had bad knees we used to do a lot of walking."*

(Gina)

A few participants reported that a loss of physical mobility had resulted in them becoming isolated within their homes:

> *"I have recently err last year, had a fracture on my hip and the err, fractured the femur so I was in the house for ... from October to March without going out."*

(Anne)

After undergoing hip surgery, Anne also discussed that her friends struggled to visit her at home:

> *"People were very, a lot of people around me are elderly and I live up steps, like this (shows steep angle with arm) and they don't like coming up the steps."*

(Anne)

Anne described being housebound, which led to social isolation further compounded by friends who themselves had a lack of physical mobility. Along with participants' own loss of mobility, participants also attributed experiences of distress to a spouses' loss of physical mobility:

> *"My husband had sciatica for two years, for the first four months he didn't move out of the chair except to go to the toilet and back, I had to take his food to him, everything. He was in so much pain and that stressed me out a lot."*

(Helen)

Participants reported taking on a caring role for their spouses to ensure that their spouses' basic needs were met (e.g. having food to eat). Helen described that she "*had to*" care for her husband, this suggested this role was obligatory.

Some participants described attributing their mood problems to illness in their grown-up children:

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"My son got diagnosed with schizophrenia when he was seventeen, signs of it since he was fourteen apparently, so there has been a lot of times since then that it has been very, very stressful."

(Helen)

Helen's son had been diagnosed with schizophrenia for a long period of time. Other participants described having grown-up children who had been more recently diagnosed with a life-threatening illness:

"My youngest he has got, well he's still got it, well he's in remission now, Non-hodgkin lymphoma, now I'm not saying it because he's my son but he's one of the nicest lads you'll ever want to meet … this depression is anger and ... that is what makes me more depressed than anything because I think about him all the time."

(Frances)

The potential loss of a child caused some participants' mood problems. Frances' feelings of anger stemmed from a sense of unfairness that her child had suffered from a life-threatening illness.

Whilst some participants attributed their experiences of distress to taking on a caring role for their spouses, other participants described that the loss of a caring role for a friend was a contributing factor towards their distress; Gill describes this and uses the term "*fed up*" to describe her mood problems:

"I looked after this lady until she passed away, God rest her soul, erm she was a very good friend to me and erm she made me her executor of her will and everything, not as she left me much money but that is how she was, she hadn't got another living soul

she'd never married, her Mother and family had died and then I sat at home one day

and I thought, I'm bloody fed up of this all."

(Gill)

Some participants attributed their experiences of distress to the simultaneous loss of a caring role and death of a friend.

A few female participants attributed their experiences of distress to grief. Carol described her grief following the death of her husband:

"When my husband died, I thought ... I'd be saying to friends that had lost someone

dear to them, 'I am sorry and I am sorry' but I didn't know the depths of it until it

happened to me."

(Carol)

Male participants also discussed the loss of a spouse, as described by Peter when reflecting on the loss of his wife, Gina:

"Yeah, well er, er I was married to a very lovely lady called [Gina] for thirty one

years and er we had a good relationship but the sort of relationship we had er, I just

went to work and did my nursing and then [Gina] sort of, I helped with housework a

lot, physical things, but she did, she was the brains of the outfit if you like so er, er it

worked but of course when she passed away, she was diagnosed with colon cancer

when she was 48 in 2010 , October, then she passed away on the 26th January in 2015

and er, but, like [Gina] used to do everything."

(Peter)

Many participants had been married to their spouses for a long period of time, they were an integral part of the participants' lives; this was why participants attributed their experiences of distress to losing a spouse. Following the loss of a spouse participants reported feeling alone,

Diane's husband died over twenty years previously and she still described feelings of loneliness:

> *"I start dulling my mind and not being interested, I don't know, so I think keeping interests helps with loneliness but you can still be lonely at times, I still miss my husband."*

(Diane)

A few participants described that the loss of multiple friends triggered their experiences of loneliness and distress:

> *"I went to erm two funerals recently and somebody said 'are you alright [Anne]?' to me when I was at the second one, and I said not really because I had a phone call just before I came out to say another friend had died."*

(Anne)

With the loss of each friend, participants reported having to deal with an accumulation of grief and the loss of social contacts.

Within this section I have reported that participants attributed their experiences of distress to the impact of loss. The loss of a job, due to retirement, was a contributing factor to some participants' experiences of distress and sometimes also led to the loss of an opportunity for social contact. Some participants attributed their distress to a loss of physical mobility, caused by illnesses, which resulted in a loss of social contact and isolation. Participants also attributed their experiences of distress to: a spouses' loss of mobility, illness in grown-up children, the loss of spouses and multiple friends, and the concurrent death of friends and loss of caring roles. Most forms of loss were intricately liked to the loss of social relationships, highlighting that the social environment contributed to participants' distress.

5.4 Taking action

Once participants had recognised that they were experiencing distress, they each described taking some form of action. This theme will explore the actions taken by participants to manage their mood problems. Participants reported a will to initiate their own self-management strategies when experiencing distress:

> *"You can't say what everyone would do, but personally, I would try and work things out for myself."*

(Michael)

Some participants had stoical attitudes towards their mood problems, as described by Elizabeth when discussing the management of her distress, which she attributed to a hip replacement she had one year prior to the interview:

> *"Erm so I had to sort of wash myself, strip washes and things because you weren't allowed in the bath erm ... it was stressful but I just had to get on with it, I just had to get on, I think it is because all of my life I've had to work, I've never had anything given to me on a plate ... erm ... erm, I brought my children up, my first husband left and left me with two teenagers, which was a struggle, but I managed and I married again and I was married for over twenty years and he died eight years ago. But you know what? I just got on with it, so that is what I do now."*

(Elizabeth)

Participants who reported experiencing previous hardships within their lives described self-managing their distress as they held life-long stoical attitudes towards their problems.

As most participants reported a will to initiate their own self-management strategies when experiencing distress, I will now provide an in-depth description of these strategies.

5.4.1 Pursuing independent activities

Within this section I will explore the activities that participants engaged with independently to self-manage their distress, one such activity was reading. Participants reported that reading provided a distraction from their distress, in the case of Gill, reading helped to occupy her mind away from her worrisome thoughts:

> *"Oh yes, I'm an avid reader, when I go to bed at night I cannot go to sleep unless I have read, sometimes I've been known to, if it is a good book, to read all night, if it is a good book, it does help because you've got your mind on the book instead of on the things that are worrying you because you put yourself in the situation that you're in in the book."*

> (Gill)

Another independent activity that participants utilised to manage their distress was gardening, Frances described why she enjoyed gardening in the following way:

> *"A sense of pride, I love to see the colours, I love flowers and that makes me feel better when I see them … there is nothing nicer than going through peat, it just gives me pleasure and when I put a plant in and it flowers, it is marvellous."*

> (Frances)

Participants reported a sense of achievement through gardening, in terms of managing distress Frances described that this sense of achievement through gardening made her "*feel better*". Similar to reading books, participants reported that gardening provided a distraction from their distress:

> *"I don't see it as anything particular I just see [the garden] as a place where I can go out and forget about everything and I do (laughs) yeah it takes time and effort and it is an on-going job, but I like taking the cuttings and everything about it."*

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(Helen)

Participants described the need to put continuous effort into maintaining their garden; it was this aspect which provided participants with a distraction on something other than their feelings of distress.

Other participants, however, described that a lack of physical mobility presented a barrier to gardening:

> *"My garden is beginning to look a bit untidy and it erm, it is getting at me, so when I go out I start pulling weeds and what not, then my back starts so I best be careful."*

(Gill)

Another independent activity that participants utilised as a self-management strategy was walking, as described by Peter:

> *"The walks, erm well they keep me going mentally and physically, erm if I, if I stayed in I don't think that would be good, I think the mind would start to play tricks and I think I'd get problems but I go out, I have to go out."*

(Peter)

Peter suggested the importance of leaving the house to distract him from his sense of distress; going for a walk provided this distraction. Walking was a form of exercise for some participants, this was shown through Peter describing that walking kept him going "*physically*". Other participants recognised that physical health problems restricted them from exercising, as described by Elizabeth:

> *"I've got an [exercise instructor] DVD that I try and do, but I can only do five minutes and that is it because my breathing is not very good, I've got COPD so er I am limited."*

(Elizabeth)

When self-managing their distress, participants described pursuing activities on their own, these activities included reading, gardening and walking. All of these activities provided participants with a distraction from their experiences of distress. Physical health problems prevented some participants from engaging in walking or gardening.

5.4.2 Holding religious beliefs

Ten participants, of whom eight were females, reported having a religious belief and described themselves as either Catholic or Christian. A number of participants reported that having a religious belief helped them to manage their distress, as described by Diane:

> *Diane: "Yes, yes, I am a Roman Catholic."*
>
> *Interviewer: "How does that help?"*
>
> *Diane: "It equips you for when the storm hits you, somehow, I don't know what it is, you don't avoid that storm but somehow you're not alone in it and, you know someone is there, and it provides inner strength."*

Some participants valued the sense of inner strength provided by their belief in God, as reported by Carol:

> *"You've got to do it, you've got to find that something inside of you that keeps you going, now I've got God, a lot of people haven't got Him."*
>
> (Carol)

Most participants who discussed their religious beliefs perceived that God was a caring presence within their lives:

"God has a lot to do with it, he's looked after me, I feel like He has and when you think about what I've been through, I would not be here if I hadn't of had this firm conviction that He was looking after me and seeing me through."

(Carol)

The perception that God was present within their lives prevented some participants from feeling like they were facing their distress alone.

Two participants who held religious beliefs described their reluctance to attend community groups offered by the church:

"Got a strong Christian faith but I go to church to thank God and then I prefer to come home if I'm honest (laughs) I'm not into the great social aspect no, I get my inner strength and I don't go to any of the clubs that they offer."

(Kathleen)

For these two participants, attending community groups offered by the church was not a source of social contact when experiencing distress. Instead these participants attended church to independently practice their faith and valued the inner strength provided by their beliefs. Other participants, who held religious beliefs, described attending church as it provided a source of social contact:

"Going to church, there is a friend, this is how we became friends, she used to sit sometimes beside me, she lived over the other side of the village and she is a spinster, she is a lovely person and erm I, again we sat together and then we started cleaning the alter silver together."

(Anne)

Some participants described attending church as it was a resource within the community which permitted friendships to form between members of the congregation.

This section has highlighted that some participants' religious beliefs helped them to manage their distress. Holding a religious belief provided some participants with a sense of inner strength. Two participants attended church to practise their religious beliefs independently, others valued the social contact that attending church afforded as this contact enabled friendships to form. Within the next section I will explore the importance of friends as a source of social support.

5.4.3 Seeking support from family, friends and neighbours

Although participants felt that their family members were a constant presence in their lives, participants were concerned about discussing factors which contributed to their distress with them. Carol discussed how she told her sister that she was suffering from a physical health problem:

> *"I was apprehensive, erm my sister was saying 'why are you going to the hospital?' and I said, 'oh I've got a cyst' and she was saying 'are you sure it is a cyst, are you sure? What have they told you? Have they done this and that?' and I said, 'yeah they've done everything there is to do and it is alright, don't worry', oh she was on the phone at me, so I thought, no, it is alright, it is alright, it is alright, you know and then I didn't want her to know because I knew she'd fall apart, so I had to write it all down in a letter and she was on the phone five minutes after she'd opened it (makes sobbing sounds)."*

> (Carol)

Participants perceived that discussing factors which contributed to their distress (e.g. suffering from a physical illness) with family members was potentially burdensome due to the family members' emotional reactions. Such reactions from family members caused participants to reassure themselves that they could overcome the issue they were facing. Other participants

did not seek social support from family members, such as children or spouses, as they were impassive to their distress:

> *Interviewer: "So you seem to find it easier to share your problems with friends rather than-"*

> *Frances: "With family? Yes because my sons or husband won't listen, they don't want to know, in fact my youngest won't talk about anything."*

(Frances)

Female participants particularly questioned whether their spouses would understand their distress:

> *"I wouldn't talk to my husband because I don't think he'd understand how low I do get sometimes."*

(Helen, generated by transcript from online forum)

Helen's husband had suffered from poor mobility and she described taking on a caring role for him, as described in Section 5.3.1. Participants who attributed their distress to taking on a caring role for their spouses did not seek social support from their spouses, these participants needed someone outside of the relationship to confide in.

Rather than discussing their experiences of distress, participants sought practical support from younger family members:

> *"Well my son was the main one, he'd come and take me shopping and when they were shopping I'd go with them him and his partner, he'd drop her off then come back with me and he'd get it all out and pack it all away."*

(Helen)

Some participants described that their children were a means to access supermarkets; this helped participants to fulfil their basic need of having food to eat.

Many participants sought social support from their friends to self-manage their distress:

> *"I'm a talker, I always have been but more so than ever over the last few years, many friends of mine are talkers (laughs), being able to talk to your friends, talking is great!"*

(Irene)

Female participants particularly reported seeking social support from their female friends:

> *"Call my friend [Helen] who I'm here with today and erm we talk a lot, we talk a lot on the phone, erm and sometimes I shall say right I'm going see [Helen] and my husband will say 'oh I'll come with you' and I say, 'no you're not it is going to be a ladies' afternoon'."*

(Irene)

Female participants expressed a preference to discuss their problems with female friends, rather than their spouses. Participants also placed significance on having friends of a similar age to themselves:

> *"I mean the family, you've always got family contact, but it isn't the same as having friends someone your own age, yes, yes."*

(Michael)

Most participants valued socialising with their friends as they often had similar problems, as reported by Diane:

> *"I always feel better having been out and had a good gossip, usually we start off with all our ailments then we have a good laugh and get on with it, oh yes, having a laugh*

is very important, you feel better with your friends because we all suffer from one

thing or another."

(Diane)

Participants illustrated the importance of being able to talk to friends as they were described as sources of honest support:

"There are friends who I can talk to, trust them, you know and they will be an honest

opinion and all the rest of it, yes."

(Diane)

Participants also reported that friends were a source of empathy and support:

"You know, because friends aren't that close that they got miserable about it erm but

they weren't that far away that they couldn't say 'oo what a shame, never mind you'll

be alright'."

(Carol)

Participants suggested that their friends understood their mood problems and were a source of social support, but also perceived that friends would not let the participants' distress affect their own mood.

Neighbours were also important social contacts for participants who lived in rural areas:

"If she sees my blinds not up in the morning she'll ring to see if I'm alright, and vice-

versa, so really it is a nice little village, a little community of bungalows, so you're in

an old people's community more of a erm, erm comradeship."

(Elizabeth)

Living in close proximity to those of a similar age gave a few participants, particularly those who lived in rural areas, a sense of being connected to other older adults who mutually supported each another.

Data presented in this section has shown that some participants reported being concerned about discussing factors which contributed to their distress with family members due to their emotional reactions. Other participants did not discuss their distress with family members as they were impassive to the participants' distress. Younger family members were described as sources of practical support such as enabling access to supermarkets. Participants described the importance of seeking social support from friends, particularly those of a similar age to themselves. Female participants also valued seeking social support from female friends. Neighbours were important sources of support for participants living in rural areas.

5.4.4 Community groups

I will now describe the role of community groups in how participants self-managed their distress. Some participants reflected that unless they joined a group they would feel lonely, therefore, attending community groups was necessary to achieve social contact with other individuals:

> *"Actually, it is the contact it is, well unless you join a group you tend to lose contact with people and you're more or less on your own."*

> (Michael)

Participants reported friendships at the community groups they attended:

> *"They're super people and are friendly and erm it gets you out of the house and you have a laugh, or you cuddle somebody if they're miserable, or something like that, it is lovely … I come here and they are 'how are you?' you know, erm and I've got friends as I say that are there for me."*

(Carol)

Participants attended community groups to feel socially connected to other individuals. As Carol reported "*you cuddle somebody if they're miserable*", this also highlighted attending community groups provided physical contact and the opportunity to provide affection to other individuals. As participants sought social support from friends to self-manage their distress, it was important that community groups helped participants to retain friendships, particularly for participants who had been bereaved of multiple friends:

> *"You need groups like this, for me, it is a saviour because, I wouldn't be able to cope otherwise because now, as the years go by, I've lost so many close friends, you know."*

(Diane)

Participants also reported the value of attending community groups to seek social support following the loss of a spouse, as reported by Anne:

> *"You're reaching out to people being here, and all these people have you noticed, there is not one with a husband, they have all died and we all have a little moan."*

(Anne)

Participants received support from other older adults who had been through similar bereavements; this support was reciprocated.

The purpose of attending community groups slightly differed between genders. Female participants valued the social aspects of attending community groups:

> *"We just come in and we have a chat about different things and what we're going to do and we have a moan and erm, just talk about things in life really, so this group is quite good."*

(Janet)

Male participants reported attending community groups to learn a skill, as described by Owen

who attended a community group which taught computer and internet use:

> *"I think the thing with the group is that it is good in the sense that it is teaching you things but the essential part of it is that you're getting used to computers, that is the essential part of it."*

(Owen)

The value of attending computer groups as a facilitator of internet use is presented in Section 6.5.1.

As females particularly valued the social aspect of attending community groups and preferred to seek support from other females, these participants appreciated gender specific community groups:

> *"I think a group of the same sex is good you know because you can't talk to a man always like you can talk to a woman, or if your husband's annoyed you it makes you feel better talking to a woman, it is a woman thing, I think it is a brilliant idea and that there should be far more of them … there's a division, women's problems, men's problems, simple as that, you know? So as a woman, discussing women's problems, it isn't going to go with a bloke."*

(Kathleen)

Gender specific community groups seemed to enable female participants to comfortably discuss their thoughts and feelings with other group members.

Data within this section has illustrated that participants attended community groups as a source of social contact and reported having friends at such groups, this resulted in participants feeling connected to other people. Participants sought social support from friends within community groups, particularly after suffering the loss of a spouse or friends. Females described valuing the social aspects of community groups, males reported attending to learn a skill.

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Within the next section I will explore why some participants took the decision to seek help from healthcare services when distressed, and describe why other participants did not pursue help from such services.

5.5 Help-seeking from healthcare services

Within the twelve months prior to being interviewed, five participants described seeking help from healthcare services, in the form of consulting a GP, for their mood problems. Although some participants described their distress as temporary (see Section 5.3), a few participants described taking the decision to consult a GP due to persistent experiences of distress:

> *"It is this niggle, chip, chip, chip and in the end I thought, I don't feel very well and I went to the doctors."*

> (Owen)

Diane further illustrated that persistent experiences of distress resulted in her seeking help from a GP:

> *Interviewer: "What do you think about going to the doctors [about] mental health problems?"*

> *Diane: "Yeah, I tried to do it on my own until I realised I was getting churned up and I thought, I need some help."*

Diane reported reaching a point where she could not manage her distress alone as this was not alleviating her mood problems. By reporting "*I need some help*", Diane is gaining a sense of control over her mood problems by consulting a GP.

Only one participant, Helen, reported seeking help from healthcare services in the distant past for mood problems. Helen described having a history of mental health problems dating back to when her first child was born:

"I first went to the doctors when I had depression after having my son, yeah I did, we were living abroad we had no back up."

(Helen)

Helen also described recently seeking help from a GP when experiencing distress in the following way:

"I had to go to the doctor and she knew that my husband had been ill like that and I said I'm just so low … I would encourage anyone to go and have something done about it from the doctor, there is too much to enjoy in life."

(Helen)

Helen's history of mental health problems could have supported her logic to consult a GP when recently experiencing distress.

Within this section I have illustrated that participants who took the decision to consult a GP reported persistent experiences of distress, described needing help as managing alone had not alleviated their mood problems, or had a history of mental health problems.

5.5.1 Relationship with GPs

Participants' reported relationship with a GP affected their decision to seek help from healthcare services. Participants who had received a label of a mental health problem described existing positive relationships with GPs:

"My doctors are very good they are yeah, so I feel as though I can speak to them and I've seen how they are with my husband when they've come out to him when he's been really poorly."

(Helen)

Participants who took the decision to seek help from healthcare services when experiencing distress reported that they could discuss their problems with a GP.

When asked if they had sought help from healthcare services when experiencing distress within the twelve months prior to the interview, thirteen participants disclosed that they had not consulted a GP. Reasons for this included a lack in continuity of care:

"I don't bother with the GP if I'm honest at all, having the same GP is important and seeing a different one all the time well that stops me from saying I need something, seeing a familiar face would be important."

(Kathleen)

Continuity with the same GP was required before some participants would decide to seek help from healthcare services when experiencing distress. Other participants reflected upon previous encounters with a GP which affected their decisions to seek help:

"My brother rang one-one-one and they said 'go and see the doctor the next day' and erm ... so I did ... I rang down but I could only get in to see a nurse practitioner, erm she examined me and then she went out and I heard her say to the doctor, because I know this doctor, erm 'do you think we should send her for an x-ray?' and he said 'oh no, I think it'll be alright' and he hadn't even examined me! So, but erm, I got over it but erm I won't see a doctor ... I'll never go to him again because I don't trust him anymore ... well I haven't got any confidence in him."

(Elizabeth)

Some participants reported that negative previous encounters resulted in them losing a sense of trust in GPs.

This section has identified that the participants' perceived relationships with a GP affected their decision to seek help from healthcare services. Participants who consulted a GP described positive relationships with such healthcare professionals. A lack in continuity of care, or

negative past encounters with GPs, prevented other participants from seeking help from healthcare services when experiencing distress.

5.5.2 Stigma

Along with negative past experiences and a lack of continuity to care, stigma also impacted some participants' decisions to seek help from healthcare services. Participants who had not consulted a GP when experiencing distress discussed the negative perceptions associated with mental health problems:

> *"Hm, yeah, I think, well with depression and that, I don't want to be seen as having stuff like that, do I? Its frowned upon and you shut up and shut shop and you find people say 'no that doesn't happen to me or in my family'."*

(Elizabeth)

Some participants themselves held stigmatised attitudes towards mental health problems and did not wish to be labelled as having such problems, this perhaps prevented them from consulting a GP. The concern regarding stigma may have driven participants to assert that they were not experiencing a mental health problem:

> *"I think most older adults would be in denial of stuff like that, I wouldn't see myself as having a problem like anxiety or stuff, they don't think that they'd have a problem so they'd just get on with life."*

(Leslie)

The assertion that they were not experiencing a mental health problem, and the preference to self-manage their mood, prevented some participants from consulting a GP.

Within this section I have presented data in relation to help-seeking from healthcare services with a particular focus on stigma and the perceived relationships that participants had with GPs. The next section will describe participants' perceptions of treatments offered in primary care.

5.6 Perceptions of treatments offered in primary care

To fully understand the participants' management of mood problems, it was important for this research to explore participants' perceptions and acceptability of treatments offered in primary care settings. Participants who had consulted a GP expected to be offered antidepressants:

> *"You go to the doctor and say 'I'm feeling low, I'm feeling depressed erm I can't be bothered to get out of bed in the morning', he'll give you antidepressants."*

(Owen)

After receiving a label of depression, Owen reported that the offer of medication was made by the GP too quickly, before understanding his difficulties:

> *"Essentially until they've looked at the problem, how can you diagnose a problem and give medication quite frankly? Well it is erm it is a stop-gap."*

(Owen)

Owen is suggesting that he wanted his mood problem to be understood by a GP before a treatment was suggested. The five participants who consulted their GP reported being offered medication but preferred to act by managing their problems themselves:

> *Frances: "My doctor, well he offered me, erm, Valium I think, but I will not-not-not take tablets for it, no way."*

> *Interviewer: "What would you rather do to manage your mood, other than take medication?"*

> *Frances: "Erm, well … er, doing my garden, I love my pots or, er, seeing people,*
>
> *coming to these groups actually helps a lot."*

Rather than taking medication for mood problems, participants suggested that pursuing independent activities, or social contact with other people, would be a more acceptable solution.

Participants who did, and did not, consult a GP when experiencing mood problems described that their negative perceptions of medication stemmed from hearing other peoples' experiences with the treatment:

> *"But I've heard all tales from people about tablets which is what put me off really, that*
>
> *is what put me off really, these bad tales about them."*

<div align="right">(Leslie)</div>

Hearing other peoples' experiences prevented participants from perceiving medication as an acceptable treatment option for mood problems. Participants without a label of a mental health problem from a GP also suggested that distressed older adults would benefit from self-managing their mood:

> *"Tablets … I don't know how to say it but find another way, a less medically intensive*
>
> *way, erm more getting over things themselves."*

<div align="right">(Leslie)</div>

Medication was just one of two main treatments that participants were aware of, participants also had some knowledge of 'talking therapies'. Two participants, Owen and Diane, had been offered 'talking therapies' by a GP and referred to this form of treatment as "*counselling*". Both participants who had been given the opportunity to participate in 'talking therapies' had not attended, Diane described this in the following way:

> *"Well the doctor once directed me to a spin-off, to a mental health charity, for an*

appointment for an interview, I didn't go … they said 'if you feel the need to go, would

you like to talk to someone?' and I said well that might be good, helpful, other than

talking to the family because you don't want to burden them well, they are there for

me, I know they are but they've got their lives bless them, but I didn't go."

(Diane)

Whilst Diane reported the potential benefits of 'talking therapies' by not burdening family members with her problems, both she and Owen described an uncertainty of what counselling exactly was:

"Erm a doctor saying you need counselling, I don't really understand the counselling

aspect of that because like I say with my experience, what I've been through if the

doctor suggested I go here, which was [a mental health charity] group, is that

counselling? What do you class as counselling?"

(Owen)

Diane and Owen also had a lack of understanding about the role of a counsellor:

"A counsellor is somebody who is going to diagnose something, to me it is like a

doctor saying 'I've run you through these tests and you've got a cancer', that kind of

thing, so I say you'd be terrified of a counsellor."

(Owen)

Possibly due to not understanding their role, participants were fearful of a counsellor.

Both Diane and Owen also described the perceived stigma associated with counselling:

"If a doctor says 'I want you to go counselling' that is pretty much like saying you're

going doo-lally and we're going to stick you in a strait-jacket and stick you in a

cubicle."

(Owen)

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Owen and Diane did not attend the 'talking therapies' offered to them due to a lack of understanding of counselling and the role of a counsellor, and the stigma associated with the treatment.

Some participants, who had not consulted a GP when experiencing distress, also used the term counselling when describing 'talking therapies' and suggested re-naming the treatment due to stigma, as reported by Robert:

> *"Perhaps counselling is a word that is frightening, if you called it something else, you know, 'Mother's meeting' or you know, something, I don't know and then if they felt a bit relaxed and then, then yeah they could open up their heart and talk."*

> (Robert, data generated from Storyboard one)

The term "*Mother's meeting*" was used by Robert to refer to a group counselling session, this term was believed to be more socially acceptable and disassociated counselling from a formal medical treatment. Other participants, who had not consulted a GP when experiencing distress, questioned the need for counselling:

> *Interviewer: "May I ask, what do you think about counselling when feeling low?"*

> *Stephen: "It is a thing that never used to happen to people and I can't understand why it is necessary now when it wasn't fifty years ago, what do you think erm happened to them fifty years ago when something bad happened? You had to live through it didn't you?"*

A few participants suggested that counselling was an 'easy' option and reported the need to take a stoical approach to managing mood problems. Participants who had not sought help from healthcare services also discussed that distress was a "*private*" matter and perceived that older adults would not feel comfortable in discussing their experiences with a counsellor:

"Some people feel like that sort of stuff is private and might not like talking to a stranger about it you know? They might prefer to talk to a friend."

(Kathleen)

Participants viewed a counsellor as a person with whom they would be unfamiliar with. This unfamiliarity potentially impedes older adults from discussing their "*private*" mood problems with a counsellor. Older people may prefer discussing their mood problems with a friend as they had often been through similar experiences of distress (as described in Section 5.4.3).

Rather than discussing their problems with a counsellor, most participants, with or without a label of a mental health problem from a GP, reported a preference to self-manage their mood:

"Like talking to a stranger, erm if it helps them but I'd just get on with it you see, yeah just keep ticking along."

(Kathleen)

Participants reported that other individuals may benefit from talking to a healthcare professional who is not known to the individual, but described a stoical attitude towards the management of their own mood problems.

Participants who did, and did not, seek help from the healthcare system when experiencing distress suggested that GPs should direct older people with mood problems to third sector services:

Interviewer: "What do you think doctors should do for distressed older people?"

Stephen: "Hm, well, er ... maybe sending them to [community] groups like this, yeah, so they can get out and meet people and have a joke and a laugh, and maybe a piece of cake if it is somebody's birthday (laughs) yeah, these groups are wonderful."

Participants suggested that GPs should direct older adults to community groups where they

can have social contact with other individuals. Attending community groups as a self-management strategy of distress was described in Section 5.4.4.

This section has summarised participants' views on treatments offered in primary care settings. Participants were aware of medication and 'talking therapies', in the form of counselling, as treatment options. Some participants, who had been labelled with a mental health problem by a GP, expected to be offered medication. One participant wanted his mood problems to be understood before the GP offered him a treatment. Rather than taking medication that had been offered by a GP, participants preferred to self-manage their mood. Participants who did, and did not, consult a GP when experiencing distress reported that their negative perceptions of taking medication for mood problems stemmed from hearing other peoples' experience with the treatment. The two participants who reported being offered 'talking therapies' were unsure of what counselling entailed, misunderstood the role of a counsellor and described the stigma associated with the treatment; these participants did not attend the 'talking therapies' offered to them. Medication and 'talking therapies' were deemed unacceptable treatments and participants preferred to self-manage their mood. Participants suggested that GPs should direct older adults to third sector services (e.g. community groups).

5.7 Visual representations of the analysis

The concentric circle represented in Figure 4 identifies the management strategies participants used when distressed, however, the figure does not represent a linear process. Individual participants did not necessarily move from independent activities to seeking social support and then to engaging with community resources to manage their mood problems.

Figure 4 Self-management strategies
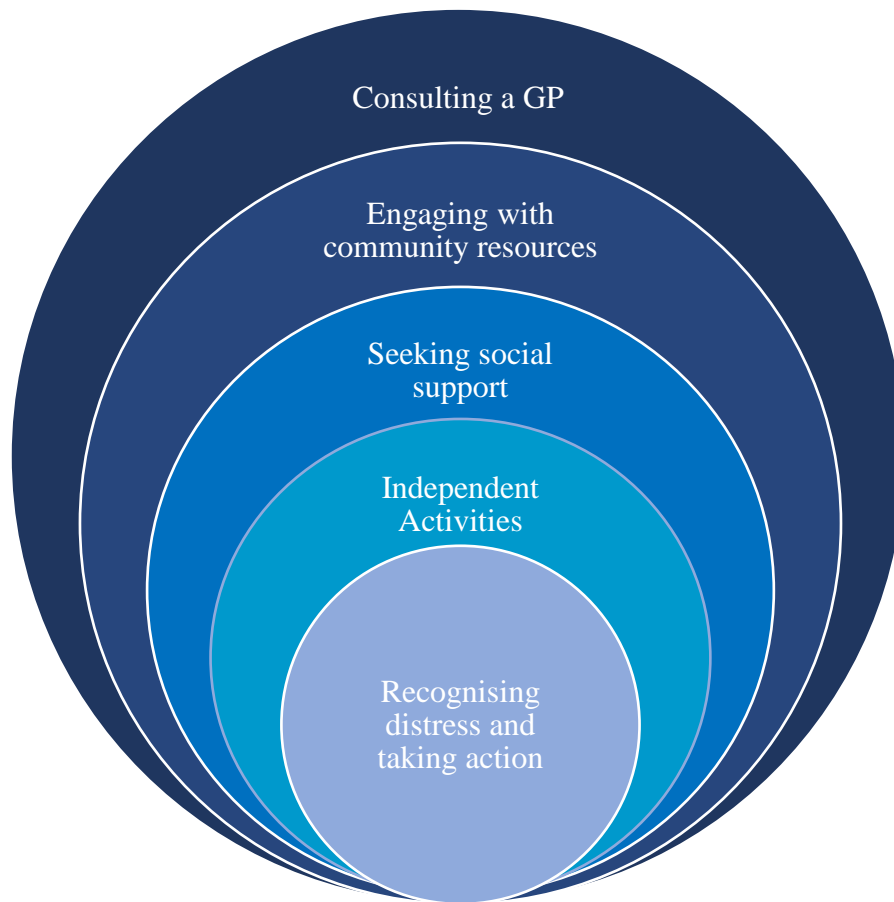
I am now going to present two diagrams which illustrate how two participants managed their

distress in different ways. Figure 5 is a diagram of Anne's self-management strategies and

Figure 6 represents how Owen managed his mood problems. The colour of each self-

management strategy represented in the diagrams corresponds to Figure 4.

Figure 5 Anne's management strategies

Attending church

Socialising with friends

Seeking social support

Attending community groups

Taking action

Distress due to loss of mobility and social contact

Taking action

Independent activities (reading)

Figure 6 Owen's management strategies

Independent activities (gardening)

Attending community groups (to learn a skill)

GP consultation (lack of acceptable treatments offered)

Taking action

Distress due to physical health problems
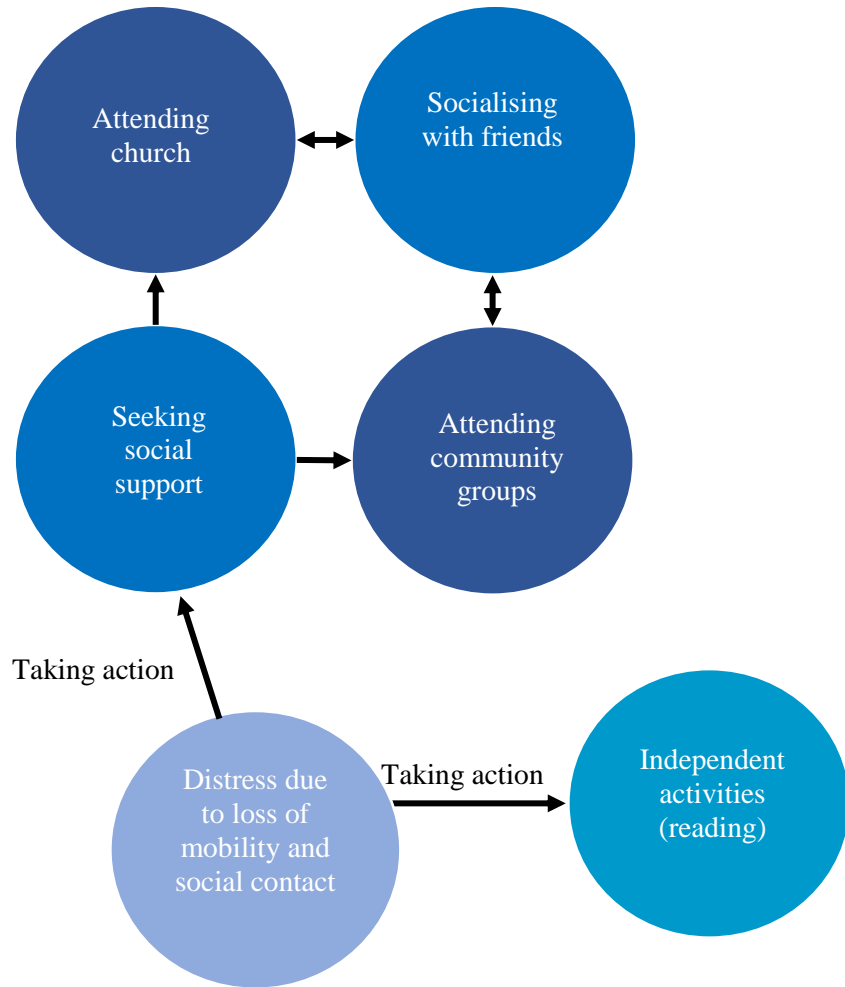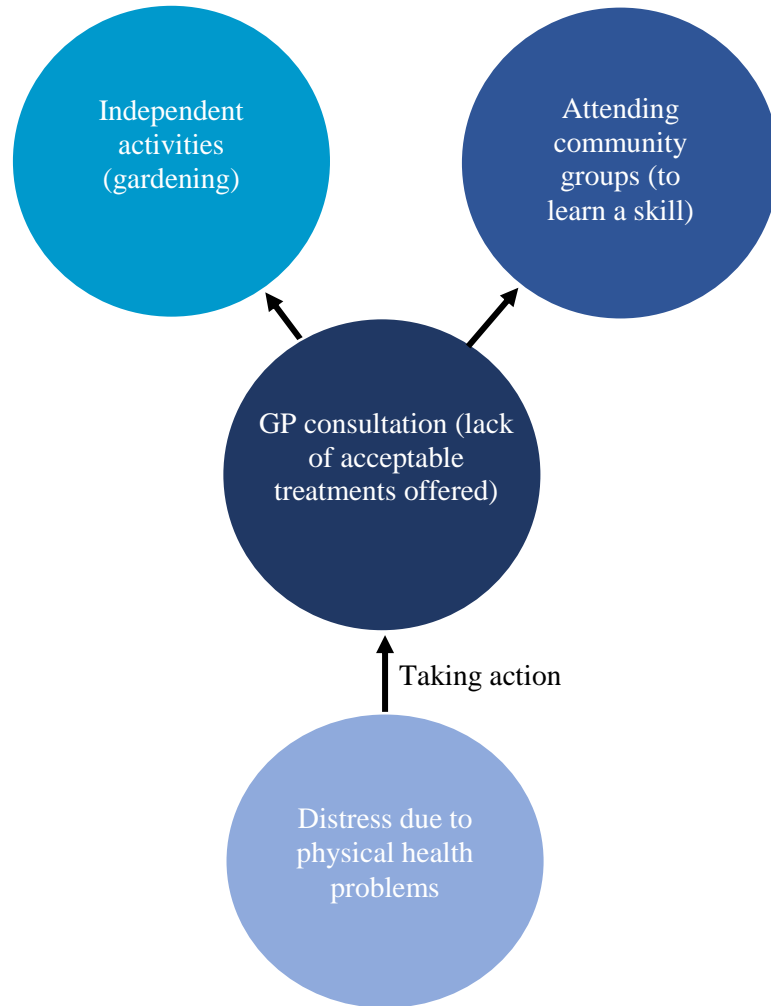
Figure 5 shows that once Anne had identified as experiencing distress, due to a loss of mobility and social contact, she took action by initiating self-management strategies. While Anne utilised reading as an independent activity that she did alone, most of the self-management strategies Anne employed revolved around seeking social support, such as socialising with friends. Seeking social support was linked to attending church and community groups as Anne sought support from individuals who also attended these community resources.

Unlike Anne, once Owen had recognised that he was experiencing distress due to physical health problems, he took action by consulting a GP who suggested a label of depression. Owen perceived the treatments offered by a GP (medication and 'talking therapies') as unacceptable and reported self-managing independently from healthcare services. Similar to Anne, Owen attended community groups. Owen did not report attending community groups to seek social support but to learn a skill. Owen also described gardening as an independent activity he did on his own to self-manage his feelings of distress. Figure 5 and 6 show the nuances in how different participants managed their mood problems. Each participant utilised strategies that they deemed appropriate for the management of their own mood problems.

5.8 Reflection on the social construction of the self-management of distress

This thesis is underpinned by social constructionism (see Section 3.1 for more details). The importance of knowledge being sustained by social processes and language is evident throughout the current findings. For example, participants gave meaning to their distress through the terms they used to describe their experiences; the language used by GPs to describe participants' distress sometimes changed the participants understanding of their mood.

Some participants pursued independent activities to distract themselves from their distress, arguably the development of these strategies could fall under a constructivist approach to knowledge formulation (see Section 3.1.4) as participants are using cognitive resources to develop ways to manage their experiences. However, language provides the basis of thought and cognitive processes, and is a key tenet to a social constructionist framework. Most self-management strategies were social processes (e.g. talking to friends, attending community groups, seeking help from the healthcare services) which highlights the importance of social relationships and communication in the management of mood problems. Engaging in social processes occupied participants' minds which also distracted them from their distress.

Distress was linked to a loss of social contact (e.g. the ability to interact and communicate with other people). A loss of social contact was caused by bereavement, retirement or a reduction in physical mobility which contributed to feelings of loneliness or isolation. Participants perceived that engaging in social processes such as talking to friends or attending community groups increased the amount of social contact they had with other people, which was why most self-management strategies of distress involved some form of social interaction. Some participants particularly valued having the opportunities to interact with their friends, who were perhaps facing similar distressing situations; through these interactions participants felt like their distress was being understood and that they could receive honest and trustworthy support.

Previous interactions with healthcare professionals impacted participants' decisions to seek help from healthcare services. Interactions which were interpreted positively by participants (e.g. an understanding GP) encouraged help-seeking from healthcare services, whilst interactions which were perceived as negative discouraged other participants from seeking help. This shows how the interpretation of interactions shaped participants' help-seeking behaviours. Some participants' decisions to seek help were also influenced by their

stigmatised views of mood problems. These participants did not want to be labelled as having a mental health problem as they viewed that the wider society has constructed such problems to be negative and shameful. This exemplifies how a participant's perception of mental health problems is influenced by the wider society which, in turn, effects help-seeking from healthcare services.

Within social constructionism language creates meaning. The language surrounding medication (e.g. participants had '*heard tales*' about the treatment) impacted participants' understanding of medication and resulted in participants stopping the treatment. Whilst most of the self-management strategies participants employed required social interaction, the two participants who were offered counselling perceived that communicating their problems with a counsellor was inappropriate. Participants' language when describing the role of a counsellor suggested a misunderstanding of a counsellor's role, which could have been compounded by their stigmatised attitudes towards the treatment. The management of distress was dependent on the source of social interaction; participants were comfortable talking to their friends of whom they trusted, but did not perceive talking to a counsellor as an acceptable.

Summary

Within this chapter I have introduced the participants and their reported experiences of distress. Whilst all participants took some form of action when experiencing distress, most preferred to employ self-management strategies independent from healthcare services. Participants pursued independent activities, these included reading, gardening and walking. Holding a religious belief helped some participants to manage their mood, most of these participants valued the social contact that attending church provided. Some participants did not seek social support from family members and questioned if their spouses would understand their feelings of distress. Younger family members were seen as sources of

practical support. Participants accessed social support through their friends, neighbours were importance sources of support for participants who lived in rural areas. Five participants did seek help from healthcare services but perceived the treatments offered as unacceptable and preferred to self-manage their mood. Rather than offering medication or 'talking therapies', participants suggested that GPs should direct distressed older people to community groups.

I have provided a visual representation to show the range of self-management strategies used by participants. I have also illustrated the nuances in how different participants self-managed their mood problems. I concluded the chapter by offering a philosophical reflection in regards to social constructionism. The following chapter responds to the second research question and explores the role of the internet in how participants self-managed their experiences of distress.

Chapter Six: The role of the internet

Introduction

In the previous chapter, I described how participants identified and managed their distress. Self-management strategies included perusing independent activities, seeking social support and engaging with community resources. A small subset of participants sought help from a General Practitioner (GP). In the current chapter I aim to address the second research question, which is to explore the role of the internet, particularly online forums, in how older adults self-manage distress. I begin the chapter by identifying the key themes and then describe each theme in detail. I conclude the chapter by offering a philosophical reflection on the social construction of the internet.

6.1 Findings

Analysis resulted in the emergence of four themes: access and general use of the internet, using the internet as a health resource, views on accessing social support via the internet and facilitating internet engagement. A table of the analysis and thematic maps can be found within Appendices 11c, 11d and 11e. Illustrative data is identified by the participants' pseudonym, it is also stated if the data was generated during the 'think aloud' activities. Data extracts have been modified to ensure anonymity and to support readability.

6.2 Access and general use of the internet

All participants reported having access to the internet within their own homes. Table 10 describes the devices each participant could have used to access the internet.

Table 10 Participants' access to the internet

Participant	Devices which could provide access to the internet
Anne	Laptop
Barbara	Tablet computer
Carol	Laptop
Diane	Desktop PC
Elizabeth	Smartphone
Frances	Laptop
Gina	Desktop PC
Helen	Laptop
Irene	Desktop PC
Janet	Smartphone, tablet computer, desktop PC
Kathleen	Tablet computer
Leslie	Tablet computer, desktop PC
Michael	Laptop
Nigel	Desktop PC
Owen	Desktop PC, laptop
Peter	Desktop PC
Robert	Laptop
Stephen	Laptop

Table Notes: Access to the internet reported at time of participation, PC-personalised computer

Participants owned a variety of devices which permitted access to the internet, such as; laptops, tablet computers, desktop Personalised Computers (PCs) and smartphones. Janet described how she and her husband had access to the internet via multiple devices:

Interviewer: "Do you have access to the internet?"

Janet: "Yeah, we have internet on our phones, iPad and computer yeah, everything."

Four participants described using tablet computers and preferred to use these devices rather than a laptop, as alluded to by Leslie when comparing his and his wife, Brenda's, access to the internet:

> *"I've got an iPad, which I use all the time, [Brenda] uses the one she has got today, the [laptop], but the iPad is so quick, so quick."*

<div align="right">

(Leslie)

</div>

A few participants valued the speed of a tablet device. Other participants reported using a desktop PC to access the internet as they faced usability issues and lacked confidence in using smartphones:

> *Interviewer: "And how do you access the internet?"*
>
> *Diane: "I have a computer, I don't have it on my phone because I'm not that technical and it is just so small! (laughs)"*

Diane described her computer as "*a big thing with a keyboard*" which suggested that the device was a desktop PC and highlighted that Diane was unfamiliar with technological terminology.

Some participants also described that access to devices was provided by younger family members:

> *"My son-in-law got me my iPad, we call him the 'Internet kid' and he's just taught me how to stream programmes off erm BBC I-player onto the TV too!"*

<div align="right">

(Kathleen)

</div>

Younger family members sometimes encouraged internet use, this is further described in Section 6.5.1.

6.2.1 Hobbies and/or interests

Although all participants reported having access to the internet, only a small number of participants engaged with the resource. A small number of participants described using the internet to find information about home maintenance:

"So I wanted to know, I've got black gutters and red doors, and I wanted to know about my window frames, grey apparently would go, it is this old cottage, and things like that, practical things and that is the only real way at the moment I use the internet."

(Peter)

A few participants also reported engaging with the internet as a hobby to research their family history:

"Family tree, so that I absolutely love, I've gone back to 1725 and erm some of them couldn't write so they signed their name with a cross and things, but the thing I'm most pleased with is that my husband, his mum died when he was three and left him and his sister as babies, well youngsters, and he knew that she died having a baby but nobody could tell us what the baby was or where it was, so I thought I will find out, so I'm researching all this online."

(Helen)

Helen further described the hobby as "*absolutely fascinating*", participants who used the internet to research their family history had an interest in researching their genealogy.

6.2.2 Online shopping

Two participants reported using the internet to conduct online purchases, as described by Kathleen:

"I love Amazon because I can't get out and shop without someone taking me and I get tired and very confused quickly so I end up buying the wrong thing, but on Amazon I can sit quietly and do it."

(Kathleen)

The two participants who used the internet to conduct online purchases reported that the internet provided an alternative means of accessing goods. When purchasing goods online, participants valued having the time to browse and consider goods at their own pace, this prevented the two participants from purchasing items they did not want.

6.2.3 Communication with family members

One participant, Michael, described engaging with the internet via Skype to keep in contact with his son, who lives abroad:

> *"I get on Skype see he is online, click on him and it comes up with sometimes what he's doing and I just leave a little message underneath like 'hi, how are you? Do you want to talk?' And invariably he'll say 'yeah, okay', but just recently he'll say 'no, busy at the moment, I'll get in touch with you later,' yeah."*

> (Michael)

Michael used Skype as in-person communication was unavailable.

Whilst a few participants were familiar in using the internet for hobbies and/or interests, online shopping and as a means of communication with family members, many participants did not describe engaging with the resource. The next section describes barriers to general internet use.

6.2.4 Barriers to general internet use

Participants who did not use the internet reported a lack of knowledge about what the internet might offer them:

> *Interviewer: "What are your overall views of the internet?"*

> *Michael: "I still have my computer in the corner since last Christmas and I've hardly used it since, I think you can take that as an answer (laughs) I'd never ever resort to*

the internet because it's, because it's an unknown country, it is Greek to me (laughs) if

they're capable of using it fair enough, but erm it can be dangerous can't it?"

Michael reported that the internet was an unfamiliar environment, this is shown through how

he likens the resource to a foreign language. By also describing that he would not "*resort*" to

using the internet suggested that Michael preferred to utilise alternative resources, particularly

as he viewed the internet as an unfamiliar environment. However, Michael did describe that

other individuals, who were competent in engaging with the internet, could value the

resource.

Some participants did not use the internet due to the perception that they were not a

generation of internet users, as described by Frances:

> *"I think if we'd have been raised with them, I mean my son is a computer man because*
>
> *it is the jobs and the daughter-in-law is, and grandchildren, that is their jobs, and that*
>
> *is how you learn today but we never did, and I think that is why I'm not interested."*

(Frances)

Participants did not perceive themselves as an 'Internet generation' as they had not engaged

with widespread internet use, or learnt about the internet, from a younger age. Participants

described younger generations as the 'Internet generations' as they were raised using the

internet and familiarity with Information Technology (IT) was a reported requirement of

employment roles.

A lack of knowledge about how to use the internet, and the perception that they were not a

generation of internet users, also resulted in some participants being fearful of engaging with

the resource:

"The older you are because you're not au fait with this technology you are behind, you're in a different world and we're frightened of it."

(Owen)

Owen used the phrase "*a different world*" to describe how he perceived using the internet this, along with the view that the internet was an "*unknown country*" and the perception that they were not a generation of internet users, suggests that participants felt like they were outsiders to engaging with the resource.

Although Michael used the internet to communicate with his son via Skype (described in Section 6.2.3), some participants questioned what social media platforms were, and reported not needing to use such sites:

"Facebook, I've never ever tried it, I don't know what it is, I say what is Facebook? Oh, it is where you talk to people? Yeah well I talk to people all day! (laughs)"

(Carol)

Participants described not needing to engage with social media sites as they received social contact in different ways. Along with sites such as Facebook, participants did not describe using online forums:

"Never been on one, never been on a chat forum so I can't comment really."

(Janet)

Although participants did not report using social media platforms, they did hold negative perceptions of such sites:

"There is a lot of rows and ... a lot of unpleasantness going on Facebook and Twitter and stuff, so that is my only objection to it, so no I won't use it."

(Kathleen)

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Participants associated social media platforms with negative behaviours such as arguments and these perceptions prevented participants from potentially engaging with the sites. Kathleen further reported that her negative perceptions of social media platforms had been shaped by her friend, Enid's, experiences:

> *"[Enid] told me this, she said she did it to keep in touch with her daughter but she said that there was a lot of negative things on, so I won't be involved for that reason nothing else."*

> (Kathleen)

Other participants' perceptions of social media sites seemed to be based on print-based news articles:

> *"I mean you read in the papers about these young children and that who've been taken by strangers they've met on sites like that, erm teenagers too, so, to me who isn't used to that sort of thing, no I wouldn't like to use them."*

> (Helen)

Negative news stories and friends' experiences with social media sites prevented some participants from wanting to engage with the platforms.

Some participants who were unfamiliar in using the internet described a lack of interest in engaging with the resource:

> *"I don't get any interest in it, I don't get any enjoyment out of it should I say so, I just don't bother with it (laughs)"*

> (Elizabeth)

Elizabeth expressed a lack of interest as she perceived that internet use would prevent her from engaging in other activities of which she enjoyed:

"I don't know whether I'm thinking if I get too involved in it that I shall lose interest in my other things I'm doing, or it'll keep me in when I should be going out."

(Elizabeth)

Participants suggested that using the internet could be isolating as it would prevent them from leaving the house.

Within this section the findings have shown that all participants had access to the internet via a number of devices such as laptops, desktop PCs, smartphones and tablet devices. A small number of participants were familiar in using the internet and engaged with the resource for hobbies and/or interests, to conduct online purchases or to communicate with family members when in-person communication was unavailable. Most participants did not use the internet and had a lack of awareness of what the resource could offer them. Participants described that other individuals, who were competent in using the internet, could value the resource but did not perceive themselves as a generation of internet users. A lack of knowledge about how to use the internet, and the perception that they were not a generation of internet users, resulted in feelings of fear. Participants did not use social media sites, particularly online forums. Participants associated social media sites with argumentative behaviours, such perceptions stemmed from hearing their friends' experiences with the sites and print-based newspapers. Other participants reported a lack of interest in engaging with the internet as they perceived that internet use would prevent them from leaving their homes and engaging in other activities.

6.3 Using the internet as a health resource

Within this section I report data which captured the role of the internet as a health resource, particularly for the provision of health information. Some participants reported that the internet was not an acceptable source of health information as it provided a wide-range of information that could have been irrelevant to their health needs, as reported by Owen:

> *"Never done it, surely that is like having a medical encyclopaedia, you start reading it and you've got every damn thing in the book, I've not done it, no, I've not done it."*

(Owen)

Owen suggested that access to an extensive amount of health information could have caused him to self-identify with an illness he was not suffering from, this was further highlighted by Elizabeth:

> *"Won't look up nothing on the T'internet, will not look up illnesses on there because it can make you worse than when you bloody started, you're a bit paranoid really aren't you? You see all of these things and say 'I've got that'."*

(Elizabeth)

For some participants, the internet was not an acceptable source of health information as the information provided was potentially worrying. Participants further described that people should not label themselves with an illness when searching the internet for health information:

> *"Erm, you can't take everything that is said on there as gospel because you can't try and diagnose yourself, if that is what you're thinking and, erm … if you've got a diagnosis you can look it up and you can deal with it from there."*

(Irene)

Participants suggested that a diagnosis of a physical health problem from a healthcare professional was needed before the internet was seen as an acceptable source of health information:

> *"I was sent to the erm, neurologist and I'd had the scans and that and they'd told me it was a benign tumour in my brain and, erm, so it is a very slow growing one, apparently, and I went and Googled the brain tumour, yes, its a slow growing one."*
>
> (Helen)

A diagnosis of a health problem, from a healthcare professional, provided participants with a search term, participants sometimes used this term to check if the information provided by the healthcare professionals was accurate. A diagnosis of a physical health problem also reassured some participants that they were searching for information relevant to their health needs, as described by Kathleen:

> *"It is probably better to have a diagnosis before looking things up because you can give yourself everything, so I wait to be told what it is, so then I'll Google."*
>
> (Kathleen)

Kathleen also reported that she searched for information online regarding a forthcoming operation:

> *"I like to know what is coming, like with this operation, it is a bowel resection, and I want to know what is going to happen and why, so yes I do look."*
>
> (Kathleen)

Accessing health information about surgical operations increased some participants'

understanding of the treatment which allowed them to feel better prepared. Other participants

described how they accessed health information about medication on the internet:

> *"The only thing I've ever looked up is about Warfarin because I needed to know what*
>
> *I can eat and what I can't, and what I can't do and what I can do, yeah, but that is the*
>
> *only thing I've ever looked up."*

(Frances)

Some participants searched online for health information about medication for physical health

problems as they believed this information prepared them for potential side-effects.

Participants did not perceive the internet as an acceptable source of information about

distress, Leslie reflected upon his wife, Brenda's, physical illnesses when discussing this:

> *"It is alright sending people to the internet like to [Brenda], they've said just check*
>
> *such and such thing on the internet, like exercises for a bad back and things like that,*
>
> *more what you'd call physical I guess but not stuff like that."*

(Leslie, generated from Storyboard two)

Unlike physical health problems, distress is not a diagnosable illness and as participants

needed a diagnosis of a health problem before they would use the internet as a source of

health information, this could have prevented participants from using the resource to access

information about distress.

Some participants described that they would not search for information about distress or

mental health problems via the internet as, unlike physical health problems, they

conceptualised mood problems as "*personal*":

> *Interviewer: "Would you ever use Google to look up things about low mood, distress*
>
> *or mental health problems?"*
>
> *Kathleen: "It is ... sometimes if I can see like physical problems with friends I'll have*
>
> *a look and think how can this be handled? But I don't go into mental health in-depth*
>
> *because it's personal."*

The five participants who reported receiving a label of a mental health problem from a GP did not use the internet as a source of mental health information, as described by Carol:

> *"Most people of my age are either ... good at it and erm, forward thinking, active*
>
> *people who don't need you know, to go online for depression, or they are like me and*
>
> *computer goes vvrrrrrm (makes fast arm movement away from herself) you know*
>
> *(laughs)."*

(Carol)

Some participants perceived that searching mental health information was not taking a proactive approach to managing mood problems. Carol also suggested that a lack of knowledge about how to use the internet prevented her from using the internet as a source of mental health information.

Within this section, the analysis has shown that some participants described the internet as an unacceptable source of health information as it provided surplus information which could have been irrelevant to their health needs, and might have resulted in participants self-identifying with a health problem they were not suffering from. A diagnosis of a physical health problem, made by a healthcare professional, was needed before the internet was used as a source of health information. A few participants used a diagnosis of a physical health problem as a search term and checked if the information provided by healthcare professionals was accurate. Other participants suggested that a diagnosis from a healthcare professional

provided reassurance that they would search for health information appropriate for their health needs. Some participants researched information about operations and medication online. As distress is not a diagnosable illness, this perhaps prevented some participants from using the internet as a source of information about such mood problems. Some participants reported that the internet was inappropriate for information about mood problems as such problems were *"personal"*. A few participants who had received a label of a mental health problem from a GP suggested that older adults did not perceive searching mental health information online as proactive management of their mental health problems. A lack of knowledge about how to engage with the internet may have also prevented some participants from searching mental health information online.

6.4 Views on accessing social support via the internet

Accessing social support was described as a self-management strategy of distress in Section 5.4.3. Instead of accessing social support via the internet, participants proposed that talking to a friend would be more beneficial:

> *"I think sometimes you're better off speaking to a friend rather than this, rather than talking to a machine as I always say (laughs)"*

> (Elizabeth)

The view that socialising on the internet was like "*talking to a machine*" portrayed the internet as impersonal and devoid of human emotions. When discussing their distress a need for in-person communication was reported by all participants, Janet described this in the following way:

"I'd want to talk to someone. I do think there is a difference in communication I think you're more likely to, to open up if you do have any problems if you speak face-to-face."

(Janet)

Participants appreciated in-person social contact and the presence of another individual when seeking social support as a self-management strategy of distress:

"I just find in times of stress that you, you do need, well I do anyway and perhaps a lot of other people do, the contact of another person to talk with rather than a computer, the computers can only bring so much comfort and erm you can't beat, that can't take the place of a human and the contact with another human being."

(Peter, generated by transcript from online forum)

Participants also described that they would find it difficult to switch from forming friends via in-person communication to forming friendships online:

"Thing is you see, when you've spent a life without that it is very difficult at this age to start and think about making friends like that because you're so used to that personal, face-to-face contact."

(Nigel, generated from storyboard one)

Participants perceived that in-person social contact with friends was an appropriate source of social support as they did not identify themselves as a generation of internet users.

Some participants also viewed that it was not human nature to socialise on the internet, as reported by Kathleen:

> *"Yeah but face-to-face is better because humanity wasn't meant to be on their own, you're not born to be an isolated person on the internet, man is a social being and I think it makes a massive difference having someone there."*

<div align="right">(Kathleen)</div>

Participants perceived that it is human nature to socialise in-person; as the internet could not permit in-person social contact it did not meet the social needs of participants.

Participants particularly reported a reluctance to engage with online forums due to the anonymity of other online forum users, as described by Elizabeth:

> *"I know there is a person on the other side but you know, but you don't know who it is."*

<div align="right">(Elizabeth, generated from storyboard one)</div>

As described in Section 6.2.4, negative news stories and friends' experiences prevented some participants from engaging with social media platforms. Participants perceived the anonymity afforded by online forums as negative as they could not place anonymous online forum users within a social context:

> *"See, that Person One, hasn't put his actual age in, so how can you weigh him up, if you don't know his actual age, and how can you weight them up through a computer?"*

<div align="right">(Stephen, generated by storyboard one)</div>

Participants particularly reflected on the need to know the age of the other online forums users. Due to the anonymity of online forum users, participants viewed the potential support gained from online forums as untrustworthy:

<div align="center">152</div>

"It isn't trustworthy you get cranks in everything don't you (laughs) maybe that is why I don't go on because its talking to a complete stranger."

(Janet, generated by transcript from online forum)

Participants described the uncertainty of not knowing if anonymous online forum users had suffered from mood problems:

"You wouldn't know if that person had actually had depression, you've got to trust somebody to talk to them like that, about things like that, yeah."

(Helen, generated from storyboard two)

Participants also questioned if anonymous online forum users would understand their distress:

"Erm, you can't really believe that somebody feels like you, can you? It could be advice, but it could be advice from people who haven't felt like you've felt."

(Carol, generated by transcript from online forum)

Participants questioned if anonymous online forum users would provide suitable advice, this prevented some participants from perceiving online forums as an acceptable means of accessing social support.

One participant suggested that online forums needed to be overseen by a qualified healthcare professional:

"It should be moderated … I am not a qualified person, so how do you know that these people at the other end of the computer are a qualified person? They can put anything that they want on there and they can put signs and I've done this, this and this but you don't know."

(Irene, generated by transcript from online forum)

Participants suggested that they might engage with an online forum in the future, but only if they were overseen by a professional organisation:

> "If it was sort of a local group you'd be more trusting wouldn't you, than someone far away of where do they live? In your own area groups, I think that would work well, there might be occasions then when you could organise a face-to-face get together, I think that would be a great idea, a bit of both if you like, I'd be more inclined to trust them if they were local and that someone would be vetted rather than just go online because it could be anybody, that is always the danger isn't it?"
>
> (Diane, generated by transcript from online forum)

Participants suggested that online forums should disregard the notion of anonymity and be comprised of individuals who live in the participant's local community; this could potentially facilitate in-person social contact. Participants also described the importance of continuity within online forums:

> "It would definitely take more than one time of going on there you wouldn't just open up, no you'd have to, I mean, you wouldn't be talking to the same person all the time presumably you'd be speaking to different people."
>
> (Helen, generated from storyboard one)

Some participants suggested that to seek support from individuals within an online forum, they would need to build up a sense of rapport with the same online forum users.

The current section has distinguished that participants did not seek social support via the internet to self-manage their experiences of distress; the internet did not meet their social needs. Participants preferred in-person communication when seeking social support as it permitted social contact with other individuals. Participants also did not perceive themselves as a generation of whom socialised via the internet and reported that they would struggle to

form friendships online. Due to the anonymity of online forums, participants deemed them as untrustworthy and questioned if the anonymous forum users would understand and give suitable advice for their mood problems. Participants suggested that online forums need to show the identity of other users, be overseen by professional organisations and be populated by other users who live near to the participant before they would engage with such platforms.

6.4.1 The internet as 'a last resort'

Participants distinguished that the internet may be useful for *other* older adults who struggle to socialise and to establish social contact:

> *"Someone who uses sites like that I can just in my imagination, or in my mind, I'm thinking maybe erm they are not sociable people, they struggle to meet people erm I think it has a place for those sorts of people but definitely not for me, I prefer face-to-face social interaction."*

(Irene)

Participants reported a divide between themselves and older people who struggled to socialise.

As reported in Section 5.3.1, some participants reported that feelings of loneliness contributed to their experiences of distress. Although not for themselves, participants described that the internet may provide a source of social support for other lonely older adults who could not access in-person social contact:

> *"Erm probably you would get more use out of the internet where you hadn't got company or you hadn't got family or neighbours or anything, yeah ... loneliness that is, so probably they would benefit by using internet or something, they've only got that to fall back on."*

(Elizabeth)

Elizabeth described that lonely older adults may have the internet to *"fall back on"*, which suggested in-person communication would still be preferred and that seeking social support via the internet would only be done as a last resort.

A few participants also described that online forums could help housebound individuals who could not access community groups:

> *"Better going like I do to a group really, but then not everyone is well enough to go out and I appreciate that I can do it, erm some people are really housebound then it might be more useful to these sorts of people because there isn't an alternative like there is for me, face-to-face, for me personally, I'd rather be with people that are there than go to on an online forum, but I mean if ever there came a time when I couldn't get out at all, this is where the computer could be more wonderful."*

> (Diane, generated by transcript from online forum)

Some participants saw the value of engaging with online forums in the future, but only if in-person communication was not available.

Within this section I have shown that participants perceived that the internet may be used by other older adults, who perhaps struggle to socialise or who may be lonely or housebound, as a last resort if other self-management strategies cannot be utilised. A few participants may engage with online forums in the future; if in-person support was inaccessible.

6.5 Facilitating internet engagement

This section presents factors which facilitated internet engagement for some participants, one such factor was a will not to be left behind in a changing society:

> *Interviewer: "What are your opinions on the internet?"*

Robert: "Well it is getting better but I think, it was like a red rag to a bull erm, I use old telephones and letters and cheques, they talked about stopping doing cheques and the reaction was you can't stop doing cheques, you know, but eventually you think no, be sensible, you've got to do something about it and learn."

Participants were initially resistant in wanting to learn how to engage with the internet, however, the perception that internet use may be beneficial in a changing society motivated some participants to learn how to use the resource. As described in Section 6.2, Kathleen reported how her son-in-law, who she described as the "*Internet kid*", provided access to a tablet computer which she could use to access the internet. Family members' ability to use the internet sometimes motivated participants to want to learn how to engage with the resource, Peter compared his internet use to his late wife, Gina's, son, Robbie's and daughter, Nina's internet use:

"[Gina] was a whizz on it she could make then do had stands but, and [Robbie] can, and [Nina] can, so I just feel as though I need to you know, I don't want to get left behind."

(Peter)

When comparing their own ability to use the internet with that of their family members', participants reported that family members were often more proficient at engaging with the resource and participants did not want to be *"left behind"*.

This section has illustrated that participants described two motivating factors which encouraged them to learn how to engage with the internet, these being: a will not to be 'left behind' in a changing society and the comparison of their internet proficiency with family members' proficiency.

6.5.1 Learning how to use the internet

Within this section I report the ways in which participants described learning how to engage with the internet. Participants reported that younger family members tried to teach them how to use the internet, but also described the importance of courses which taught computer and internet use:

> *"The children tried to teach me, but they aren't there and if things went wrong I had to wait for them to come again, but then at my local school, erm the council were putting some computer courses on during the day, mostly for older people, so I went to, erm one and I learnt there that was a six week course and then there was one or two courses following on which were helpful."*

> (Diane)

Family members were not always available to support participants in their learning, therefore, computer courses were essential in teaching some participants how to engage with the internet.

All male participants were recruited from community groups which specifically taught older adults how to use the computer and internet. The community groups which taught computer and internet use ran on a weekly basis, unlike computer courses which, as Diane reported, were scheduled for a set amount of time (e.g. six weeks). Attending such groups helped some participants to overcome their lack of knowledge and fear of using the internet, whilst also increasing their confidence when engaging with the resource:

> *"Coming here has helped, we're more confident with it now, things don't scare me anymore now with it from coming here, yeah, it doesn't scare me because coming here helps."*

> (Leslie)

A few participants, who did not attend community groups which taught computer and internet use, suggested that this was something they might like to attend in the future:

> *"I'd love to go to a computer class! Because I would like to learn about it, but they are all in the evenings and I don't go out very much in the evenings and elderly people don't go out very much in the evenings."*

(Carol)

Some participants were motivated to learn how to engage with computers and the internet, but suggested that the arrangement of such groups should suit the needs and preferences of older adults. Female participants also valued the social contact afforded by attending community groups which taught computer and internet use:

> *"More social, yeah, that is what that computer place is, I mean some of them are really into it and interested but not me … I don't really want to know, I talk there."*

(Frances)

Community groups which taught participants how to use the computer and internet served both an educational and social role.

This section has identified that participants learnt how to engage with internet via family members, computer courses and community groups. Attending community groups, which specifically taught participants how to use computers and the internet, provided participants with a space to learn, thus overcoming their unfamiliarity of using the internet. Some participants, who did not attend community groups which taught computer and internet use, suggested that this is something they wished to do in the future, but proposed that such groups need to be suitably scheduled for older adults. Attending community groups which taught computer and internet use increased some participants' confidence and reduced feelings of

fear when engaging with the internet. Female participants also valued the social aspect of attending such groups.

6.6 Reflections on the social construction of the internet

Social constructionism (see Section 3.1) suggests that knowledge is developed through social processes, particularly language. Through discussion with family members a few participants were motivated to use the internet as it was seen as a useful tool in a society which was becoming ever-more technologically advanced. However, most participants did not use the internet as they did not perceive themselves as a generation of internet users, this perception stemmed from watching younger generations engage with the resource. Participants viewed younger generations as more proficient and familiar with using the internet, particularly as it was required for employment roles. Participants conveyed their unfamiliarity with the internet using metaphors (e.g. '*its like Greek to me*'). Through the use of metaphors, participants could problematize their unfamiliarity with the internet. Participants' negative perceptions of social media were developed through friends talking about their experiences on such sites and the discourse within the wider media, such as newspapers. Participants' views and understanding of the internet were influenced by their interactions with family members, friends and the media.

Some participants suggested that society was changing and that the internet was evolving as a source of information and social contact. Although, self-management strategies were often social processes (e.g. talking to friends, attending community groups), participants did suggest that learning how to use the internet is important for older adults who cannot access in-person interaction. Participants believed that the internet could be a possible source of communication in the future, if they were ever housebound, this highlights the influence of time and social circumstances upon how older adults may self-manage their distress; two key tenants of the social constructionist approach.

Summary

Within this chapter I have explored the role of the internet in how participants self-managed their experiences of distress. All participants reported having access to the internet, but only a few participants used the internet for hobbies and/or interests, online shopping or communication. Most participants did not report using the internet and described a range of barriers to general internet use.

When self-managing their experiences of distress, participants did not use the internet as a source of health information about mood problems, or as a means to access social support. For the internet to be seen as a source of health information, a diagnosis of a physical illness was needed from a healthcare professional. Participants also described that the internet did not meet their social needs, a preference for in-person communication was reported.

A small number of participants were motivated to learn how to engage with the internet. Participants learnt how to use the internet from younger family members, computer courses and community groups which specifically taught computer and internet use. I concluded the chapter with a philosophical reflection on the social construction of the internet.

In the next chapter I describe the impact of a Patient and Public Involvement and Engagement (PPIE) group upon the study.

Chapter Seven: The impact of patient and public involvement and engagement on my study

Introduction

Patient and Public Involvement and Engagement (PPIE) has been influential throughout this study. From the outset of this study, I acknowledged that older adults may hold stigmatised attitudes towards mood problems (Cornford, Hill, & Reilly, 2007; Connor et al, 2010). Thus, I sought advice from older people with experience of such problems to ensure that the research questions I posed were relevant and framed appropriately, and that the methods selected to address these questions were acceptable. I also recognised that use of the internet may not have been familiar to all older adults (Office of National Statistics [ONS], 2018), therefore, working with PPIE members increased the likelihood that the research questions and methods were inclusionary.

This chapter focuses on the role of PPIE in my study and the impact it has had. I begin by providing a summary of literature that I engaged with to support my approach to PPIE activities, including discussion of the definitions and history of PPIE for context. Following this, I discuss: involving the public in health research, the challenges of PPIE and training PPIE members in research methods. I then apply the Guidance for Reporting the Involvement of Patients and the Public, version 2 (GRIPP 2) framework to report PPIE in relation to the current study.

7.1 Background to PPIE

To contextualise the research focusing on PPIE, I conducted a narrative literature review. I approached reviewing the literature using the same method I employed when conducting the narrative literature review for the study. The review was guided by Keary, Byrne and Lawton's (2012) recommendations (as described in Chapter two, Section 2.1). I first began by

identifying subjects and key words that were relevant to PPIE, such as: 'patient involvement', 'public involvement', 'lay involvement', 'user involvement', 'patient engagement', 'public engagement', 'research user groups' and 'patient and public involvement and engagement'. I utilised these terms to search the literature to identify key authors and sources. The electronic databases I searched were: Web of Science, PubMed, Medline, Psycinfo, Psycarticle and CINAHL. I identified full-text articles and searched their reference lists to ensure literature was not overlooked. Literature was selected on the basis of which it could inform how I integrated PPIE within this study.

7.1.1 Defining PPI(E)

Within the United Kingdom (UK), the involvement of patients and members of the public to inform health research is established through a national coordinating body called INVOLVE, an arm of the National Institute for Health Research (NIHR). INVOLVE (2010) define patient and public involvement (PPI) as 'doing research 'with' or 'by' the public, rather than 'to,' 'about' or 'for' the public' (p3). For the purpose of PPI, members of the public include: patients, potential patients, carers of patients and individuals from organisations that represent people who use healthcare services (INVOLVE, 2015). INVOLVE (2012) make a clear distinction between PPI and public engagement. INVOLVE (2012) define public engagement as 'where information and knowledge about research is provided and disseminated' (p6). INVOLVE (2012) believe that research should engage with the public to ensure a flow of knowledge between research institutes and society. The National Coordination Centre for Public Engagement (2018) suggest public engagement is a two-way process which involves researchers and members of the public interacting, discussing, and listening to each other's views on research, particularly research findings.

To identify the impact that PPIE has had on my study, I refer to Crocker et al's (2016) definition of PPIE impact which is as follows:

> '…any effect, positive or negative, that members of a PPIE group have on the research process and outcomes, this includes an individual's impact within a given study, and the impact of PPIE more generally on the culture of research.'

(Crocker et al, 2016: p586)

Crocker et al were one of the few authors who offered a definition of PPIE impact.

7.1.2 A brief history of PPIE

The history of PPIE within the UK is rooted in service user involvement within mental health services. NHS England defined service user involvement in the following way:

> '… the process by which people who are using, or have used a service, become involved in the planning, development and delivery of that service.'

(NHS England, 2015: p1)

Over the past five decades, mental health services have undergone significant changes in the UK with the views and experiences of service users being used to inform the planning, and delivery, of services. The changes in the mental health services were reported to be due to the de-institutionalisation of mental health patients in the 1960s (Pilgrim & Waldron, 1998). Pilgrim and Waldron suggested that, due to de-institutionalisation, an increase of individuals with mental health problems are living in community settings, this has heightened these individuals' expectations of the right to mental health services which best suit their needs. In 1973 service user involvement extended from the mental health field and became a key policy driver which underpinned health services (Tait, 2005). Service user involvement gained more momentum in the 1990s and expanded to include members of the public, not just patients who

used healthcare services (Department of Health, 1999). In 2006 the UK government aimed to create a patient centred National Health Service (NHS) and made it a legal requirement that all NHS organisations engaged with service users, and members of the public, in the planning and delivery of local services (Department of Health, 2006). The Department of Health (2006) also replaced the term 'service user involvement' with 'patient and public involvement'.

Following the restructure of the NHS in April 2013 (described in Section 1.1.3), a key political aspiration was to ensure that patients and the public had more control over the healthcare system (NHS England, 2014). The UK government has given more power to the public in the design and delivery of healthcare services. Within the 'Five Year Forward View' NHS England described that 'patients and communities offer the healthcare system a renewable energy' (p9). This quote from NHS England suggests that healthcare services should use the public as a resource which implies that healthcare professionals and researchers have power over when to include the 'renewable energy' in the design and delivery of healthcare services.

The issue of power when including the public in decision-making for healthcare services cannot be ignored. According to Arnstein (1969) public (or citizen) participation in decision making and planning processes is a categorical term for power. Therefore, understanding participation means understanding power dynamics between the public and powerholders. According to Arnstein powerholders include politicians, project leaders and bosses of companies. Arnstein believed public involvement is when members of the public are trying to acquire the power to make institutions receptive to their views and developed a 'ladder of citizen participation'. Figure 7 is an amended version of Arnstein's ladder (p217).

Figure 5 Arnstein's (1969) 'ladder of citizen participation'
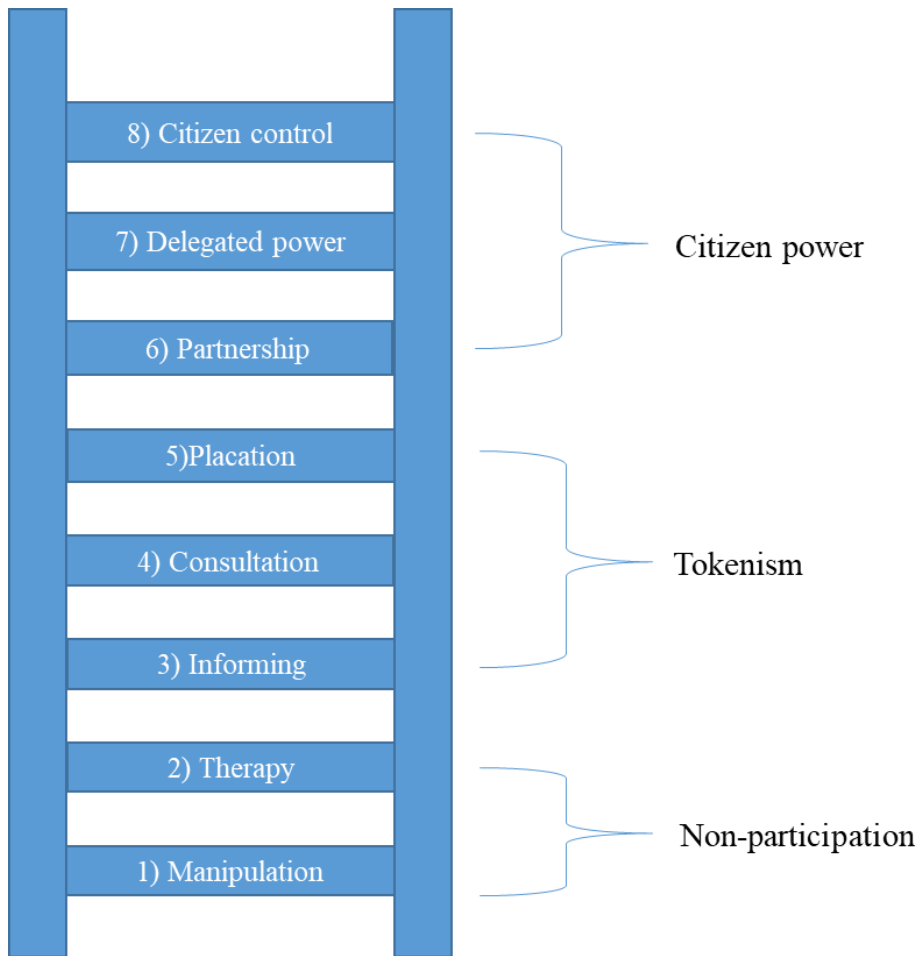
The bottom rungs of Arnstein's (1969) ladder, manipulation and therapy, are levels of non-participation. The aim is for powerholders to educate citizens. When conducting health research, Arnstein's levels of non-participation go against INVOLVE's (2010) aim of doing research with the public, rather than to the public. The ladder then progresses to levels of tokenism which includes: informing, consultation and placation. The public are allowed to voice their opinions to the powerholders, however they lack the power to ensure that their voice will change the powerholders' decisions. Placation is a higher level of tokenism, it allows citizens to advise or plan programmes but, ultimately, powerholders have the right to judge the legitimacy of the advice. The ladder then progresses to forms of citizen power whereby the public have increasing degrees of influence over decision making. Partnership is

whereby power is exchanged and redistributed through negotiations between the public and powerholders. At the upper rungs are delegated power, whereby the public make most of the decisions, and citizen control, where the public hold full power. Achieving delegated power or citizen control is not always possible: different political, social and economic contexts may create different environments, offering different opportunities and constraints (Davidson, 1998). For example, in the context of completing a PhD which needed to be my own work, I could not give members of the public full control of this study.

Arnstein's (1969) model has influenced public involvement in health services (Tritter & McCallum, 2006), however, there are limitations of the framework. Lithgow-Schmit (2006) argued that Arnstein's ladder was value laden meaning that judgements are built into the model. The lower rungs are seen as poor citizen participation whereas the upper rungs are perceived as good participation. Tritter and McCallum also argued that Arnstein ignores that there may be different forms of knowledge and expertise. For example, an individual living with a mood problem is more knowledgeable about managing that problem on a day-to-day basis than a healthcare professional who does not suffer from the said problem. Tritter and McCallum argue that for public involvement to improve health services, it must acknowledge the diversity of knowledge and experiences of both health professionals and the public.

Arnstein's (1969) framework demonstrates an overt struggle for power between members of the public trying to progress up the ladder and powerholders, accordingly giving power to one group (i.e. members of the public) ceases power to another (i.e. powerholders). Arnstein's hierarchy of participation fails to capture the complexity of public involvement. Arnstein assumes that any power differences between members and non-members of research institutions are replicated without being given any thought. In contrast to Arnstein's hierarchy framework, Tritter (2009) suggests that research participants and researchers are equal co-creators of knowledge. Although Tritter's work ignores the effects of power and hierarchies

which are inherent within social structures, Tritter proposed that bringing together a partnership of different groups (e.g. those with a mood problem and healthcare professionals), can result in better research, health services and health outcomes.

7.1.3 PPIE and health research

INVOLVE (2010) propose that involving the public in health research should consist of 'an active partnership between the public and researchers in the research process, rather than the use of people as the 'subjects' of research' (p6). INVOLVE suggest that members of the public bring their own expertise and knowledge to the research process, a perspective that may differ from researchers' beliefs and viewpoints.

In order to conceptualise PPIE activities in health research, Buckland (2007) sought to build a theoretical framework. Buckland (p7) condensed Arnstein's (1969) ladder of participation into three categories, described in Table 11.

Table 11 Buckland's (2007) categories of participation

Category of participation	Explanation
Consultation	Asking the public for their views and using those views to inform decision making
Collaboration	An active, on-going partnership with the public. The public may collaborate with researchers to design, undertake and/ or disseminate the results of a research project
User-led	The public designs, undertakes and disseminates the results of a research project

INVOLVE (2018) suggested that co-producing research projects between researchers and the public involves both consultation and collaboration. Central to INVOLVE's idea of co-producing research is valuing the public's expertise and sharing power over the research project. When compared to health research which has collaborated or consulted the public, little user-led research has been funded (Staniszewska, 2007). Oliver et al (2008) suggested

that user-led projects do not get funded as there is not enough time or financial resources available to train the public in how to conduct quality research.

The integration of PPIE within the review of grant applications can identify issues that were perhaps missed by health researchers (Tarpey & Royle, 2006). Oliver et al (2008) argued that PPIE ensured that the perspectives of patients are explicitly addressed within research questions; this makes the questions more meaningful to target populations. PPIE activities have also shaped studies by providing feedback on a study design or by offering a new perspective on findings (Brett et al, 2014; Mohor et al, 2010; Shippee et al, 2013). Jinks et al (2016) used a case of a Primary Care Research Centre to provide a historical account of PPIE in that specific centre, particularly focusing on the sustainability and impact of PPIE. The authors found that study teams reported enhanced ethical practices and improved validity of research instruments. The ability to test out the feasibility of study designs increased researchers' confidence that their study design was viable in a context outside of academia. Ennis and Wykes (2018) also found that studies which included PPIE activities when developing study methods were more likely to achieve recruitment targets. PPIE can also ensure that the research findings are disseminated outside of the academic sphere and to relevant sections of the wider community (Howe et al, 2010).

7.1.3.1 Challenges of PPIE

I will now discuss the challenges of integrating PPIE into the research process. One of the main challenges is ensuring that PPIE members reflect the study's sample population. 'Hard to reach' groups, such as individuals with rare diseases and people from minority ethnic groups, are less likely to be involved in PPIE workshops (Hussain-Gambles, 2003; Crome et al 2011). Such groups may have different research priorities or perspectives on research processes.

Within a narrative synthesis, Boote et al (2011: p111) identified common challenges when integrating PPIE into research; I present these challenges within Table 12.

Table 12 Boote et al's (2011) challenges of PPIE

Challenge identified by Boote et al (2011)	Description of challenge
Time pressures	The involvement of PPIE has time implications for the research process
Resources	Adequate resources such as funding and researchers' time is needed to conduct PPIE
Continuity	Research may struggle to involve the same PPIE members throughout the research process
Group dynamics	Building a positive relationship between the researchers and PPIE members, and between the PPIE members themselves
Research ethics	Identifying if obtaining ethical approval is needed
'Representativeness' of members involved	Ensuring the PPIE members represent the wider population

Hyde et al (2016) suggested that the examples described by Boote et al (2011) provided a comprehensive framework for reporting the challenges of integrating PPIE within a study. I acknowledge the challenges provided by Boote et al's framework when taking a critical perspective on PPIE in Section 7.2.5. I also draw upon wider literature as Boote et al did not specifically identify the challenges of integrating PPIE into qualitative research.

7.1.3.2 Training PPIE members in research methods

When integrating PPIE into the analysis phase of a study, it is important to decide if PPIE members should be offered a research methods training package. Williamson, Brogden, Jones and Ryan (2010) conducted a qualitative study that aimed to identify the strategies that older adults used to prevent and manage loneliness. To inform the research process, researchers recruited 10 PPIE members aged 55 years old and over. Williamson et al ran classes which

taught PPIE members how to conduct a thematic analysis (Braun & Clarke, 2006). Following on from this training, each member of the PPIE group independently analysed and interpreted each interview transcript produced from data collection. These interpretations were used to critically examine and agree on the final findings of the study. Williamson et al argued that the PPIE group's interpretation ensured that relevant themes were identified and explored, adding credibility to the overall interpretation of the findings. Lovell (2012) also aimed to enhance PPIE members' knowledge of qualitative data collection and analysis methods by providing a training course for PPIE members. Lovell's training course comprised of six sessions over the course of six months. The thirteen PPIE members that participated all reported an increase in knowledge about qualitative methods. Although the training course was resource intensive and required two to three trainers per session, one of the key messages that came through from the PPIE members was the view of being perceived as an equal amongst researchers throughout the training course. This contrasts Arnstein's (1969) view that power differences exist between researchers and the public which are replicated without being reflected upon. However, Lovell's research failed to explore if the researchers viewed the PPIE members as having equal power to themselves.

Bayliss et al (2016) aimed to identify an effective way of involving the public in a qualitative meta-synthesis study. The process of being involved in a meta-synthesis study was evaluated by eight PPIE members via an open-ended questionnaire. To enable them to understand the task, PPIE members highlighted the importance of training ahead of the workshop. The questionnaire was emailed to PPIE members by researchers who were involved in the meta-synthesis study; PPIE members may have been more critical if they had been asked to evaluate the study by a third party. Bayliss argued that training PPIE members is vital to enable them to be involved in research processes. However, it is debatable if trained PPIE

members are representative of the wider public who may not be as knowledgeable about research methods.

7.1.3.3 Potential negative impacts of PPIE

PPIE could have a potential negative impact upon the relationship between researchers and PPIE members. Ali et al (2006) aimed to include PPIE activities within the design of a study upon oxygen supplementation in acute stroke patients. The PPIE group which informed this study included stroke patients and their carers. As a result of a stroke, researchers highlighted that potential participants could suffer from cognitive problems and may not have the capacity to give informed consent. The PPIE group felt that an inability to give informed consent should not prevent patients from participating in the study. There was an ethical conflict regarding the protocol design which resulted in tension between PPIE members and researchers. Ultimately, the researchers were responsible for the research and made the final decision. Ali et al's study highlights that researchers need to clearly define how PPIE can influence studies as PPIE members may lack knowledge about research governance.

A lack of clarity around the aims of integrating PPIE into the research process may result in confusion on PPIE members' behalf (Coglianese et al, 2003). Coglianese et al found that feelings of confusion led to PPIE members feeling disempowered and questioning how they could contribute to the research process. Coglianese et al did not explore if such feelings prevented PPIE members from contributing to subsequent PPIE workshops. Researchers must try to foster an environment whereby PPIE members feel confident to voice their opinions (Bayliss et al, 2016). To feel confident to engage in PPIE activities, Bayliss et al suggest that PPIE members need clear instructions and examples of how they might inform the research process. Bayliss and colleagues also discussed that a PPIE member may develop a negative perception of PPIE activities if they do not feel comfortable in providing their feedback on the research; this may deter them from attending PPIE workshops in the future (Farrell, 2004). To

build a PPIE member's confidence, PPIE meetings need to be conducted in a clear and organised manner to prevent confusion.

An overarching problem is when PPIE activities are conducted in a tokenistic manner. Tokenistic PPIE is when the purpose of PPIE becomes less about the value of public perspectives, and more about how such activities will appear to others (e.g. funders) (Domecq et al, 2014; Green, 2016). Research funders such as the NIHR, charities and research councils often require an element of PPIE within health research projects. The Research Excellence Framework (REF) also assesses higher education institutions and takes into account PPIE activities (Higher Education Funding Council for England, 2009). In a review of the literature, Shippee et al (2013) reported that PPIE is often done as a 'tick box' activity to meet the requirements of funders. Tokenistic PPIE fails to reap the benefits of integrating the public's viewpoints within the research process and PPIE members may not feel as though their contributions are valued; this could have a negative impact upon PPIE members' relationship with researchers (Ocloo, 2016).

7.2 Reporting PPIE

Petit-Zeman et al (2013) and Esmail et al (2015) argued that the evidence regarding the impact of PPIE in health research is weak. The GRIPP 2 was the first international, evidence-based framework developed to improve the reporting of PPIE within health research (Staniszewska et al, 2017). The GRIPP 2 has been integrated into the 'Enhancing the Quality and transparency of health research' network, an international initiative aimed at promoting transparent and accurate reporting of health research (Simera, Moher, Hoey, Schulz & Altman, 2010). I used the short form of the GRIPP 2 when reporting the current study's use of PPIE. Staniszewska et al suggested that the short form of the GRIPP 2 can be used in relation to studies which are not purely focused on PPIE. The longer version of GRIPP 2 is more

suitable for studies which are solely reporting PPIE activities. As seen in Table 13 the GRIPP 2 (p358) proposes that the researcher must address five key topics.

Table 13 GRIPP 2 short form

Topics	Item
Aim	Report the aim of PPIE in the study
Methods	Provide a clear description of the methods used for PPIE in the study
Results	Report the results of PPIE in the study, including both positive and negative outcomes
Discussion	Comment on the extent to which PPIE influenced the study overall. Describe positive and negative effects
Taking a critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not

I will now use the GRIPP 2 framework to report PPIE activities within the context of my study.

7.2.1 Aims

The aim was to integrate PPIE into four key stages of the research process:

- When developing the research questions

- When developing the methods

- When interpreting the findings

- When creating a dissemination plan

Figure 8 identifies where and how PPIE has impacted the current study. Each stage of PPIE corresponds with one of the four aims to integrate PPIE into the research process.

Figure 6 Impact of PPIE
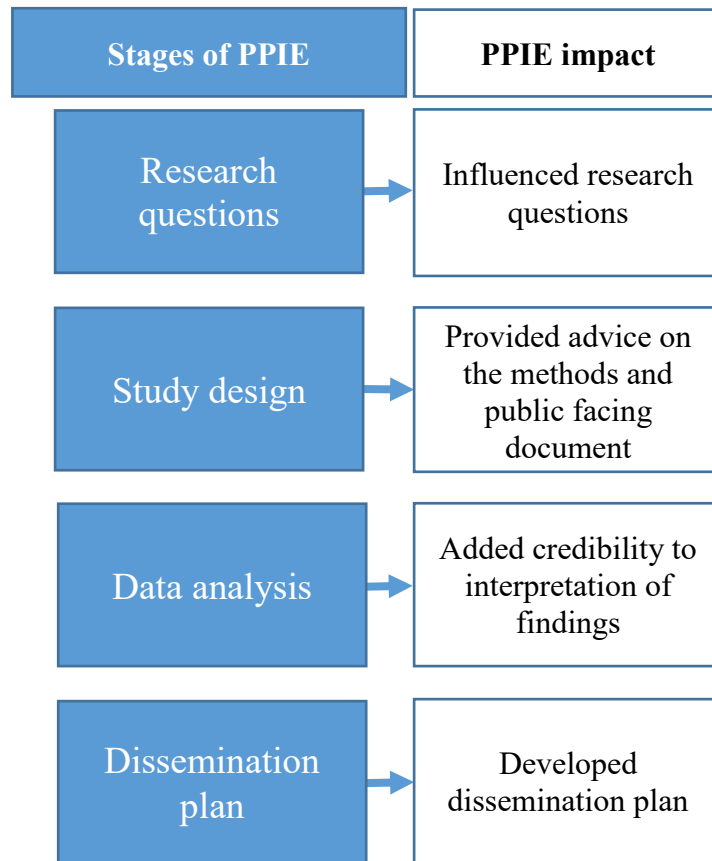
This study was funded by an ACORN studentship. PPIE perspectives were sought on the application for the ACORN studentship where phrases such as low mood, self-management and the internet were discussed.

I integrated PPIE into the research process when developing the research questions as I aimed to ensure relevant questions were being addressed. I also aimed to ensure that the methods were appropriate for the target sample by including PPIE perspectives. To increase trustworthiness and credibility, I aimed to seek feedback from PPIE members upon the interpretation of the data. To identify relevant audiences who may be interested in the findings, I also aimed to create a dissemination plan with a PPIE group.

7.2.2 Methods

The Research Institute (RI) for Primary Care and Health Sciences at Keele University has an established Research User Group (RUG) which supports the integration of PPIE within research (Jinks et al, 2016). The RI has been chosen as a test-bed to implement the six national standards for public involvement in research over the course of 12 months from April 2018 to April 2019 (Standards Development Partnership Group, 2018: p7). Table 14 describes each of the six national standards.

Table 14 The national standards for public involvement in research

Standards	Description of standards
1) Inclusive opportunities	To offer public involvement opportunities that are accessible and that reach people and groups according to research needs
2) Working together	To work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships
3) Support and learning	To offer and promote support and learning that builds confidence and skills for public involvement in research
4) Communications	To use plain language for timely, two way and targeted communications, as part of involvement plans and activities.
5) Impact	To capture and share the difference that public involvement makes to research
6) Governance	To involve the public in our governance and leadership so that our decisions promote and protect the public interest

At the start of the research process, I aimed to recruit older adults, aged 65 years old and over, who currently, or had previously, suffered from low mood. To register my intentions to use PPIE throughout the research process, I sent a PPIE request form (see Appendix 12a) to the PPIE team within the RI. With support from the PPIE team, older adults with low mood were invited to attend three workshops which addressed the four aims of integrating PPIE into the

current study. At the beginning of the research process, I liaised with a Project Coordinator from the PPIE team who provided me with training material. The Project Coordinator was involved prior to preparation of the first workshop and gave advice on how to approach the workshops; together we agreed the aims and design of the first workshop. The Project Coordinator suggested that the first workshop should be facilitated by myself and a supervisor (HB), but proposed the following workshops could be facilitated by myself alone. I also liaised with a User Support Worker (USW) from the RI's PPIE team. The USW recruited PPIE members to take part in my workshops and was a point of contact for PPIE members.

I contacted the PPIE team three months prior to each workshop, this allowed the USW time to recruit PPIE members. Workshops were planned by myself and then reviewed by the Project Coordinator. Each workshop lasted three hours and used a mixed format of presentations and group discussions. I allowed plenty of time for each activity within the workshops, particularly when asking members to read and comment upon public facing documents (e.g. the poster and information leaflet).

Four members of the PPIE group attended the first workshop which was held on the 4th February 2016, I introduced myself and my research interests. The group discussed the proposed research questions and described key issues that they thought were important regarding the mental health of older people and self-management. I also introduced the concept of 'think aloud' methods and we discussed the use of a transcript from an online forum and storyboards. The group and I started to work together to create two storyboards. On the 26th March 2016, three of the same people who attended the first workshop also attended the second workshop. I presented the storyboards that were co-created in the prior workshop and invited further feedback. I also gathered feedback on public facing documents and the topic guide. I held the final workshop on the 27th July 2017 and this group was attended by

five PPIE members, three of the members had attended all three workshops. The group and I discussed the study's findings and created a dissemination plan.

All workshops were audio-recorded. I obtained permission to digitally record discussions for the purpose of clarity, and to enable me to write detailed summaries of the workshops for both myself and PPIE members to reflect upon. The audio-recordings were deleted once I had written summaries of the workshops. No verbatim quotes from PPIE members were used in these notes. Once I had produced a summary of each workshop, I sent these to the USW who then distributed the summaries to the PPIE members. I invited PPIE members to provide feedback on the summaries and gave them my contact details to do so. As recommended by INVOLVE (2013), PPIE members were offered reimbursement for their time and travel. A summary of each meeting is provided within Appendices (12b, 12c and 12d).

To capture how PPIE influenced the study, I documented how the research changed after each workshop. Before each workshop, I recorded mine and my supervisors' viewpoints and discussions about the research from supervisory meetings. Within the workshops PPIE members and I discussed our views on the research. After each workshop, I liaised with my supervisors and discussed how the advice from PPIE members could affect the research. When writing the summary of each workshop, I described any changes made to the research as a result of PPIE members' contributions.

7.2.3 Results

I will now report the results of including PPIE in my study. I will begin by describing the impact of PPIE upon the research questions and then go onto discuss the impact upon the methods, data analysis and dissemination.

7.2.3.1 Impact upon research questions

The PPIE members agreed with the literature presented in Section 2.4 and suggested that older adults hold stigmatised views of anxiety and depression. The PPIE group thought that such views would prevent older people from self-identifying as experiencing anxiety or depression. I wished for the research to focus on low mood, however, the PPIE group thought that the research should incorporate symptoms of anxiety. The group thought that whilst some older adults often experience symptoms of depression (e.g. feeling low), other older adults may experience symptoms of anxiety (e.g. feeling stressed). The PPIE group's suggestion that older adults could experience symptoms of depression, or anxiety, fits in line with literature presented in Section 2.2 which proposed that such mental health problems are prevalent among older people.

Members of the PPIE group thought that the research should focus on the concept of distress. The group thought that the term distress alludes to symptoms of depression and anxiety (e.g. low mood and stress). Social constructionism stresses the importance of language, terms such as distress are socially constructed between members of groups within society (Gergen, 2009). As the PPIE members were older adults with mood problems, it is likely that participants in the study would interpret distress in the same way as the PPIE group. Due to the stigma surrounding anxiety and depression, PPIE members believed that older adult would more likely self-identify as experiencing distress. The advice from the PPIE members, along with the literature, resulted in the adaption of the research questions, as detailed in Table 15.

Self-management was deemed an appropriate research topic by the PPIE group as they believed that self-responsibility of health should be encouraged. One PPIE member was sceptical that older adults would not use the internet to self-manage their experiences of distress. However, the whole group agreed that it would be important for this study to explore

why people do, or do not, use the internet to self-manage distress. PPIE members believed

that this information may be useful for healthcare professionals when directing older adults to

certain self-management strategies.

Table 15 Modification of research questions

Research Questions prior to PPIE input	Research Questions after PPIE input
What self-management strategies do older adults with low mood use?	How do older adults self-manage their experiences of distress?
What is the role of the internet in the self-management of low mood for older adults?	What is the role of the internet, particularly online forums, in how older adults self-manage distress?

7.2.3.2 Impact upon methods and materials

I will now describe how PPIE members' feedback shaped the methods used in this study.

PPIE had an impact upon public facing documents, the topic guide and the 'think aloud'

activities.

I showed a PPIE group a draft poster and received advice on how to modify it. The group

thought that the poster should have slips, containing my contact details, which potential

participants could rip off and take with them. PPIE members thought that slips would be

valuable as potential participants would not have to write down my contact details. To make

the poster more aesthetically pleasing, the group recommended including a picture of a

Cherry Blossom tree. The poster can be found in Appendix 4.

I also presented PPIE members with a draft information leaflet. Similar to the poster, the PPIE

members suggested including a picture of the Cherry Blossom tree to make the information

leaflet more aesthetically pleasing. PPIE members also recommended that the leaflet should

state that the study is being conducted to aid mental health research, they believed this may

motivate potential participants to take part in the study. Some of the PPIE members suggested

that allowing participants three months to withdraw their data after the interview was

inappropriate, this was not modified due to ethical reasons which were explained to the group. The information leaflet can be found in Appendix 3.

A PPIE group were also shown the topic guide that I planned to use within the interviews. The PPIE members did not modify the wording of any questions. However, the group did propose that I add an additional question which revolved around the self-management strategies an older adult employed on their own. I incorporated this within my topic guide which can be found in Appendix 6. The PPIE group also commented upon the structure of the topic guide. PPIE members proposed that the interview needed to explore other self-management options before the internet was introduced as not every older adult may use the resource. Taking the PPIE members' feedback into account, I ensured that questions regarding the internet and 'think aloud' activities were at the latter end of the topic guide. However, semi-structured interviews are dictated by a participant's narrative, therefore, the structure of the topic guide was not followed definitively in all interviews.

PPIE members were invited to critically discuss the potential of including 'think aloud' activities within the interviews. The PPIE members all believed that the 'think aloud' activities would be a good way to create discussion. Guided by the literature presented in Sections 3.2.4 and 3.2.5, I discussed using a transcript from an online forum and storyboards as potential 'think aloud' activities with PPIE members. The group thought that using the transcript from an online forum would be a good way to create discussion on the support gained within such forums. The transcript used within the interviews is documented in Appendix 8.

When first discussing the use of storyboards in the study, I suggested that participants could be asked to create their own storyboards. Feedback from the PPIE group suggested that potential participants would be more comfortable verbalising their opinions on pre-created

storyboards. The PPIE group believed that asking participants to create their own storyboard would deter older people from participating in the study. PPIE members thought that using pre-created storyboards would be a good way to create discussion on why, or why not, a participant would use an online forum to access health information or social support. The challenge of using pre-created storyboards is ensuring that they are suitable for potential participants, for this reason it was important that the storyboards were co-created between myself and the PPIE group. I showed PPIE members two basic storyboards (Figure 9 and 10) to create discussion. One storyboard depicted a positive encounter within an online forum, the other depicted a negative encounter. PPIE members believed that the storyboards created a context regarding how an older adult may come into contact with an online forum. Figure 11 and 12 are the co-created storyboards which were used in the interview. Table 16 documents the key comments on the storyboards.

Figure 7 Draft storyboard one

Catherine is suffering from a low mood but feels apprehensive to join an online forum to talk about her problems.

Catherine signs up to an online forum and finds a supportive environment to discuss her problems in and gets helpful advice.

Catherine's low mood is feeling alleviated after a positive encounter within the online forum.

Figure 8 Draft storyboard two

Lillian is suffering from a low mood and is hopeful an online forum will give her information on how to cope.

Lillian receives a lot of unhelpful information, most of which she does not understand.
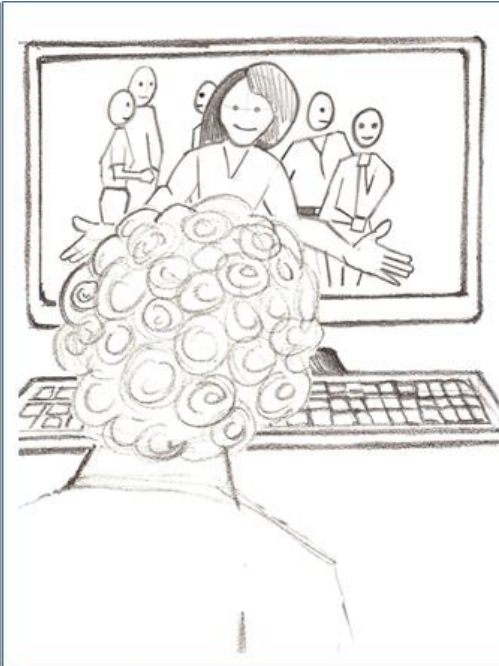
Lillian is left feeling frustrated.

Figure 9 Storyboard one

Frame One | Frame Two | Frame Three

Catherine has just lost her husband and is feeling lonely and thinking about the future makes her stressed. Catherine decides to look on the internet for help.

Catherine signs up to an online forum and finds a supportive environment to discuss her problems and gets helpful advice about how to deal with grief.

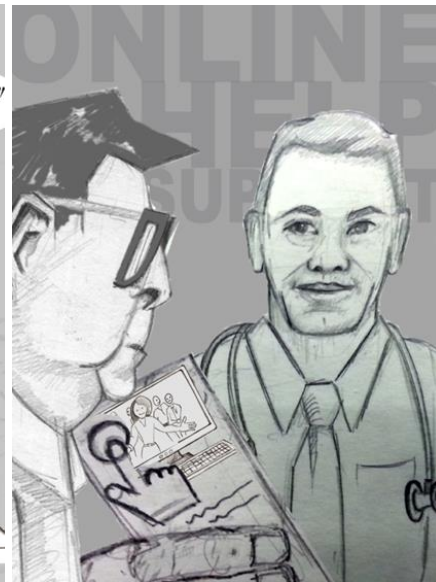Catherine's mood has improved after a positive experience using an online forum.

Figure 10 Storyboard two

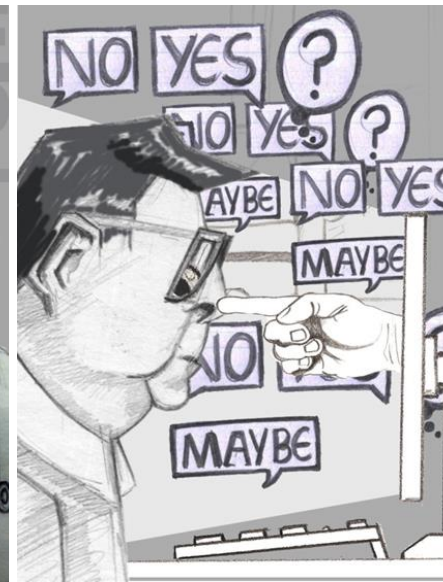Frame One   Frame Two   Frame Three   Frame Four

Peter has been feeling low for a while. He decides to go and see his GP.

Peter's GP diagnoses Peter with depression and offers him some medication. Peter doesn't want to take the medication. The GP gives Peter some health information leaflets which suggest going online to access information

Peter joins an online forum where unhelpful advice was given, Peter was told it was his fault he was feeling this way and he should "pull himself together".

Peter doesn't feel much better, and is not sure what to do. Peter worries about going back to see his GP.

Table 16 PPIE comments on storyboards

Overall comments	• The PPIE members' feedback suggested that the pictures should be simplistic, hand-drawn and the colour scheme should be black and white, I agreed.
Storyboard one	• The PPIE members and I thought that the drawing of Catherine had the characteristics of an older female who lived in North Staffordshire. The PPIE group thought that this would make the character more relatable to participants.
Frame One	• The group felt that Catherine should have faced a situation that would cause distress that potential participants could relate too. Myself and the PPIE members agreed that being bereaved was a relatable situation for many older people. • PPIE members thought that Catherine needed a reason to use an online forum as a source of information or support. The PPIE group and I thought that feeling alone and stressed about the future could be a motivation for Catherine to use an online forum. • The PPIE members believed the picture should show Catherine in her home in front of a computer, I agreed.
Frame Two	• Myself and the PPIE members thought that the second frame should show Catherine signing onto an online forum. The PPIE members also thought that this frame should relate to Frame One by continuing the thread of being bereaved. The group though the wording should state that Catherine got 'helpful advice about how to manage her grief', I agreed. • The PPIE group advised that the picture should show people with open arms, within the computer screen, to represent a welcoming community. I agreed.
Frame Three	• The advice given from the PPIE members was to show Catherine smiling with a computer screen compiled of smiling faces behind her. I thought the text should describe how Catherine's mood had improved after using an online forum, the PPIE group agreed.
Storyboard two	• The PPIE members suggested that the character should be a man. I thought that this would ensure a gender balance. • Both the PPIE group and I believed that the drawing of the character, Peter, represented an older man who lived in North Staffordshire that potential participants could relate too. • The PPIE members thought that four frames were necessary for the scenario to include enough detail, I agreed.

Table 16 PPIE comments on storyboards continued

Storyboard two	
Frame One	• The PPIE group thought that, unlike Catherine who was stressed, Peter should be suffering from low mood. I agreed as this related to the subjective concept of distress which could allude to feelings of stress or low mood. • I thought that Peter's low mood should result in him seeking help from a GP, PPIE members agreed. • Both myself and PPIE members believed that the picture should depict Peter on the phone to a GP within his home.
Frame Two	• I and the PPIE group thought the frame should indicate that Peter was attending a GP consultation which resulted him being diagnosed with depression. • The PPIE members suggested that Peter should be offered medication that he did not wish to adhere too. The group thought that this reflected an older adult's negative perception of medication for mental health disorders, I agreed. • PPIE members and I thought that Peter should be signposted to the internet and online forums via a leaflet given to him by his GP. • The PPIE group suggested that the picture should represent the GP handing Peter an information leaflet which includes an image of a computer on it, I agreed.
Frame Three	• Myself and PPIE members thought that Peter should sign onto an online forum and receive unhelpful information. The PPIE group thought that the text should indicate that other online forum users told Peter it was 'his fault' he was feeling this way and that he should 'pull himself together'. The PPIE members believed that this was representative of the views of some older adults. • Both myself and the group believed that the picture should indicate a hand coming out of the screen pointing at Peter. This emphasises that the online forum users were suggesting his mood problems were 'his fault'.
Frame Four	• PPIE members thought that the storyboard should end with Peter showing no improvements and worrying about going back to see his GP, I agreed. • Myself and PPIE members believed that the picture should depict Peter worrying with a faded picture of a GP in the background.

The group thought that using both the storyboards, and a transcript from an online forum, would not only create discussion regarding online forums, but also on wider uses of the internet when experiencing distress (e.g. using the internet as a source of information about mood problems).

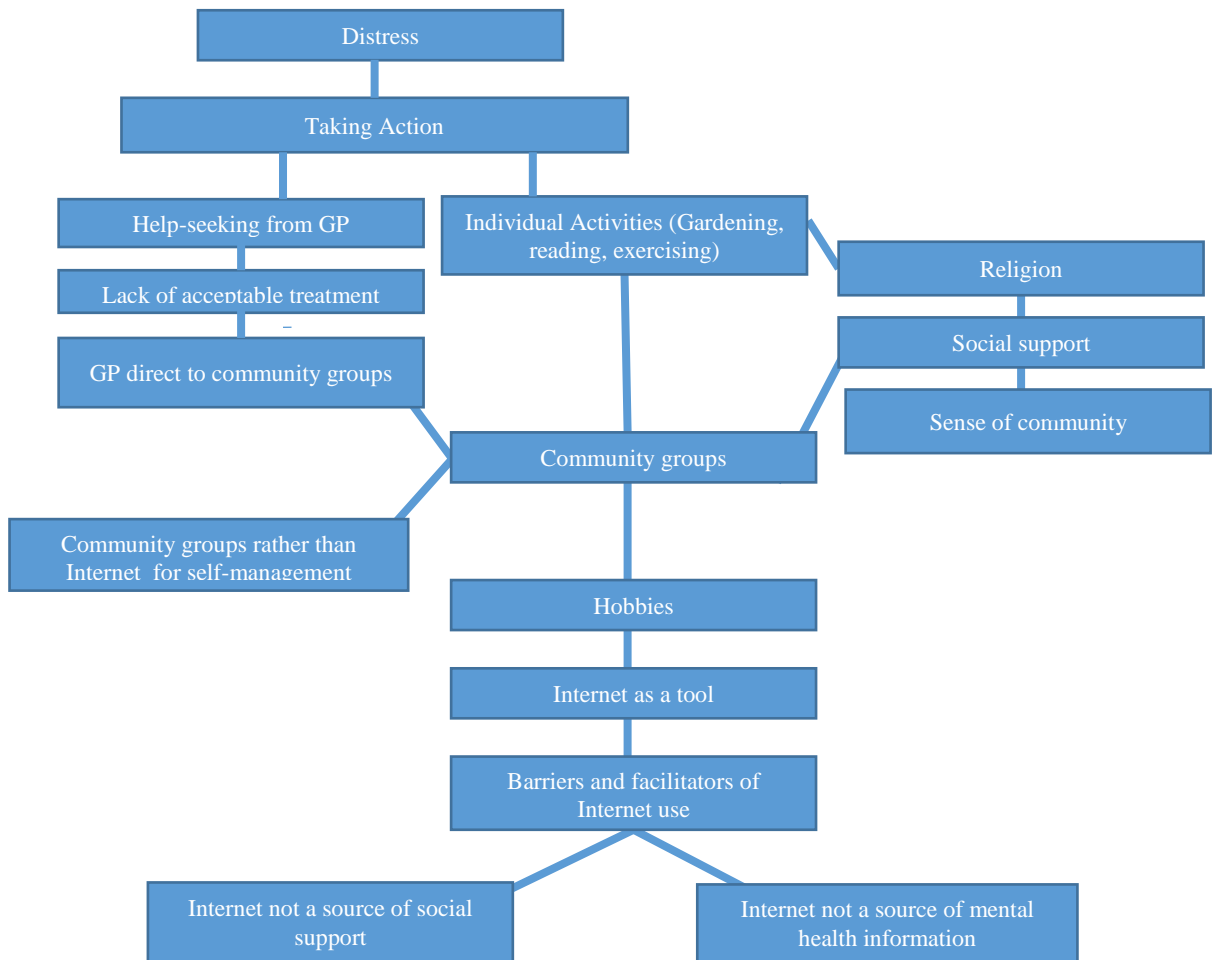### 7.2.3.3 Impact upon findings

PPIE members were also invited to share their perspectives on the interpretation of the data. One member of the PPIE group had knowledge about qualitative analysis methods, the other members did not. I provided a short and basic overview of the qualitative analysis methods I used in the study. The PPIE members were shown a thematic map of the data, as shown in Figure 13, and were also shown 18 anonymised quotes taken from interview transcripts. The quotes were chosen to illuminate an emerging theme (e.g. the internet and social support) or if they were discrepant by nature. I told PPIE members how I interpreted the data before asking them their opinions, I thought this may encourage discussion. The PPIE members' perspective of the data did not differ from the interpretation of the data presented to them, this arguably enhanced the credibility of the findings. When re-reading the notes and listening to the audio-recordings I noted three re-occurring threads that the PPIE members discussed. The threads were: the subjective nature of distress, the importance of in-person communication and the need for educational opportunities.

Similar to myself and my supervisory team, the PPIE members interpreted that experiences of distress were unique to each participant. Participants' experiences of distress are discussed in Section 5.3. The PPIE members also believed that the subjective nature of distress prevented participants from engaging within online forums. According to the PPIE group, the data illustrated that participants questioned if other online forum users would have been through similar experiences of distress. Participants' views upon socialising within online forums are discussed in Section 6.4.

The PPIE group interpreted that in-person communication with friends was important for participants when managing their distress. Seeking support from friends is discussed in Section 5.4.3. PPIE members also believed that participants saw the internet as a prevention of other activities (e.g. attending community groups or receiving in-person social contact). The internet as a prevention of other activities is explored within Section 6.2.4. The PPIE members discussed that participants were raised in a society with no access to the internet and believed this was why participants self-managed by communicating with their friends in-person. I report how participants did not view themselves as part of a generation of internet users in Section 6.2.4, whilst a preference for in-person communication is described in Section 6.4.

PPIE members discussed that the data indicated the need educational opportunities which teach older people how to use the internet. The PPIE group suggested that community groups, which taught computer and internet use, were vital educational opportunities for participants. PPIE members also suggested that an increase in educational opportunities may encourage older people to use the internet as a means to communicate in the future, if they wished too.

Figure 11 Thematic map shown to the PPIE group

7.2.3.4 Impact upon dissemination

I invited PPIE members to discuss relevant dissemination channels. I had concentrated on disseminating the findings within academic settings (e.g. at conferences and seminars). I also planned to disseminate the findings to third sector services, PPIE members strongly suggested I did this to ensure the findings were not purely disseminated within an academic context. Using their local knowledge of the area, the PPIE group recommended that I targeted third sector charities such as:

- The Beth Johnson Foundation

- Age UK

- North Staffs Carers

I plan to contact these charities in April 2019 and to disseminate my research in the summer of the same year. Dissemination will involve presentations and group discussions about my PhD findings.

7.2.4 Discussion

I have reported the use of PPIE within the current study by utilising the GRIPP 2 framework. An advantage of using the GRIPP 2 framework was that the aims, methods and impact of PPIE could be clearly addressed. The framework also encouraged me to offer a critical perspective of PPIE, as described in Section 7.2.5. In regards to the challenges of implementing PPIE, my critical perspective could be useful to other researchers who seek to integrate PPIE into future studies.

Shippee et al (2013) found that PPIE is often used as a 'tick box' activity to meet funding requirements. The current study was funded by an ACORN studentship which did not require me to integrate PPIE into the research process. A strength of this study is that I appreciated PPIE members' opinions, I think this is shown through how I integrated PPIE at key stages of the study. A limitation of this study's use of PPIE is that there was no critical evaluation of PPIE members' experiences of contributing to the study. Understanding PPIE members' experiences of contributing to a study may be useful for researchers when integrating PPIE into future research projects.

The PPIE work within this study shows how researchers can empower PPIE members without compromising their own sense of power. I gave PPIE members the power to give me advice on the research questions, methods, analysis and dissemination plan. I tried to empower PPIE members to give advice on the research process by: trying to create an environment where they felt comfortable to voice their opinion, and by showing them I valued their feedback by

providing notes of workshop which described how the study had, or had not, been adapted in light of their feedback. This challenges Arnstein's (1969) notion that giving power to a group, in this instance PPIE members, ceased my own power over the study. However, there are obvious hierarchies within research institutes. Unlike Tritter's (2009) work, I acknowledge such hierarchies. As I initiated the PPIE activities, had in-depth knowledge about the research process and held responsibility for the study, it was ultimately my decision to modify the research in light of PPIE members' feedback. As PPIE members were not trained in research methods, I did not give them the responsibility of carrying research decisions through.

7.2.5 Taking a critical perspective

There is the belief that although PPIE could add value to research, it should be critiqued and evaluated (Barber et al, 2012; INVOLVE, 2014). Taking Boote et al's (2011) framework (see Table 12 in Section 7.1.3.1) and the wider literature into account, I will now report the challenges of incorporating PPIE into the current study.

Boote et al (2011) proposed that, as researchers are often busy, a challenge of using PPIE may be time pressures. This research was a three-year funded PhD project and PPIE activities took place over 19 months. I had to carefully plan when to incorporate PPIE within the allotted timeframe. I allocated myself specific time to contact the PPIE team, to meet with the Project Coordinator and USW, to develop materials, to run the workshops and to write summaries. One resource that PPIE activities need is funding, which could be another potential challenge. I was fortunate that my ACORN funded studentship had funding allocated for research related costs, such as PPIE.

Ensuring the continuity of PPIE members attending the workshops is also a challenge (Boote et al, 2011). I invited each PPIE member who attended the first workshop to attend the two supplementary workshops. Three PPIE members attended all three of the workshops, one

member dropped out due to physical ill-health. The literature presented in Section 2.5.1 suggests that older adults with mood problems may also suffer from physical illnesses, therefore, I anticipated that some members may have wanted to limit PPIE involvement due to physical health problems. An additional two members were recruited for the final workshop.

Another challenge of running PPIE workshops is managing group dynamics (Boote et al, 2011). This included the dynamics between myself and PPIE members, and also the dynamics between PPIE members themselves. When developing the research questions, methods and a dissemination plan, PPIE members were keen to discuss their ideas or feedback. The members perhaps believed that they had power to influence the study as they were knowledgeable about being an older adult with a mood problem. However, PPIE members' perspectives on the data did not differ from the interpretation I presented to them. Although this arguably enhances the trustworthiness of the findings, it could have also been due to power dynamics. Whilst I gave a short overview of the qualitative analysis methods I used, it is unrealistic to expect PPIE members to develop complex analysis skills within one PPIE workshop. Therefore, PPIE members may not have challenged the interpretation presented to them due to the perception that they did not have enough power to influence the analysis.

To ensure that the PPIE members felt appreciated, I allocated time before, during and after each workshop to liaise with them on an informal level. During this time PPIE members could raise any concerns or provide further feedback on the study. After each workshop I gave each PPIE member my contact details and encouraged them to provide additional comments on the study. Although no members did contact me after the workshops, it was important to show that I valued PPIE members' contributions as this created a positive dynamic between myself and them.

One PPIE member had a basic knowledge of qualitative analysis methods, the other members had no knowledge of such methods. I did not want any PPIE members to feel like their contributions were inadequate because they were not knowledgeable about analysis methods. I gave a brief overview of the analysis methods I used in the study, this was important to address the power balance between PPIE members with varying degrees of knowledge.

Although not explicitly measured, I did seek to identify PPIE members who had suffered from mood problems. I sought guidance to ensure PPIE activities did not require ethical approval. I consulted the joint statement from the National Research Ethics Service (NRES) and INVOLVE (2012). The statement suggested that PPIE does not require ethical approval as PPIE members do not act in the same context as research participants. Based on their experiences and expertise, a PPIE member's role is to provide advice on the research process.

Boote et al (2011) did not detail any specific ethical considerations that may challenge the integration of PPIE into the research process. I reflected on my approach to PPIE activities using Pandya-Wood, Barron and Elliot's (2017) ethical framework. Pandya-Wood et al suggested ten ethical considerations that researchers should be mindful of when integrating PPIE into the research process (see Table 17). One of the considerations was registering public involvement work with an NHS Research and Development Trust Office, this was not applicable to the current study as the research was not conducted on NHS sites and participants were not recruited through NHS channels.

Table 17 Ethical considerations

Ethical consideration	Challenge	Overcoming the challenge
Allocating sufficient time for PPIE activities	Inadequate allocation of time within workshops to complete activities may contribute to stress and burden felt by PPIE members	I ensured that I allocated ample amount of time for each workshop and each activity within the workshop (e.g. to discuss research questions or to read draft public facing documents). I also provided breaks and refreshments
Avoiding tokenism	Ensuring PPIE involvement is not just a 'tick box' activity	I valued all contributions made by each PPIE member, I did this by considering all of the comments made by each member within the workshops. I also documented how PPIE has impacted the research process from the research design phase to the dissemination of results.
Communicating clearly about PPIE members' role from the outset	Not communicating clearly about roles and expectations can lead to disengaged PPIE members who feel unable to contribute to the study	I was clear to all PPIE members that they were invited to advise and provide feedback on the research process
Allowing individuals to stop their involvement for any unstated reason	PPIE members may become overwhelmed by the workshops	Although I encouraged members to continue involvement, I made it clear that they could withdraw themselves from involvement at any stage, without detailing their reasons for doing so
Operating 'fairness of opportunity'	Not taking issues around diversity and inclusion of PPIE members may result in disempowering, discriminatory research	This study focused on older adults, therefore, it was in my interest to include older adults as PPIE members. Although I did not exclude PPIE members from ethnic minorities, all PPIE members were White and British
Differentiating between public involvement activities and qualitative research methods	Referring to public involvement activities using research terminology may confuse PPIE members about whether they are advising the research or are participants in the research	I made it explicit to PPIE members that they were advising the study and were not participants

Table 17 Ethical considerations continued

Ethical consideration	Challenge	Overcoming the challenge
Working sensitively	Some of those involved in PPIE activities may find the experience emotionally upsetting	I was sensitive to the fact that PPIE members had experiences of mood problems. I made it clear that they could stop involvement at any stage. If the PPIE members did not wish to consult me about their distress, the USW was also a source of support
Being conscious of confidentiality	Disclosure of sensitive information during PPIE workshops could occur. Permissions to record the workshops may be overlooked	At the beginning of each workshop I tried to foster a confidential environment by proposing that any personal information would not be disclosed to anybody outside of the workshops. I obtained each PPIE members consent to audio-record the workshops. I explicitly stated that the recordings would be used so that I could reflect and write concise notes. The recordings were only available to myself and my supervisory team. I deleted the audio-recordings once I had written summaries of the workshops
Valuing, acknowledging and rewarding public involvement	Not valuing, acknowledging and rewarding the contributions of PPIE involvement may lead to PPIE members feeling disempowered. There can be financial burdens for PPIE members which may deter people from getting involved	PPIE members were offered reimbursement for their travel. In terms of valuing PPIE input, I made sure to thank each PPIE member within the workshop and after the workshop within the summaries I sent to them. I also acknowledged PPIE members within this thesis (p ix), and within a publication (see Appendix 13a)

The 'representativeness' of PPIE members relates to how well those involved in PPIE activities represent the wider public (Boote et al, 2011). PPIE members are more likely to have an interest in research and may be more knowledgeable about research processes in comparison to other members of the public. I sought to include older adults who resided in North Staffordshire as PPIE members; these individuals reflected the study's sample population. All PPIE members who contributed to the development of this study were White British, which is arguably a limitation as individuals from different ethnic backgrounds may have offered different perspectives on the research. For example, when reflecting upon the use of the 'think aloud' activities I noticed that each character within the storyboards were White older adults, if PPIE members from different ethnic backgrounds advised the development of the storyboards these individuals may have suggested creating a character which represented an ethnic minority. However, participants in my study and PPIE members were of the same ethic origin, were of similar ages and all resided in North Staffordshire. Due to their similar demographic backgrounds, PPIE members could have identified factors about the research that were relevant to participants. The PPIE members were also a mixture of male and female older people, this was valuable as it captured feedback from both genders.

Another challenge I encountered was identifying the most appropriate way to generate the PPIE members' perspectives on the data. Williamson et al (2010) and Lovell (2012) trained PPIE members in qualitative research methods which was time-consuming and labour intensive. I did not offer a training course in qualitative research methods. I wanted PPIE members' perspectives to possibly reflect that of the wider population of older adults who reside in North Staffordshire; such older people may not be knowledgeable about qualitative research methods. My supervisors and I agreed that whole, anonymous, interview transcripts would not be given to PPIE members. We believed that reading these transcripts may have been burdensome for PPIE members, yet this is arguably presumptive on our part. If I

conducted this PPIE workshop again, I would perhaps ask the PPIE members if they would find reading whole interview transcripts burdensome as I removed this choice from the group. However, showing a thematic map and quotes of the data was successful in giving PPIE members a brief overview of the findings without them having to read lengthy transcripts. When invited to offer their perspectives on quotes taken from interview transcripts, this sometimes triggered PPIE members to discuss managing their own mood problems. The value of having PPIE perspectives on the study was that each member had their own lived experience of a mood problem, the challenge was facilitating a discussion on the study's findings which did not become side-tracked with the personal narratives of PPIE members which lost sight of the data. I had to decipher if PPIE members were interpreting the quote or talking about personal experiences.

Summary

Within this chapter I have examined the literature focusing on PPIE. I described definitions and the history of PPIE and also discussed: the impact PPIE has had upon health research, challenges of PPIE, training PPIE members and potential negative effects of PPIE. Following this, I reported how I integrated PPIE into the current study using the GRIPP 2 framework. The next chapter will provide a discussion of the study's findings. The three re-occurring threads that were discussed by PPIE members when interpreting the data will be highlighted within the context of the study's broader findings.

Chapter Eight: Discussion and implications

Introduction

In this final chapter I summarise the findings reported in Chapters Five and Six, and note the main threads of discussion that the Patient and Public Involvement and Engagement (PPIE) group described when interpreting the findings. Next, to contextualise the findings I compare them with wider literature. I then discuss the strengths, challenges and limitations of the study, provide my reflections on the study and discuss the implications of the findings for older adults, healthcare services, third sector services and policy-makers. I conclude the chapter by identifying areas for future research.

8.1 Summary of findings

My two research questions were:

1) How do older adults self-manage experiences of distress?

2) What is the role of the internet, particularly online forums, in how older adults self-manage experiences of distress?

To answer the first research question, and to fully understand how older adults self-manage distress, it was important that this study explored how older people understand their experiences of distress. As reported in Chapter Five, participants used terms such as "*low*", "*stressed*", "*worry*", "*run down*", "*off*", and "*anger*" to describe their mood problems. Only participants who had consulted a General Practitioner (GP) and received a label of anxiety, or depression, used terms such as "*depressed*" or "*anxious*". The PPIE group suggested that distress is an individualised experience; this was why participants used a range of terms to describe their mood problems. Participants attributed their experiences of distress to various forms of loss, such as: the loss of a job due to retirement, reduced physical mobility, bereavement and reduced social contact.

Participants initiated their own self-management strategies to support themselves through experiences of distress. Self-management strategies included: pursuing independent activities (reading, gardening, walking and practising religious beliefs), seeking social support from friends or neighbours and attending community groups including church groups. Five participants sought help from healthcare services when distressed; these participants reported persistent experiences of distress, described needing help as managing alone had not alleviated their mood, or had a history of mental health problems. Concern regarding stigma prevented other participants from seeking help from healthcare services as they did not want to be defined by a mental health problem. Some participants also reported that previous negative encounters with GPs, or a lack of a relationship with one GP, prevented them from seeking help from primary care. The five participants who consulted a GP expected, and were offered, medication but preferred to self-manage their mood. Both participants who had, and had not, consulted a GP formed negative perceptions of medication as a treatment for mood problems after hearing other peoples' experiences with the treatment. Two participants who consulted a GP were also offered 'talking therapies'. A lack of knowledge about the treatment, and perceived stigma, prevented these participants from engaging with 'talking therapies'. Participants suggested that, rather than offering medication or 'talking therapies', GPs should direct older people with mood problems to third sector services (e.g. community groups).

To respond to the second research question, I explored distressed older adults use of the internet to self-manage their mood. The majority of participants did not engage with the internet as a health resource, of those that did, the internet was used as a source of information about physical health problems, but only after they had received a diagnosis of an illness from a GP. Participants did not use the internet to research information about mood problems.

Distress was characterised as a *"personal"* problem, some participants perceived that the resource was an inappropriate source of information about such problems.

Participants did not use social media sites and did not specifically seek social support via the internet to self-manage their experiences of distress; the internet did not meet participants' social needs. When offering their interpretation of the data, the PPIE group suggested that participants valued in-person communication, particularly with friends. However, for one participant using the internet did enable him to communicate with a family member who lived abroad. A small number of other participants also used the internet to support hobbies and/or interests, and to conduct online shopping.

A lack of skills was a key barrier to engagement with the internet; a lack of awareness about what the internet could offer in the context of supporting distress was also reported. Most participants did not perceive themselves as part of a generation of internet users which resulted in feelings of fear. Yet, a small number of participants described two motivating factors which encouraged them to learn how to engage with the internet, these were: a determination not to be 'left behind' in a changing society and the comparison of their internet proficiency with that of their family members' proficiency. A few participants learnt how to engage with the internet via younger family members, however, these family members were not always available to provide support or guidance on how to use the resource. Therefore, older adults valued computer courses and community groups which taught older people how to use computers and the internet. The PPIE group suggested that community groups, which taught computer and internet use, were vital educational opportunities which should be available for older people.

8.2 Comparison with wider literature

Within the next section I discuss the findings of this study in relation to the wider literature. I begin by discussing distress and the effect of loss.

8.2.1 Distress and the effect of loss

Older adults may describe their experiences of distress using terms such as feeling "*low*" or "*stressed*", the use of similar terms to describe distress has been reported elsewhere (Clover et al, 2016; Geraghty et al, 2017). To support access to treatments believed to be the appropriate solutions for distress, Geraghty et al reported that GPs were likely to label a distressed individual as 'depressed' because this enabled access to a broader range of treatment options such as antidepressants or 'talking therapies'. However, the current study indicates receiving a label of a mental health problem may change how older adults view their distress as only participants who consulted a GP, and received a diagnosis of a mental health problem, used terms such as 'anxiety' or 'depression' to describe their mood problems.

Individuals have previously described that grief, or a series of events or stressors, contributed to their experiences of distress (Dowrick & Frances, 2013; Geraghty et al, 2017). In my study, experiences of distress were associated with various forms of loss, these findings are similar to previous studies reporting that older people view loss as a contributing factor towards low mood or stress (Fässberg et al, 2016; Kingstone et al, 2017; Taylor, Taylor, Nguyen & Chatters, 2018). Some participants within this study attributed their distress to the loss of a job, due to retirement. Phongsavan et al (2006) found that retirement contributed to experiences of distress as older adults valued the social role of being in employment. Building upon Phongsavan et al's conclusions, this study also highlighted that the loss of a job contributed to older peoples' experiences of distress due to the loss of social contact with former co-workers and the wider public.

Previous research has reported that adults with physical health problems commonly experience mood problems such as depression, anxiety or distress (Pratt, Dey & Cohen, 2007; Chittleborough, Winefield, Gill, Koster, & Taylor, 2011; Sharma, 2016; Askari et al, 2017). The reasons for increased prevalence rates of distress, anxiety and depression in individuals suffering from physical health problems are complex, evidence suggests that a combination of biological, psychosocial, environmental and behavioural factors may all be involved and that the causal relationship is likely to be two-way (Prince et al, 2007). The findings from this study suggest that some older adults may attribute experiences of distress to a loss of mobility, caused by physical health problems. A loss of mobility resulted in a lack of ability to peruse certain activities (e.g. gardening or walking) and a reduction in social contact which lead to some participants being isolated. However, two participants within this study did not report suffering from any physical health problems when experiencing distress. The findings illustrate that both physical health problems and social factors contribute to older adults' distress.

The loss of social contact and social isolation as contributing factors towards distress is consistent with Taylor, Taylor, Nguyen and Chatters' (2018) conclusions. Taylor et al analysed data from the National Survey of American Life (NSAL; Jackson et al, 2004) to assess whether social isolation impacted older adults' scores of distress, as measured by the Kessler 6 Scale (K6; Kessler et al, 2003). Taylor et al found that being isolated from friends was associated with higher scores of distress; this highlights the importance of friendships in the context of distress, yet Taylor et al did not explore the possible reasons for this. The present study found that older adults and their friends often face similar losses (e.g. bereavement of spouses) and that older people perceive friends as honest and empathetic sources of social support; this could explain why being isolated from friends contributes to older people's mood problems.

The possibility of losing a child was also associated with participants' experiences of distress, these findings are similar to van Oers' (2014) study which found that having a chronically ill child increased parents' symptoms of anxiety and depression. Van Oers' sample consisted of parents who were under the age of 65, this study has shown that having an ill child as an older person may contribute to mood problems.

8.2.2 Influences upon actions taken

The concept of candidacy for care could explain why most participants acted by developing their own strategies to manage distress. According to Dixon-Woods et al (2006), candidacy describes the negotiation of eligibility for care and treatment between individuals and healthcare services. This negotiation is a complex process which is constantly being redefined via interactions between healthcare professionals and users of health services. Dixon-Woods et al developed a framework for candidacy which takes into account people's perception of health and healthcare services, whilst also highlighting the importance of the context in which interactions between healthcare professionals and services users take place. Table 18 provides definitions of the seven dimensions of candidacy proposed by Dixon-Woods et al (p35).

Table 18 Dixon-Woods et al's (2006) candidacy for care framework

Candidacy dimension	Definition
Identification of candidacy	The ability of individuals to recognise their symptoms when they first manifest as requiring medical assistance or treatment
Navigation	The need for knowledge about services which best suit the person's needs
Permeability	The ease with which people can gain access to different healthcare services
Appearances at health services	The assertion of a claim to candidacy for medical attention or treatment by going to a service
Adjudications	The judgements and decisions made by professionals which allow or inhibit continued progression of candidacy
Offers and resistance	The offer of care or treatment made by services, and the resistance to those offers by users
Operating conditions and the local production of candidacy	Context-specific influences on interactions between patients and practitioners

As most participants in my study preferred to self-manage their mood, this suggests that participants did not identify distress as a problem which required seeking help from healthcare services and, therefore, they did not identify themselves as candidates for care. This finding has been reported in Bristow et al's (2011) work and is consistent with Chew-Graham et al's (2012) study which found that older adults were reluctant to identify and name symptoms of depression as reasons to consult a GP. The findings from Bristow et al and Chew-Graham et al may be similar (i.e. individuals perceive that mood problems do not warrant seeking help from healthcare services), as the similar research teams were involved in both studies. In relation to identification of candidacy, some distressed older adults may not identify

themselves as candidates for care due to stigmatised attitudes and a reluctance to receive a label of a mental health problem from a healthcare professional. Past research has also found that depressed older people, who held stigmatised attitudes towards depression, did not consult healthcare services for their mood problems (Cornford, Hill, & Reilly, 2007; Conner et al, 2010).

Perceptions of candidacy are influenced by local contexts such as interactions with healthcare professionals. Having a positive relationship with a GP was necessary before participants in this study would seek help from healthcare services for their mood problems. Similar findings have been described by Kharicha et al (2017) who suggested that a good patient-physician relationship was essential before older people would disclose personal matters, such as feelings of loneliness, to a GP. This study further found that some older adults may not view themselves as candidates for care for any health problem (physical or distress) due to context specific influences, such as prior negative interactions with a GP. Recursivity refers to the ways in which health behaviours are shaped by the interactions that take place between patients and professionals within healthcare settings (Rogers, Kennedy, Nelson & Robinson, 2005). Prior negative interactions between a GP and an older adult could cause the older person to question the GPs' capabilities and to lose a sense of trust in that GP.

One way for positive relationships to evolve between healthcare professionals and patients is via continuity of care (Freeman & Hughes, 2010). Continuity of care refers to how an individual's healthcare is connected over time (Haggerty et al, 2003). Guthrie, Saultz, Freeman and Haggerty (2008) suggested three types of continuity to care, which are: informational, management and relationship. Informational continuity is where formally recorded information is complemented by the healthcare professional's knowledge of the patient's preferences, values and social context. Management continuity is when a patient is receiving care from more than one clinician or care provider, it concerns co-ordinating,

integrating and personalising treatment plans. Relationship continuity is where healthcare professionals build upon their accumulated knowledge of patient preferences and circumstances that are not documented in formal records. Patients and healthcare professionals have a sense of interpersonal trust which is based upon previous episodes of care. Continuity of care with the same GP is important for older adults to feel comfortable in discussing feelings of distress within a consultation. Haggerty, Roberge, Freeman and Beaulieu (2013) support these findings as they suggest that continuity, with one GP, encouraged patients to be more open about their health problems. However, a lack of continuity with the same GP reflects changes in the organisation of general practices (Baird, Charles, Honeyman, Maguire & Das, 2016). Practices are now larger, have more GPs working part-time hours and are comprised of multidisciplinary teams, all of which reduce the likelihood of older adults having continuity with the same GP (Campbell et al, 2009). Yet, this suggests a misalignment between the needs of distressed older adults who perceive continuity with the same GP as necessary in order to view themselves as candidates for care, and the organisation of healthcare services.

Participants who consulted a GP in the current study expected to be offered medication, but preferred to self-manage their mood. One participant highlighted that he wanted his mood problems to be understood before a GP offered medication. This supports GPs taking a person-centred approach when presented with a distressed older adult. A person-centred approach takes into consideration a person's lived experience of a health problem and sees people who use health services as partners in the planning and monitoring of their care (Epstein, 2000). Epstein suggested that the fundamental idea behind person-centred care is that 'the process of healing depends on knowing the patient as a person' (p1). Person-centred care values activities that work on supporting self-management and shared decision-making between the patient and clinician (Moscrop, 2012). Shared decision making means putting

people and their families at the centre of decisions and seeing them as experts, working alongside clinicians to get the best outcome (Shay & Lafata, 2015). When working alongside distressed older adults to develop an appropriate management plan this may, or may not, include medication or 'talking therapies'.

Two participants in my study reported that a GP offered them a 'talking therapy' and described this as 'counselling'. Both of these participants did not perceive themselves as candidates for this treatment due to stigma and a lack of knowledge about counselling and the role of a counsellor. These findings support the Department of Health (2011b) and Pettit et al's (2017) suggestions that older adults are unlikely to engage in 'talking therapies'. One qualitative study indicated that younger adults experiencing mental health problems find their relationship with a therapist to be important to their well-being, recovery, and treatment satisfaction (Escobar-Koch, Mandlich, & Urzua, 2012). In order for older adults experiencing mood problems to perceive that they are candidates for 'talking therapies', the role of a therapist, and the nature of the treatment, needs to be explicitly explained to these older people.

Instead of seeking help from the healthcare system, or engaging with treatments offered in primary care, this study has shown that older adults self-manage their mood problems. In the next section I discuss self-managing distress in relation to the wider literature.

8.2.3 Self-managing distress

Older people use a diverse range of self-management strategies when experiencing distress. Depressed younger adults self-managed their mood problems by using strategies such as: seeking social support from family or friends, trying to reframe negative events more positively and exercising (Ramirez & Badger, 2014; Van Grieken, Kirkenier, Koeter & Schene, 2014; Brijnath & Antoniades, 2016). This study's findings infer that some older

adults may not pursue activities such as gardening or walking, which are forms of exercise, due to a lack of physical mobility caused by physical health problems. The ways in which older adults self-manage distress may differ between older people, this supports Miller, Lasiter, Ellis and Buelow's (2015) conceptualisation of self-management. Miller et al proposed that individuals self-manage health problems within the context of their own daily living, which varies from person to person.

My study has indicated that, whilst some older adults may live alone, other older people may attribute their mood problems to taking on a caring role for their spouse (of whom they live with). These older adults may not perceive that they can confide in their husband or wife when distressed as caring for their needs is a source of distress. Additionally, distressed older adults may not confide in wider family members (e.g. children) as these individuals might not be viewed as empathetic sources of support. A lack of confiding relationships has been associated with an increased risk of depression following a stressful life event (Brown, Andrews, Harris, Adler & Bridge, 1986; Werner-Seidler, Afzali, Chapman, Sunderland & Slade, 2017). Instead of confiding in family members, older adults value discussing their distress with friends. The suggestion that friends, rather than family members, are important sources of social support is concurrent with previous literature (Fiori, Antonucci & Cortina, 2006; Shiovitz-Ezra & Leitsch, 2010; Rogers et al, 2011). This study further highlights the importance of building and maintaining friendships by attending community groups or church.

Kidwai, Mancha, Brown and Eaton (2014) found that attending church, and socialising with friends, correlated with reduced feelings of distress in adults who had recently experienced a stressful life event. By attending church each week, older adults have a continuity of social contact with the same friends, this continuity permits older people to feel connected to other individuals. Social identity theory proposes that feeling connected to other individuals may

result in some older adults deriving a sense of identity from group membership (Tajfel, 1979; Tajfel & Turner; 1986). Female older adults value the social aspects of attending community groups and may perceive themselves as being part of a group who have faced similar losses (e.g. the bereavement of a spouse). Individuals differentiate between their own group (the in-group e.g. as an older woman) from other groups (the out-group e.g. older men) (Haslam, O'brien, Jetten, Vormedal, & Penna, 2005; Isaksson et al, 2017). Gender specific community groups are appreciated by female older people who perceive that such groups permit comfortable discussion of their feelings with female peers (members of the in-group). Female older adults may also question whether males (members of the out-group) would understand their experiences of distress. Although I draw the comparison tentatively due to the small sample size, I did note that male participants reported attending community groups to learn a skill, not to necessarily socialise.

As most participants preferred to self-manage their mood and valued attended community groups or church, the current findings support Kennedy et al (2014) who concluded that the self-management of physical health problems require resources which extend beyond primary care settings. Participants in my study also suggested that GPs should direct distressed older adults to third sector services (e.g. community groups). Social prescribing, sometimes referred to as community referral, is a means of enabling GPs, nurses and other primary care professionals to refer people to a range of local, non-clinical services (Bickerdike, Booth, Wilson, Farley & Wright, 2017). The Bromley by Bow Centre in London has been open since 1997 and is one of the oldest social prescribing projects in the (United Kingdom) UK (Kings Fund, 2017). Staff at the centre work with patients suffering from physical or mental health problems and support them to get involved in more than 30 local services.

Social prescribing was highlighted in the White Paper 'Our health, our care, our say' (Department of Health, 2006) as a means of promoting access to third sector services. The

'NHS five year forward view' (Department of Health, 2014) also called for the better integration of services between primary care and the third sector. The Royal College of General Practitioners (RCGP; 2018a) recommended that general practices introduce social prescribing initiatives such as having a database of relevant local services. Professor Helen Stokes-Lampard, Chair of the RCGP, said:

> 'GPs will always consider the physical, social, and psychological aspects of the person sitting in front of them, and this means they often identify non-medical needs. So, patients might benefit from an exercise class, a social group, or another activity which helps them get out of the house and meet other people.'

(RCGP, 2018b: p8)

Although health policy and the RCGP seem to support social prescription, in a critical review of the literature the King's Fund (2017) found that most research which has explored social prescribing are small-scale qualitative studies. Bickerdike, Booth, Wilson, Farley and Wright (2017) conducted a systematic review of 15 evaluations of social prescribing programmes. Similar to the King's Fund, Bickerdike et al found that most programmes were small scale and limited by poor design and reporting. Common design issues included a lack of standardised and validated tools which measured the impact of social prescribing, missing data and a failure to consider potential confounding factors. Social prescribing is being widely advocated, but current evidence fails to provide sufficient detail to judge if the programmes are successful.

The South West Forum (2015) is one of the few studies which aimed to quantitatively measure the impact of a social prescribing intervention that was delivered to 128 adults, aged 65 and below, living in the South of England. Potential participants were identified by GPs from several GP practices. Three months after being introduced to the intervention participants reported a reduction in symptoms of anxiety, depression and social isolation.

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Whilst the South West Forum's (2015) did not recruit any older adults experiencing mood problems, this study has indicated that distressed older people may value GPs directing them to third sector services, rather than offering medication or 'talking therapies'.

8.2.4 Use of the internet

Younger adults have been found to use the internet to self-manage depression (Gunn et al, 2018), yet, research has suggested that a 'digital divide' in terms of internet access may have prevented older adults from using the resource (McDonough, 2016; Hargittai & Dobransky, 2017). All participants in this study described having access to the internet within their own homes, yet they still may be digitally excluded. One barrier to older people's internet use is a lack of interest in using the resource, perhaps due to a lack of awareness of what the internet could offer them. Harley, Howland, Harris and Redlich (2014) found that older adults had a resistance towards a 'digital imperative' (the need to use the internet to socialise and to access goods and services). Similarly, some participants in this study did not view using the internet as essential, this contributed to these older adults' digital exclusion.

Some older adults may be digitally excluded due to a lack of skills in using the internet. Previous research has found that older people may face digital exclusion due to not knowing how to use the internet (Gatto & Tak, 2008; Helsper & Reisdorf, 2013). In a review of the literature, Hunsaker and Hargittai (2018) proposed that a clear disparity exists among older adults when making age group comparisons. Younger older adults (those aged between 65 and 69 years old) were described as more likely to have access to the internet, better internet skills, and to feel more digitally included, than their older counterparts. Findings from my study did not suggest a disparity between young and old older adults. The oldest participant in my study was the only participant who used the internet as a means of communication and each participant had access to the internet, regardless of their age. Therefore, older adults, of all ages, may lack the skills to use the internet.

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Some older adults who do not have the skills to use the internet might be motivated to learn how to use the resource as they compare their internet proficiency to younger family members' proficiency, and do not want to get 'left behind' in a society that is becoming increasingly internet based; these older people may value having access to learning opportunities. Learning how to use the internet may increase some older adults' digital inclusion. The government has suggested that digital inclusion has become an important aspect of social inclusion as many services and resources are accessible through digital means (McMellon & Schiffman, 2002; Lam & Lee, 2006). Older people who are interested in learning how to engage with the internet may particularly appreciate attending community groups which teach computer and internet use. Such groups could help older adults to overcome their fear of using the internet by increasing the older person's ability and confidence to engage with the resource. Shapiro et al (2007) found that depressed adults who engaged in community groups, which taught individuals how to use the internet, reported a reduction in depressive symptoms. Attending community groups which teach older adults how to use the computer, or the internet, could be a self-management strategy of distress.

using data from the National Health and Aging Trends Study (NHATS; 2012), Choi and Dinitto (2013) found that symptoms of depression and anxiety were negatively associated with internet use among older adults. However, Choi and Dinitto found that social capital, defined as indicators of social ties (e.g. relationships with family and friends), and access to social support were positively associated with internet use. The authors argue that their findings point to the importance of social capital in facilitating older adults' leaning and adoption of using the internet. My findings both support and contradict Choi and Dinitto's conclusions. Some participants were encouraged to learn how to use the internet by family members and attending community groups which provided access and motivation to learn

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how to engage in the resource. However other social ties, such as friends, discouraged some participants' from using social media sites due to the relaying of their negative experiences with such sites. Therefore, my findings propose a complex interplay between the types of social ties, and potentially social capital, and older adults' internet use.

As older adults may develop their own strategies to support themselves when distressed, one such activity could have been using the internet as a source of health information (Gunn et al, 2018). The present study suggests that some older adults may not use the internet as a source of health information due to material and information being perceived as irrelevant to the older person's health needs. Participants in my study also suggested that health information accessed on the internet may lead some older adults to believe that they are suffering from an illness they do not have. A small number of other participants in my study used the internet as a source of physical health information, similar results have been reported in research which has sampled younger adults (Ybarra & Suman, 2006; Beck et al, 2014). Unlike Ybarra and Suman and Beck et al's research, older adults in my study reported needing to have received a diagnosis of a physical health problem, from a GP, before searching for health information on the internet. Older people in this study sometimes used a diagnosis as a search term to check if the information provided by a GP is accurate, this may also provide reassurance that they are searching for health information appropriate for their health needs. In contrast, some older adults in my study who had received a label of anxiety or depression from a GP did not perceive searching online for mental health information as proactive management of their mood problems. Other depressed or anxious older adults might have a lack of skills to use the internet as a source of mental health information.

Along with using the internet as a source of mental health information, younger adults also seek social support and discuss the self-management of a variety of health problems via social media platforms, particularly online forums (Lasker, Sogolow & Sharim, 2005; Gooden &

Winefield, 2007; Coulson, Buchanan & Aubeeluck, 2007; Fredriksen, Moland, & Sundby, 2008). In contrast, my study has indicated that older adults may not use social media platforms and, therefore, do not use such sites to access social support.

It is apparent that younger adults value and use the internet in different ways than older adults, this could be explained by the Social Construction of Technology theory (SCOT; Pinch & Bijker, 1987) which is underpinned by a social constructionist approach to knowledge formulation (e.g. knowledge being sustained by social processes). The SCOT theory argues that the internet is open to interpretative flexibility, meaning that different social groups may view and use the internet in different ways (see Section 3.1.3). Younger adults may view the internet as a means of accessing social support, but older adults appreciate in-person social contact. To explain how the internet may be interpreted differently by various social groups, the SCOT theory encourages researchers to take into account the social contexts (Burr, 2015). When exploring social contexts, a social group's identity could influence how individuals within the said group engage with technology (Kline & Pinch, 1996). The findings from my study suggest that some older adults may not view themselves as part of a generation of internet users as the resource was not invented or available to use when they were younger adults. The perception that older adults are not a generation of internet users is a barrier towards older people's internet use, and use of the resource as a self-management strategy of distress. Throughout their work on the SCOT theory Pinch & Bijker (1987) do not explicitly describe that the acceptance, or rejection, of a technology may be influenced by the timing of when that piece of technology was developed.

The SCOT theory (Pinch & Bijker, 1987) suggests that knowledge about technology is shaped by social processes, such as language and communication. As participants in my study did not engage with social media sites themselves, their negative perceptions of such sites stemmed from hearing their friends' experiences of using the platforms. This shows how the

language surrounding social media sites could discourage older people from engaging with the platforms. However, social processes also encouraged some participants to engage with the internet. For example, comparing their internet use to that of their family's motivated some participants to learn how to use the resource, and attending community groups increased some participant's knowledge about how to use the internet. My findings support this aspect of the SCOT theory and suggest that social interactions can both encourage and discourage older adults from using the internet.

Older adults were particularly discouraged from using online forums as they viewed the platforms as untrustworthy due to their anonymous nature, perhaps because they could not place the other users within a social context (e.g. they could not be certain of their age, gender or if they had experienced mood problems). These findings contrast Seraj's (2012) study which suggested that the anonymity afforded by online forums permitted open disclosure of personal problems. Distressed older people may use online forums as a means of communication in the future, but only if such platforms disregarded the notion of anonymity, were moderated by a professional organisations and were compromised of other online forum users from a local area (e.g. people with whom the older adult is familiar with).

Although older adults might not use the internet as a source of information about mood problems, or as a means of accessing social support, a small number of older people may use the internet for practical purposes. Van Boekel, Peek and Luijkx (2017) used data from the national representative internet panel in the Netherlands to conduct a latent class analysis based on the internet activities that panel members reported to spend time on. Panel members aged 65 years and above were included within the study. The authors found that the highest proportion of older adults used the internet for practical and financial purposes. Similarly, the present study found that a few older adults may use the internet for practical purposes (e.g. shopping). However, unlike van Boekal, Peek and Luikjx's study, participants did not report

using the internet for financial purposes, perhaps because of a lack of knowledge of how to engage in the resource for this purpose, or a lack of trust in using the internet.

Older adults may also use the internet to engage with hobbies, such as researching their family ancestry. This finding somewhat supports Nimrod (2009) who found that older adults engage with the internet as a leisure activity. Older adults who suffer from physical conditions have been reported to engage in leisure activities which demand less physical effort, such as using a computer or the internet within their own homes (Nimrod, 2007). Contrastingly, in my study distressed older adults, who suffered from physical health problems, valued activities such as gardening, walking, and attending community groups and church.

The recruitment strategy in my study captured older people who could attend community groups. Participants suggested that older adults who cannot access in-person communication, community groups, or church, could appreciate using the internet to self-manage mood problems. This finding supports literature which has suggested that the internet provides access to information or resources that would have been inaccessible due to a lack of mobility (Olphert, Damodaran & May, 2005; Milligan & Passey, 2011). Previous research has also identified that internet use has been linked to a reduction in feelings of loneliness as the resource permits older people to communicate with other individuals regardless of time or geographical location (Leist, 2012; Bartels & Naslund, 2013; Cotton, Anderson & McCullough, 2013; Lelkes, 2013). Although there are reported benefits of using the internet, older people who cannot access in-person support may have to overcome barriers such as a lack of skills or interest before they would use the resource to support the management of mood problems.

In summary, some older adults may face barriers to internet use which contributes to their digital exclusion, including a lack of interest in engaging with the internet and a lack of skills

in navigating the resource. Some older adults may not view internet use as necessary, but others may be motivated to learn how to use the resource. These older adults may value attending community groups which teach computer or internet use. Older adults with distress in my study did not report using the internet as a source of mental health information, or as a means of accessing social support, but a small number of older people valued using the resource in other ways (e.g. to support hobbies and/or interests). Using the internet may be beneficial for some older people, especially if they cannot access in-person support.

8.3 Strengths, limitations and challenges

In this section I address the strengths, challenges and limitations of the current study.

8.3.1 Strengths

This PhD is the first study to explore how older adults self-manage distress with a particular focus on the role of the internet. Therefore, the qualitative approach towards data generation and analysis was a key strength. An exploratory approach was adopted as it provided rich, in-depth descriptions of how participants self-managed their distress. Semi-structured interviews were beneficial for this under-studied field of research as the interviews captured dimensions of the research questions, but also permitted participants to offer new meanings to the topic.

Another strength of the study was the recruitment strategy. Older adults may not seek help for their mood problems from healthcare services (see Section 2.4). Participants were recruited from the third sector, this enabled me to reach older people who would not have presented their distress within primary care settings. As I made weekly visits to the community groups I recruited from, this ensured that I had the opportunity to familiarise myself the challenges and opportunities that these community groups presented in terms of conducting the research. For example, I knew if there was a private room in which the interview could be conducted. The

time I spent engaging in the community groups' activities enabled me to build up rapport with group members and participants.

The sample characteristics were a strength of this study. Seven participants were male, this reflected the dynamics and diversity of the community groups I recruited from as less males attended than females. The sample was diverse in terms of age (65 – 91 years old), urban and rural location, and mixed in terms of living alone or with their spouses. One participant also lived with younger generations of his family. Participants had a range of previous occupations and the sample managed to include two older adults who were still working part-time.

Data analysis methods were a strength of this study. The thematic analysis incorporating constant comparison techniques was conducted inductively, this is important for an unexplored area of research as it ensured that the identified themes were strongly connected to the data. Throughout the analysis process I liaised with my supervisory team at least once a month to discuss the emerging findings, this triangulation of the data increased the trustworthiness of the interpretation.

The use of PPIE throughout the research process, which is discussed in Chapter Seven, was another key strength of the study. I sought PPIE advice when developing the research questions and methods, when analysing the data and when creating a dissemination plan. Modifying the research questions ensured relevant questions were being addressed. Developing the methods with a PPIE group ensured that public facing documents, the topic guide and 'think aloud' activities were appropriate for the target audience. Gaining PPIE members' perspective of the data could have arguably enhanced the trustworthiness of the interpretation, and creating a dissemination plan with a PPIE group has encouraged me to present the findings to a non-academic audience.

8.3.2 Limitations

This study has several limitations. I attempted snowball sampling however, it was not fruitful as I did not manage to recruit any older adults who did not attend community groups. Individuals who attended community groups may have self-managed somewhat differently than those who did not attend community groups. All male participants were recruited from community groups which taught internet use, therefore, these participants may have had more exposure to technology, and the internet, in comparison to older people who do not attend such community groups. Although the sample was diverse in some respects, all participants were White British. If the study had included older adults from different ethnic backgrounds this may have resulted in participants identifying different self-management strategies of distress, or other perspectives on the role of the internet. The community groups I recruited from also charged attendees £2.50 per session. Older people who could afford to attend these groups are perhaps more financially affluent than older adults who could not afford to attend the groups.

Conducting a thematic analysis driven by social constructionist epistemology recognises the constitutive nature of language and discourse, but does not generally involve a micro-analysis of the language used (Braun & Clarke, 2006), which is often seen in discourse analysis techniques (Potter & Weatherall, 1987). A micro-analysis of the language used could have potentially offered a richer understanding of an individual older person's meaning of distress and experiences of self-management. However, thematic analysis enabled me to compare language and social processes, across different participants, to identify shared understandings of distress and self-management strategies. Thematic analysis also has a clearly defined set of procedures set out by Braun and Clarke, whereas discourse analysis methods often lack clarity in regards to their analytic practices (Morgan, 2010). Therefore, for a rigorous analysis on how a group of older adults self-managed distress, thematic analysis was a more appropriate

method. The self-management strategies and experiences of internet use identified by participants who resided in North Staffordshire may not be representative of other older adults living in other areas. Yet, due to the heterogeneity of the sample, the findings could be transferable to older adults who did not participate within the study. Another limitation is the cross-sectional design, the self-management of a health problem is fluid and this study failed to capture if participants' management of distress changed over time.

8.3.3 Challenges

I encountered many challenges when conducting this study. Male older adults experiencing distress were initially hard to recruit. To overcome this, as data collection progressed I targeted community groups that were more heavily populated by male attendees. Another challenge was that having no, or little, experience of using the internet could have deterred potential participants from taking part in the study. I stated within the information leaflets, contact visits and subsequent visits to the community groups that potential participants did not need to have any experience of using the internet. Members of the community groups also knew I was local to the area, I felt like this might have discouraged participants from divulging certain sensitive information during the interviews. I emphasised that any data collected would be kept confidential and anonymised in any dissemination of the findings.

The exploratory nature of the interviews, and the use of 'think aloud' activities, often resulted in lengthy interviews which were difficult to manage, especially as I did not wish to burden participants. The good rapport I established with participants also sometimes resulted in discussions within the interviews about topics unrelated to the focus of the research. I also considered that the sense of rapport caused participants to want to provide information that they thought was to be expected or wanted by myself. For example, some participants apologised when I asked them their views on the internet because they did not use the resource. Although it presented challenges, I believe that building rapport allowed me to

develop a more collaborative relationship with participants and resulted in richer data being collected.

8.4 Reflections on the study

My background in Psychology equipped me with knowledge about qualitative methods, however, I had not conducted qualitative interviews with older adults before. Immersing myself within the literature, and gaining advice from PPIE members, was important for me to gain knowledge about the possible interview experiences I might have encountered. As I now have experience of interviewing older adults, this gives me a sense of confidence in conducting further interviews with this cohort in the future.

The 'think aloud' activities used within the study aimed to illicit discussion around the role of the internet in how older adults self-manage distress. The novelty of the methods meant that I was unsure of how the activities were going to be received by participants. I gave participants a choice of completing the 'think aloud' activities concurrently or retrospectively. I found that participants who completed the 'think aloud' activities retrospectively shared their opinions on the internet and online forums without further probing and, generally, the topic of discussion was focused on the role of the internet. Participants who completed the 'think aloud' activities concurrently seemed to relate the content of the 'think aloud' activities to other self-management strategies, which did not involve the internet. I had to probe these participants to discuss their experiences or views on the internet as a self-management strategy of distress. I felt that the participants who completed the 'think aloud' methods concurrently were less familiar in engaging with the internet in comparison to participants who completed the activities retrospectively. This unfamiliarity prompted these participants to discuss other self-management strategies, rather than their experiences or views on the internet. I also gave participants a choice to read the 'think aloud' methods themselves, or if they would like me to read the activities with them. I worried that this might come across

condescending, but some participants valued having the choice. I did not identify a difference between the data generated from participants who read the 'think aloud' activities themselves, and the data collected from participants who I read the 'think aloud' activities with.

I conducted data collection and analysis with the intention to use thematic analysis with constant comparison techniques (Lincoln & Guba, 1985). I discussed this method with my supervisors which helped to develop the approach taken towards analysis. I have also developed skills in how to triangulate qualitative findings with a team of researchers and PPIE members. I have learnt the value and challenges of integrating PPIE activities into the research process, I will now be aware of such challenges in any future research I may conduct which includes PPIE.

As I attended the same community groups on a weekly basis, my role as a researcher crossed over that of a companion. I encouraged participants to take part in group activities and got to know group members on a personal level. I had a specific seat at one particular group which was referred to as 'Alice's seat', and I also received Christmas cards and invitations to special Christmas community group sessions. This relationship between myself, participants and group members identified the importance of managing expectations throughout the data collection process. Members of the community groups knew my research interests which often led to group discussions about distress, managing distress and the internet. Although I noted these conversations within a reflective journal, I could not use these conversations as data. These conversations gave me an expectation of what sort of data could be generated within the interviews.

My own use of the internet could have affected the data collection and analysis. I began being taught how to use a computer and the internet in primary school and now use the internet on a daily basis in both a professional and personal capacity. I expected some participants to use

the internet to find out general and health information, and as a source of social support. This expectation could have influenced the way I questioned and probed participants in the interview and my interpretation of the data.

8.5 Implications

The findings of this study have implications for older adults, healthcare services, third sector services and policy-makers. I begin by describing the implications for older adults.

8.5.1 Older adults

As all participants in this study reported taking some form of action once they had recognised that they were experiencing distress, this shows that older adults are not passive people in which distress is happening too, but active in wanting to improve their mood within the context of their daily lives. For distressed older adults who may struggle to manage their mood by using strategies that require them to have a degree of physical mobility (e.g. due to being housebound caused by a physical health problem), the internet could be a means of communicating or accessing information, goods or services which otherwise would be inaccessible. Older adults who can access computer courses or community groups which teach computer and internet use could use these opportunities to learn how to use the internet; engaging with the internet may be beneficial if the context of these older people's lives change and community resources become inaccessible. However, an older adult's perception of the value of the internet may affect whether an older person engages with community groups which teach computer and internet use. Some older people may view that internet use could prevent them from engaging in other activities and, therefore, may not want to be digitally included. Other older people may value learning how to use the internet as they do not want to get 'left behind' in a society where more goods and services are becoming internet-based; these older people may appreciate opportunities which could increase their digital inclusion.

To inform older adults of the potential benefits of internet use, a public health campaign could be developed. Over the past few decades public health campaigns have most notably been aimed at tobacco use and heart-disease prevention, but have also addressed alcohol and illicit drug use, cancer screening and prevention, and mental health problems. Typical campaigns have placed messages in media that reach large audiences, most frequently via television or radio, but also outdoor media, such as billboards and posters, and print media, such as magazines and newspapers (Wakefield, Loken & Hornik, 2010). Wakefield and colleagues suggest that mass media messages can increase the frequency of discussion about a particular topic within an individual's social network, which, in combination with individual exposure to messages, might encourage certain behaviours (e.g. internet use). Information about the benefits of internet use could be provided in media older adults engage with such as television, radio, and newspapers (Hilt & Lipschultz, 2016). This will hopefully create a discussion and encourage older adults to learn how to engage with the resource. The public health campaign could also direct older adults to community groups that teach older people how to use computers and the internet (e.g. computer groups provided by Age UK).

8.5.2 Healthcare services

Some older adults may not recognise distress as a reason to seek help from the healthcare services; they do not perceive themselves to be candidates for care. A lack of continuity with the same healthcare professional may prevent some distressed older adults from seeking help from healthcare services. Before disclosing feelings of distress, older adults need to build a positive relationship with a single healthcare professional and the provision of healthcare services should accommodate this.

8.5.2.1 Medical students and primary care professionals

When labelling an older adult with a mood problem, medical students and primary care professionals should be aware that the terms they use to describe an older adults' problem

may change the way in which older people view their distress. Some older adults may present their distress within primary care settings, if so, it is vital that GPs explore the person's perceptions of the causes of distress, provide information about different management options (which may, or may not, include medication or a referral to Improved Access to Psychological therapies [IAPT] services; National Collaborating Centre for Mental Health, 2018), and explore the older adult's preferences and views on different management options. If an older adult does not feel that medication or 'talking therapies' are acceptable, then the GPs should explore how a distressed older adult may self-manage their mood, how they can support this self-management (i.e. by 'active monitoring'; NICE, 2009a; 2011a) and consider the use of social prescribing to sign-post older people to local third sector services (Bickerdike, Booth, Wilson, Farley & Wright, 2017). Medical school curricula should also support this approach to managing older adults' mood problems as, due to the ageing population (Office of National Statistics [ONS], 2017), medical students are likely to come into contact with distressed older people on clinical placements, and once graduated.

8.5.3 Third sector services

Older adults may self-manage their distress by attending third sector services such as community groups. Third sector services need to be alert to the scale of distress experienced among older adults who may be using their services to manage their mood problems. The findings of this study also suggest that GPs sign-posting to third sector services may be acceptable to distressed older adults; such services should be made aware that older adults experiencing mood problems may be directed to their organisation. Individuals who work for third sector services need support in knowing how to manage older adults with mood problems and when to direct these individuals to healthcare services, this identifies the need for additional training for third sector workers (Kingstone et al, 2018).

In comparison to male older adults, female older people are more likely to attend third sector services, such as community groups (Goll, Charlesworth, Scior & Stott, 2015). To increase the number of male attendees, third sector services should be aware that male older adults value community groups which give them the opportunity to learn a skill. When developing community groups, third sector services could take into account that female older people appreciate gender specific groups.

Community groups which teach older adults how to use the computer and internet may help some older adults to overcome digital exclusion. Through attending these groups, older adults may begin to appreciate the different ways in which the internet could be used and might be encouraged to learn how the resource may support the management of their mood problems (e.g. by being a source of information or means of accessing social support).

8.5.4 Policy-makers

The Department of Health (2018) recognise that the internet may be a way for people to access health information and services within the report 'The future of healthcare: our vision for digital, data and technology in health and care'. Yet, within the same report, the Department of Health also highlight the importance of designing health services for people with different needs (e.g. individuals who cannot access the internet, or people who are not competent internet users). In comparison to younger adults, older people are less likely to use the internet (ONS, 2018), yet the Department of Health's report does not specifically state how the government would take into consideration the needs and values of older people. The 'Government digital inclusion strategy' (Maude, 2014) did aim to ensure that older adults have access to the internet. This study suggests that older people can now access the internet, but lack the skills or motivation needed to use the resource. Policies which aim to embed the internet into health services need to be based on a nuanced understanding of the barriers and facilitators of internet use for older adults (Centre for Ageing Better, 2018).

The importance of self-care initiatives for individuals suffering from chronic physical conditions were recognised by the Department of Health (2007) within the report 'Research evidence on the effectiveness of self-care support'. Accordingly, supporting individuals to self-care improves patient outcomes and could reduce the burden on healthcare services. In relation to mood problems, NHS England (2016) published the 'Five year forward view for mental health' and suggested that older people should have access to services that meet their needs. Healthcare policy needs to reflect the importance of older adults being able to self-manage their mood problems and particularly bring these individuals into contact with community resources. The findings support the NICE guidelines (2011b) which advocate that healthcare professionals should direct people with common mental health problems to community resources such as community groups and encourage self-management activities.

A specific mental health policy which focuses on older adults and the importance of self-managing mood problems could be beneficial for older people. The policy could also aim to embed digital inclusion support within local services (e.g. community groups which teach older adults how to use the internet). Such services could be a source of social contact and an opportunity to learn a skill; both aspects could help older adults to manage their mood problems. However, some older adults make a reasoned judgement not to use the internet based on the role the resource has within their lives (e.g. perceiving internet use as a prevention of other activities of which they enjoy). The policy would need to ensure that older adults, who are not proficient internet users, do not lose out on services or resources.

8.6 Future research

The findings from this study have indicated that the following future research is needed:

1) A qualitative exploration into GPs' views on sign-posting distressed older adults to third sector services. Social prescribing is widely advocated in health policies

(Bickerdike, Booth, Wilson, Farley, & Wright, 2017). The NHS Long Term Plan (NHS England, 2019) aims to develop social prescribing initiatives; it is hoped that over 2.5 million people will have access to social prescribing and new ways to manage their health in partnership with patient and voluntary groups. Third sector organisations are valuable community resources, they are under-utilised by GPs (Branding & House, 2009). There would be two aim of this study:

- To explore GPs' views on using social prescribing for distressed older adults
- To explore potential barriers and facilitators of GPs using social prescribing to support the management of older adults with distress.

Semi-structured interviews could be used to explore GPs' views and through these interviews barriers and facilitators of directing older adults to third sector services may be identified. Strategies to overcome barriers may also be explored. Data would be analysed thematically using constant comparison techniques (Lincoln & Guba, 1985; Braun & Clarke, 2006). Expected outcomes would include a deeper understanding of GPs' views on social prescribing and the identification of barriers and facilitators of using social prescribing for distressed older adults. This information could be useful for policy-makers and healthcare services when seeking to develop social prescribing initiatives.

2) A mixed methods investigation into if increasing older adults' skills in using the internet changes their experiences and capabilities of using the resource to manage mood problems. A quasi-experimental design could be utilised. A training package for older adults with mood problems could be designed in line with relevant literature and a PPIE group. The training package could teach:

- basic skills in how to use the internet
- how to use the internet as a source of mental health information

- how to use the internet as a means of accessing social support

The training package could be delivered to distressed older adults who are recruited from existing community groups. The training could be delivered within a community setting (e.g. town hall or community centre).

Participant inclusion criteria could be:

- Individuals who are 65 years and older

- Individuals who are currently distressed, or individuals who have experienced distress within the previous 12 months

Before the training package begins, participants would be asked to complete a questionnaire. The Computer-Email-Web fluency scale (Bunz, 2009) will be included within the questionnaire. The scale assesses basic computer skills (e.g. how to switch on a computer), email skills (e.g. how to send an email) and web navigation skills (e.g. how to use a web browser to navigate the Internet). The questionnaire would also include the K6 scale (Kessler et al, 2003) which measures distress, and two questions which ask if the participant has used the internet as a source of information about their mood problems, or as a means of accessing social support. Three months after receiving the training package, participants will be sent the same questionnaire to complete. Participants who complete the follow-up questionnaire will be invited to take part in an interview which explores their use of the internet after receiving the training package. If the training package is successful, this could set the basis for a larger randomised control trial which would aim to increase older adults' skills and use of the internet to manage mood problems.

Summary

In this chapter I have summarised the findings, whilst also illustrating the threads of discussion that the PPIE members described when interpreting the findings. I then compared

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the findings to the wider literature and discussed the strengths, challenges and limitations of

the study. I also provided my reflections on the study and described the implications of the

findings for older adults, healthcare services, third sector services and policy-makers. I

concluded the final chapter by suggesting areas for future research.

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Appendices

Appendix 1a

3rd June 2016

Alice Moult
David Weatherall Building
Keele University

Dear Alice,

Re: Self-management strategies in older adults who are distressed: A qualitative study

Thank you for submitting your revised application for review. I am pleased to inform you that your application has been approved by the Ethics Review Panel. The following documents have been reviewed and approved by the panel as follows:

Document(s)	Version Number	Date
Recruitment Poster	1	17-04-2016
Letter to Gatekeeper	1	30-05-2016
Invitation Letter	1	17-04-2016
Information Sheet	1	23-05-2016
Consent Form	1	23-05-2016
Extract from Online Forum	1	17-03-2016
Storyboard 1 & 2	1	17-04-2016
Topic Guide	1	17-04-2016

If the fieldwork goes beyond the date stated in your application (31st March 2017), you must notify the Ethical Review Panel via the ERP administrator at uso.erps@keele.ac.uk stating ERP1 in the subject line of the e-mail.

If there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator stating ERP1 in the subject line of the e-mail. This form is available via http://www.keele.ac.uk/researchsupport/researchethics/.

Appendix 1b

Keele
University

Ref: ERP1279

23rd September 2016

Alice Moult
David Weatherall Building
Keele University

Dear Alice,

Re: Self-management strategies in older adults who are distressed: A qualitative study

Thank you for submitting your application to amend study. I am pleased to inform you that your application has been approved by the Ethical Review Panel.

The following document has been reviewed and approved by the Panel as follows:-

Document	Version	Date
Participant Contact Information	1.0	16-09-2016

Just to remind you, if the fieldwork goes beyond the 31st March 2017, or there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator at research.erps@keele.ac.uk stating ERP1 in the subject line of the e-mail. This form is available via http://www.keele.ac.uk/researchsupport/researchethics/

If you have any queries, please do not hesitate to contact me via the ERP administrator on research.erps@keele.ac.uk stating ERP1 in the subject line of the e-mail.

Yours sincerely

C H Bannerman
pp

Dr Jackie Waterfield
Chair – Ethical Review Panel

CC   RI Manager
        Supervisor

Appendix 2

Research Institute for Primary Care & Health Research,

Keele University,

Staffordshire,

 ST5 5BG

 >Insert Date<

Dear Sir/ Madam,

Research Study: How older adults cope with distress.

My name is Alice Moult and I am a PhD student at Keele University I am contacting you to ask for your help in introducing me to people who attend your group, because I would like to ask them to participate in my research project. My project is about exploring how older adults cope with distress. I am hoping that some people in your group will agree to participate in one short interview with me.

I aim to;

1) Find out what older people do to cope with distress.

2) Hear whether over 65s have ever turned to the internet for help or support.

I have Keele University ethical approval to conduct the research in community groups for older adults and I am writing to ask you if it would be possible to come to your group and speak to people about my study. If any group members are interested in speaking to me, I would like to hold interviews in the community centre where the *insert group name* group is held. I have attached an information sheet which describes the study in more detail.

I will endeavour to ensure that I do not cause any disruption to your group.

I hope that you find the project of interest and will be able to help me make contact with older adults, through your community group.

If you have any questions or would like more information, I am very happy to discuss the research with your further. My contact details can be found below and on the information sheet.

Yours faithfully,

Alice Moult

PhD Researcher

Telephone: 01782 734889   Email: a.moult@keele.ac.uk

Attached: Study information shee

Appendix 3

What will happen if I take part?

I would like to interview you about how you cope with distress. I will meet you at a time and place that is convenient for you. I would like to audio-record the interview. I would also like to hear about any experiences you have had using the internet for help and support. *Using a laptop, I will show you an example of an online forum to look at.* I will also show you an example of people using the internet for advice along with cartoons about using the internet. After reading the example and cartoons I will ask you for your opinion about them.

You will not be asked to use a computer and you don't need to have had any experience of using the internet. The interview will last approximately 60 minutes and you can stop it at any time. I will also ask you if you would like a summary of the research findings.

Do I have to take part?

You don't have to take part, and if agree you can change your mind at any time. *You will be given an additional three months to withdraw your interview from the study.*

Who is funding the research?

Keele University

What if I have a concern?

Please contact my supervisors:

Dr Heather Burroughs
h.burroughs@keele.ac.uk
Telephone: 01782 7334983

Prof Carolyn Chew-Graham
c.a.chew-graham@keele.ac.uk
Telephone: 01782 7334717

If you remain unhappy about the research and/or wish to raise a complaint please write to:
Nicola Leighton, Research Governance Officer, iC1 Building, Keele University, Staffordshire, ST5 5BG
E-mail: n.leighton@uso.keele.ac.uk
Telephone: 01782 733306

Need more information?

I'm very happy to discuss the research in person or over the phone.
Please contact me at:
Research Institute for Primary Care and Health Sciences,
Keele University,
Staffordshire,
ST5 5BG
Email: a.moult@keele.ac.uk
Telephone: 01782 734889

Have you been feeling low, anxious, depressed or stressed?

Are you aged 65 or older?

We would like to talk to you about how you cope …

Keele University

The Project

You are being invited to take part in research exploring how older adults cope with distress.

Many older people suffer from distress in the form of depression, anxiety, low mood or stress. Older people may use a number of ways to cope with distress which may, or may not, include visiting their GP.

We want to;

1) Find out what over 65s do to cope with distress.

2) Hear whether you have ever turned to the internet for help or support.

Why have I been invited?

Because you are 65 years old or over.

Who wants to know?

I'm Alice Moult. I'm doing this research for my PhD. My supervisors are Dr. Heather Burroughs and Prof. Carolyn Chew-Graham.

How will my information be used?

I will type up the interview and anonymise it by removing any names or details which could identify you, your friends and family, or any other person you may mention. This anonymised information will be used in my research report, and for journal articles and presentations. *When the research report is finished, any information, such as the interview transcripts, personal information and the audio recordings, will be destroyed by August 2019. But, if you agree, the anonymised information will be kept for 10 years until 2026.* This is so that it can be used in future research. The consent form asks you to tick a box if you agree to this use of your interview in future research.

What are the benefits of taking part?

There may be no direct benefit to you, although people often say they find it helpful to talk through their experiences. However, you will be helping to build a picture of day-to-day life for older adults with distress. We hope that this may help us to understand the sorts of coping strategies used and to work out the best ways of helping other people who are distressed.

What are the risks of taking part?

Talking about your distress may make you feel unhappy. You don't have to answer any questions that you do not want to, and you can stop the interview at any time. *If you would feel it helpful, we can discuss different sources of possible support such as visiting the GP or contacting Healthy Minds, a service which provides support for distressed individuals.*

How will you protect my privacy?

All personal information will be kept strictly confidential. After the interview I will put the recording on a password protected computer at the University. *Your contact details will be stored on a separate password protected computer.* Your consent form will be put in a locked filing cabinet. The only people who will have access to your information will be me and my supervisors. However, if I feel that there is a risk of serious harm to you, or anyone else, I will have to ask for help, and this may involve giving identifying information to support services.

Appendix 4

Have you been feeling low, anxious, depressed or stressed? Are you aged 65 or older? We would like to talk to you about how you cope …

The Project

Many older people suffer from distress in the form of depression, anxiety, low mood or stress.

We want to;

1) Find out what over 65s do to cope with distress.

2) Hear whether you have ever turned to the internet for help or support.

What will happen if I take part?

I would like to interview you about how you cope. I will meet you at a time and place that is convenient for you. I would like to audio-record the interview. I would also like to hear any views you might have about using the internet.

The interview will be completely confidential and **anonymous**.

Who wants to know?

Alice Moult, a PhD researcher from Keele University. If you are interested and want more information, I'd be delighted to hear from you. Please rip off a piece of paper with the contact details and feel free to get in touch with me.

Miss Alice Moult, Research Institute for Primary Care and Health Sciences, Keele University, Staffordshire, ST5 5BG
Telephone: 01782 734889
Email: a.moult@keele.ac.uk

Miss Alice Moult, Research Institute for Primary Care and Health Sciences, Keele University, Staffordshire, ST5 5BG
Telephone: 01782 734889
Email: a.moult@keele.ac.uk

Miss Alice Moult, Research Institute for Primary Care and Health Sciences, Keele University, Staffordshire, ST5 5BG
Telephone: 01782 734889
Email: a.moult@keele.ac.uk

Miss Alice Moult, Research Institute for Primary Care and Health Sciences, Keele University, Staffordshire, ST5 5BG
Telephone: 01782 734889
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Miss Alice Moult, Research Institute for Primary Care and Health Sciences, Keele University, Staffordshire, ST5 5BG
Telephone: 01782 734889
Email: a.moult@keele.ac.uk

Miss Alice Moult, Research Institute for Primary Care and Health Sciences, Keele University, Staffordshire, ST5 5BG
Telephone: 01782 734889
Email: a.moult@keele.ac.uk

Miss Alice Moult, Research Institute for Primary Care and Health Sciences, Keele University, Staffordshire, ST5 5BG
Telephone: 01782 734889
Email: a.moult@keele.ac.uk

Contact Details

Title of research project: How Older Adults deal with Distress

Name of Researcher: Alice Moult

You have kindly read the information sheet about this study.

If you are interested in taking part in the study, and would prefer to be interviewed at home, please complete the following questions and give this back to the researcher, Alice Moult.

All information will be kept strictly confidential.

The researcher will then be in contact to organise a time and place, convenient for you, to be interviewed. By giving your contact details you are giving permission for Alice Moult to contact you in regards to the study.

Name:

…………………………………………………………………………………………….

Phone number: …………………………………………………………………………

Address:

………………………………………………………………………………………

………………………………………………………………………………………

………………………………………………………………………………………

………………………………………………………………………………………

………………………………………………………………………………………

E-mail address (if applicable):

………………………………………………………………………………………

Appendix 6

Topic Guide

1) Opening

Ethical procedures, taking consent

2) Exploring experience

- Are you local to the area?

- Do you live alone?

- Are you retired?

- What did you do before you retired?

- How old are you?

Can you tell me a little about how you came about attending this community group?

In the last year, has there been a time that you've felt low or stressed? How did you feel at the time, can you tell me about it?

What did you do to make yourself feel better?

What sort of help did you experience from friends or family?

What are the differences between the support from family and friends?

Have you tried doing more social activities? How did that help (or not)?

Have you tried to do any activities on your own which helped (or not)?

Did you seek help from your GP? What advice was given/ treatment offered? Did it help?

What are your views on medication for mood problems?

What are your views on counselling?

What is your relationship like with your GP? Explore continuity, past encounters with GPs

Are there any other things that you tried? (diet, food supplements, exercise, sleep)

Have any of your friends/family ever felt low/ stressed? Are you aware what other people do to manage?

Do you have a faith?

How do you stay independent? How do you know when to ask for help? Who do you ask for help from?

3) The internet

What are your views on the internet? Do you use the internet, if so where? What device do you use to access the Internet? What do you use the internet for?

Have you ever used the internet to look up advice or information about something? Would you ever use the internet to search for health information?

How about using the internet for information about managing stress or low mood? Why/ Why not?

What do you think about social media? What about online forums? Would you ever seek support from somebody on a social media platform?

Or (if the participant has already highlighted using the internet in the previous section)

You previously stated you used the internet to get advice, why did you decide to use the internet? What information/advice did you find? Did you follow the advice?

4) *Online Forums* and think aloud activities

Explain the purpose of the think aloud activities

Participants will be shown examples of online forums on a laptop to ensure they know what one is. The participants will then be shown a transcript of a transcript from an online forum, along with storyboards depicting experiences with an online forum. The participant will be asked "*what do you think of this?"* after they have read the transcript. The researcher will then show the participant a storyboard depicting a negative encounter with an online forum and then the participant will be asked "*what do you think whilst reading this?"* The researcher would then show the participant a storyboard depicting a positive encounter. The participant would then be asked "*what did you think whilst reading this storyboard?"*

5) *Close the interview*

Thank participant, and ask if they have any questions. Restate purpose of the interview and how data is going to be used

Consent Form
Title of project: How Older Adults cope with distress
Name of Researcher: Alice Moult

Keele University

Study ID number: *(Insert study ID number)*
Participant name:

**Please initial each
box if you agree
with the statement**

1. I confirm that I have read and understood the information sheet dated 23/05/2016
   (version no. 1.0) for the above study and have had the opportunity to ask   questions.

2. I understand that my taking part is voluntary and that I am free to withdraw at any
   time.

3. I understand that if I do take part, I can ask for my information to be removed for up to
   three months after my interview. After that, it will not be possible to remove it.

4. I agree to allow my anonymous information to be used in future research projects.

5. I agree to my anonymised quotes being used in the publication of any results.

6. I agree to take part in the study.

_____   _____   _____
Name of participant   Signature   Date

_____   _____   _____
Researcher   Signature   Date

Appendix 8

Extract from online forum

A post from an online forum called www.cureyourdepression.com

Person one: I've always been asocial and subject to mood swings. That's not to say that I don't every now and then swing back into feeling nice. But I never find anyone whose company I enjoy and I don't enjoy exercise or travel anymore. My days and nights are only filled with reading, researching banal matters on the internet, and watching T.V., all of which don't offer me much more than just the passage of time. I also don't trust or like seeing doctors, I have little faith in them.

Person two: Living to your sixties and waking up every morning is something to be grateful for. Try reaching out and being kind.
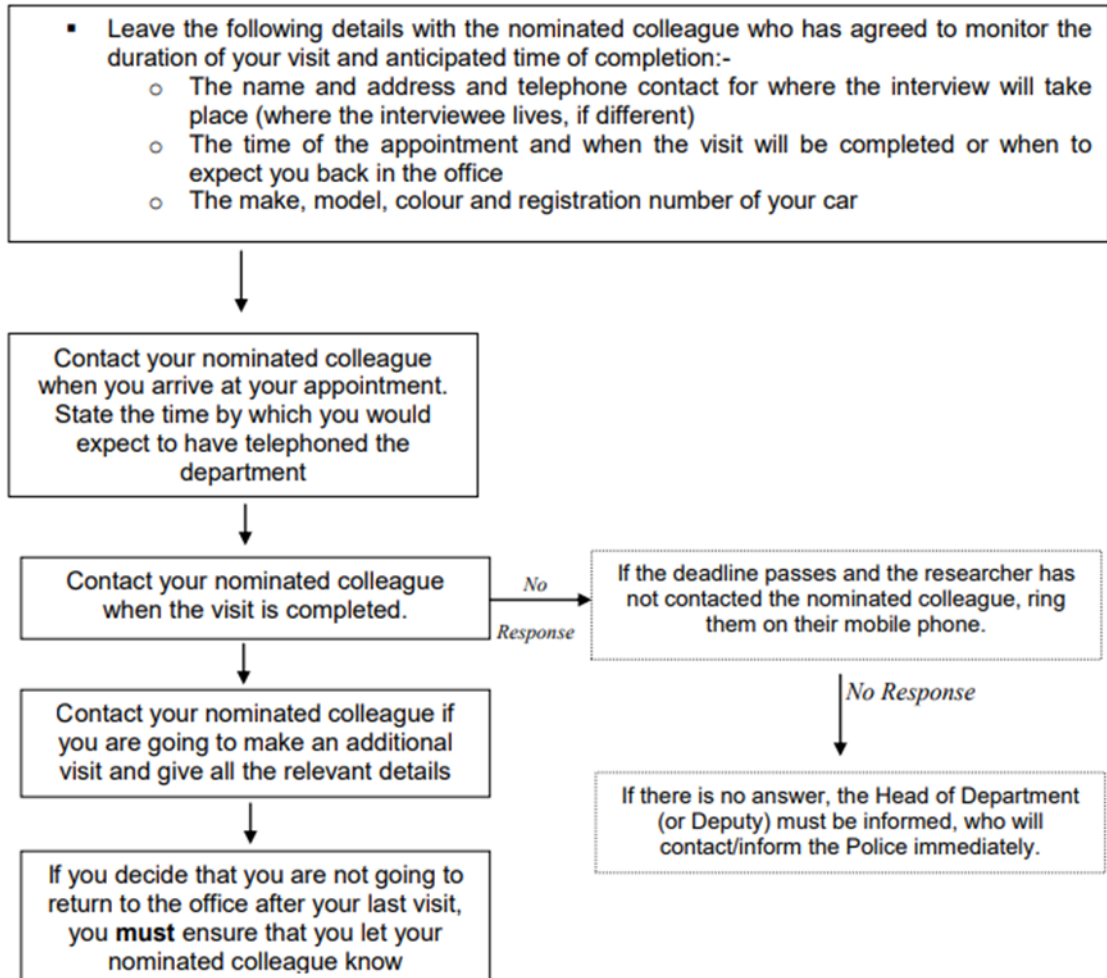
Person three: I have a sign posted on the wall that says, KEEP CALM AND CARRY ON.

Person Four: My recommendation is to participate in Recovery International meetings. Back in 1937 Abraham Lowe was not seeing any gains in his patients using psychoanalytic therapy. He created a system of cognitive and behaviour therapy. His programme is still very effective. Look up Recovery International on the web. Find a meeting or an internet meeting if there are no meetings near you. Try about 10 sessions to know if it helps you. The group sessions are free. It is by far the most powerful system I know. Go to a meeting and read the literature. Good luck!

Person Five: What helps me is reading the Bible. I believe true joy can be found regardless of age.

Appendix 9

Working alone away from the office

- Leave the following details with the nominated colleague who has agreed to monitor the duration of your visit and anticipated time of completion:-
  - The name and address and telephone contact for where the interview will take place (where the interviewee lives, if different)
  - The time of the appointment and when the visit will be completed or when to expect you back in the office
  - The make, model, colour and registration number of your car

↓

Contact your nominated colleague when you arrive at your appointment. State the time by which you would expect to have telephoned the department

↓

Contact your nominated colleague when the visit is completed. — *No Response* → If the deadline passes and the researcher has not contacted the nominated colleague, ring them on their mobile phone.

↓ | *No Response*
                                                                         ↓

Contact your nominated colleague if you are going to make an additional visit and give all the relevant details

If there is no answer, the Head of Department (or Deputy) must be informed, who will contact/inform the Police immediately.

↓

If you decide that you are not going to return to the office after your last visit, you **must** ensure that you let your nominated colleague know

Appendix 10a

Reflexive diary: Anne

The interview took place in a [village] community centre in a [village] in North Staffordshire. The interview followed a low mobility exercise group. I had met [Anne] a week before the interview was conducted whilst I was introducing my research to the group and looking to recruit participants. Anne had seemed extremely keen to be interviewed. I had got to know Anne a little in this first meeting and knew she lived alone and was recovering from a hip operation – the reason why she was attending the low mobility exercise group. I found meeting her a week before the interview was a good way to build up rapport. On the day of the interview, I joined in the low mobility group and afterwards, when the other participants went for tea and coffee in another room, me and Anne stayed in the room where the exercise class had been held. The room was quite large and was decorated with children's art work as the building is sometimes used as a nursery. We sat adjacent to each other around a small table, which I felt made it less of an 'interview' and more relaxing. Anne had a cup of coffee and seemed in good spirits and keen to talk. Anne had been a nurse before she retired and had a deceased husband who had suffered severe mental health problems, which she openly discussed.

Methods

The interview lasted 40 minutes, which was shorter than I expected. Anne had no real experience of using the internet and computers, therefore, when presented with the 'think aloud' methods Anne talked about other self-management strategies rather than engaging with the internet. There were instances where I could have probed Anne for more detail in relation to the 'think aloud' methods. I did not strictly follow the topic guide and let Anne's narrative guide the interview. The relationship between me and Anne, I thought, was to construct the answers together, for example, sometimes Anne would finish my sentences or questions I was going to ask, not in a rude way, but because she wanted to answer the questions.

Key things identified:

- Anne attributed her experience of distress to suffering from physical health problems

- Anne repeated the need for friends to socially support each other

- Anne acknowledged that reading was important for her

- Anne discussed that not many older people talk about mental health issues

- Anne did not use the internet and thought that social support should be gained by in-person encounters. However, Anne thought the internet would be a good resource to engage with if an older adult could not access face-to-face social contact

Comparison to other interviews

This was my first interview, so comparisons could not be drawn. However, in subsequent interviews I will try to probe more on participants' experiences and perceptions of using the internet as a self-management strategy.

Appendix 10b

Reflexive diary: Helen

The interview took place within an executive box overlooking a football club's pitch. A 'knit and knatter' club ran every Thursday within the board room of the football club. The interview took place after Elizabeth had taken part in the knitting group and the room the interview took place in was minimalistic with a large desk and office chairs. I had attended the 'knit and knatter' group for three consecutive weeks before interviewing Elizabeth and already knew that she was 79 years old and lived on her own in a village before the interview took place. Elizabeth seemed keen to participate and help me with my research. Myself and Elizabeth sat adjacent to each other around one corner of the large table and talked over a cup of tea whilst the participant did some knitting. Elizabeth seemed in good spirits and was quite open about her health problems, she was recovering from a hip replacement and had arthritis and Chronic Obstructive Pulmonary Disease (COPD).

Methods:

The interview lasted one hour and the participant was quite chatty. The participant hadn't got her reading glasses with her so although she could see the pictures she asked me to read the 'think aloud' methods too her. I felt that that she couldn't reflect on the material as in depth as the participants that read the 'think aloud' methods themselves, although she did share her opinions of the internet and online forums.

Key things:

- Elizabeth attributed her distress to physical health problems which had caused a loss of physical mobility
- Elizabeth reported the importance of being able to talk to her friends when she was 'stressed' and also discussed the importance of living in a close proximity to other older adults as there was a sense of 'comradeship'
- Reading books helped Elizabeth to forget about her distress
- Elizabeth discussed negative previous encounters with GPs which had prevented her from seeking help from healthcare services
- Elizabeth had a negative attitude towards medication as a treatment for mental health problems
- Elizabeth suggested that face-to-face interaction would be better than using online forums as a means of communication

Comparisons to other interviews

- Unlike the previous interviews, Elizabeth strongly talked about her negative encounters with a GP
- Unlike the previous interviews, Elizabeth had no interest in engaging with the internet as she perceived that it would prevent her from doing activities which she already enjoyed
- Similar to the other interviews, Elizabeth thought that face to face interaction would be better than using the internet as a way of accessing social support when experiencing mood problem

Appendix 11a

Appendix 11b

Participant's ID prior to giving them names

Text I was coding

Appendix 11c

Theme	Description of theme	Example of code	Example of data coded
Conceptualisation of distress	This theme captured the meanings that participants attributed to their experiences of distress. Distress was associated with various forms of loss (e.g. loss of friends or physical mobility)	Diagnostic labels to describe distress	*"Yes, it was depression ... but nowadays if I feel depressed, I come to these groups and chat and ... yeah."* (Carol) *"I'd be saying to friends that had lost someone dear to them, I am sorry and I am sorry but I didn't know the depths of it until it happened to me and I think that is the same with this anxiety."* (Diane)
		Lay terms to describe distress	*"I wouldn't talk to my husband because I don't think he'd understand how low I do get sometimes."* (Helen) *"For my stress, erm, myself I don't think I would ever take medication."* (Leslie)
		Loss of friends	*"But you find that your friends are dying off at this age, they're in the church-yard."* (Anne) *"Well unfortunately some of my best friends are no longer there, yeah, I've been to so many funerals this year it is unbelievable, yes, yes, in fact I said to someone, 'I think I'm the last women standing'."* (Diane)
		Loss of physical mobility	*"After I had the stroke I thought it wouldn't do any harm [to join an exercise group] because my left hand is still not as good and my left foot is not as good so I struggle to get that going."* (Barbara) *"And now I struggle to get about cos the small bowel needs partly removing and it is painful, it is just one thing after another."* (Kathleen)
Actions taken	Most participants held stoic attitudes towards their experiences of distress. Participants self-managed their mood	Stoic attitudes	Interviewer: *"Would you ever go to the doctor when feeling low?"* Kathleen: *"No, I would prefer to sort it out myself yeah, I'd find a way myself."* (Kathleen) *"You can't say what everyone would do, but personally, I would try and work things out for myself."* (Michael)

	problems by engaging in independent activities, seeking social support and attending community groups	Independent activities (reading, gardening, walking and religious beliefs)	*"It takes about an hour and half to do the mowing but it is therapeutic for me and gets me out of the house doing stuff, so that is a job to do, I enjoy the mowing and keep getting things looking nice in the garden."* (Leslie)
			"I love murder mystery novels and erm the ones I like best are the medieval ones, medieval ones because I'm there thinking, now how did they find out that? How do they know that?" (Gina)
			"But if I can do it once a week, I like to walk into [town] come back on this line and do like a circuit just to keep myself active." (Leslie)
			"You've got to find that something inside of you that keeps you going, now I've got God, a lot of people haven't got, and they are the ones that find it difficult." (Carol)
			"Yes, I am a practicing Catholic I would never ever … take my problems to the people at Church, the problems are my problems I mean yeah I guess you pray and your faith is strong enough to get you through it." (Janet)
		Seeking social support from friends	*"Friends are necessary. You can't do without friends and you know they've always been supportive of me."* (Carol)
			"I've known my friends for a while and I think, you know, they relate to me and you know we can have a chat about things about things that worry us and stuff … yeah." (Barbara)
		Community groups to socialise	*"I think most people now have been coming to this group for such a long time erm we know each other quite well and we all get on very well, yeah, absolutely, it is good because we just come in and we have a chat about different things and what we're going to do and we have a moan."* (Irene)
			"Yeah, this helps coming to the knit and natter, erm I always feel better having been out and had a good gossip, usually we start off with all our ailments then we have a good laugh and get on with it." (Diane)

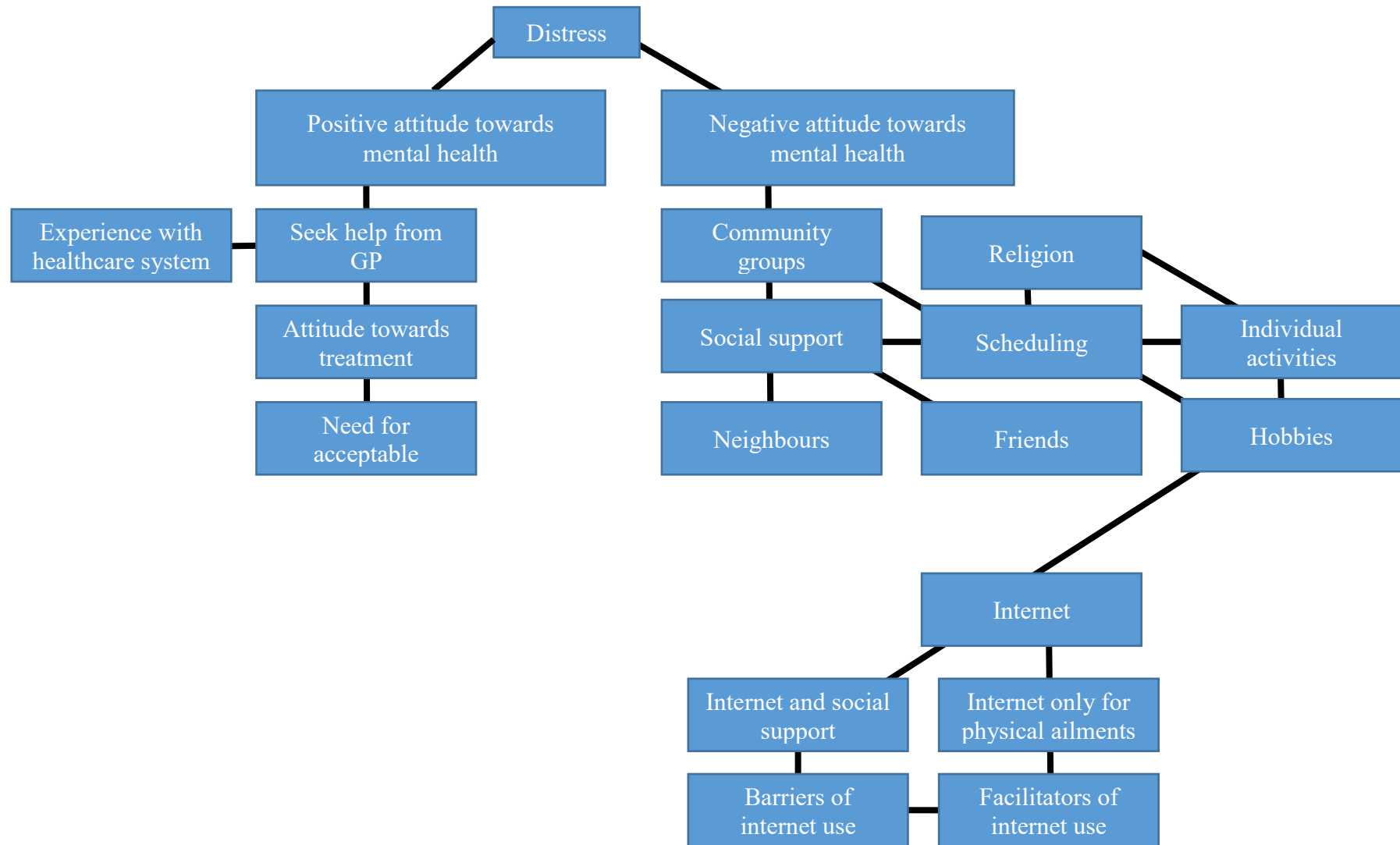| Help-seeking from the healthcare system	This theme described the factors which affected help-seeking from the healthcare system	GP seen to offer solutions for mood problems	Interviewer: *"What do you think about going to the doctors [about] mental health problems?"* Diane: *"Yeah, I tried to do it on my own until I realised I was getting churned up and I thought ... I need some help."* (Diane)
		Lack of continuity with GPs	*"Well you see so many different ones now, that is the point, erm, erm people like me who are over 75 have a doctor allocated to you, you know? That is a new ruling? Erm, but I haven't seen him for over a year because he's never available when I ring so you have to have someone else so there is no continuity like there used to be, I don't think that is a very good thing, they don't know your problems."* (Diane) *"I don't bother with the GP if I'm honest at all, having the same GP is important and seeing a different one all the time well that stops me from saying I need something, seeing a familiar face would be important."* (Kathleen)
		Negative previous encounters with GPs	*"I will not see that GP at all, because first of all, I used to keep going all dizzy and what not and I went to him and he says 'oh you're not getting enough oxygen to the brain' and left it at that, never give me anything for it, told me not to do nothing, just left it!"* (Gina) *"[The GP] has got ideas way above his station, he's going to be some consultant, he's doing something else and wants to progress, which is fine. So the point was, that I couldn't get to see my doctor and I didn't believe I was being looked after by the doctor who told me 'don't take anymore Statins', you see? So why would I go back?"* (Owen)
		Stigmatised attitudes towards mental health problems	*"People don't want to be diagnosed as having a mental health problem, yeah, somehow it has become shameful."* (Carol) *"I think people don't want to be diagnosed as having mental health, yeah, its frowned upon and that."* (Anne)
Lack of acceptable treatments offered in primary care	Participants discussed medication and 'talking therapies' (counselling) as treatment options for	Medication as a stop-gap	*"I know it is an easy fix for [GPs] because you're in for a short time, he prints of a prescription and says go and take these antidepressants and tell me how you feel in a short time."* (Owen)
		Short-term medication use	*"I would take the tablets, my husband doesn't like taking tablets but if it helps it helps just for the short term when you need it."* (Helen)

	mental health problems.		*"I did have to resort to having some erm nerve tablets or anxiety pills but not the long-term ones, I used to like the short-term ones for a fortnight so I could pick myself up and go, they would give me that little boost, you know?"* (Diane)
		Medication is addictive	*"I don't think that, that [medication] is a good thing, I mean I've got myself off them, because I knew what they could do if I didn't, you know, they get addictive."* (Carol) *"For anything to do with nerves or stuff short term yes, but long term, no, you can become that addicted to them, it is better to find ways on your own, yeah I think that."*(Gill)
		Lack of knowledge about counselling	*"Counselling for depression? I mean, what exactly is that? I'm not sure about that, I don't think it would help a lot."* (Helen) *"But actual counselling I don't understand it, I think erm essentially you've got a problem and the doctor suggests going to counselling people don't understand."* (Owen)
Use of the internet	A few participants engaged with the internet for hobbies and/or interests, to conduct online purchases or to communicate with family members when in-person communication was unavailable. Participants faced a range of barriers to internet use	Hobbies and/or interests, online shopping and as a means of communication	*"I don't know it all but I can look things up and erm erm I've done a family tree on the internet!"* (Diane) *"I love Amazon because I can't get out and shop without someone taking me and I get tired and very confused quickly so I end up buying the wrong thing, but on Amazon I can sit quietly and do* it." (Kathleen) *"I get on Skype see he is online, click on him and it comes up with sometimes what he's doing and I just leave a little message underneath like 'hi, how are you? Do you want to talk?'* (Michael)
		Barriers towards internet use	Interviewer: *"May I ask your views on the internet?"* Elizabeth: *"Do you know love, I haven't got a clue and I don't know whether, I have no interest in learning (laughs)"*(Elizabeth) *"I think if we'd have been raised with them, I mean my son is a computer man because it is the jobs and the daughter-in-law is, and grandchildren, that is their jobs, and that is how you learn today but we never did, and I think that is why I'm not interested."* (Frances) *"The pensioners being hacked and all this and I think it is frightening really and I mean the older generation I mean erm it is a bit fearful, it is isn't it though really? Me, personally, I*

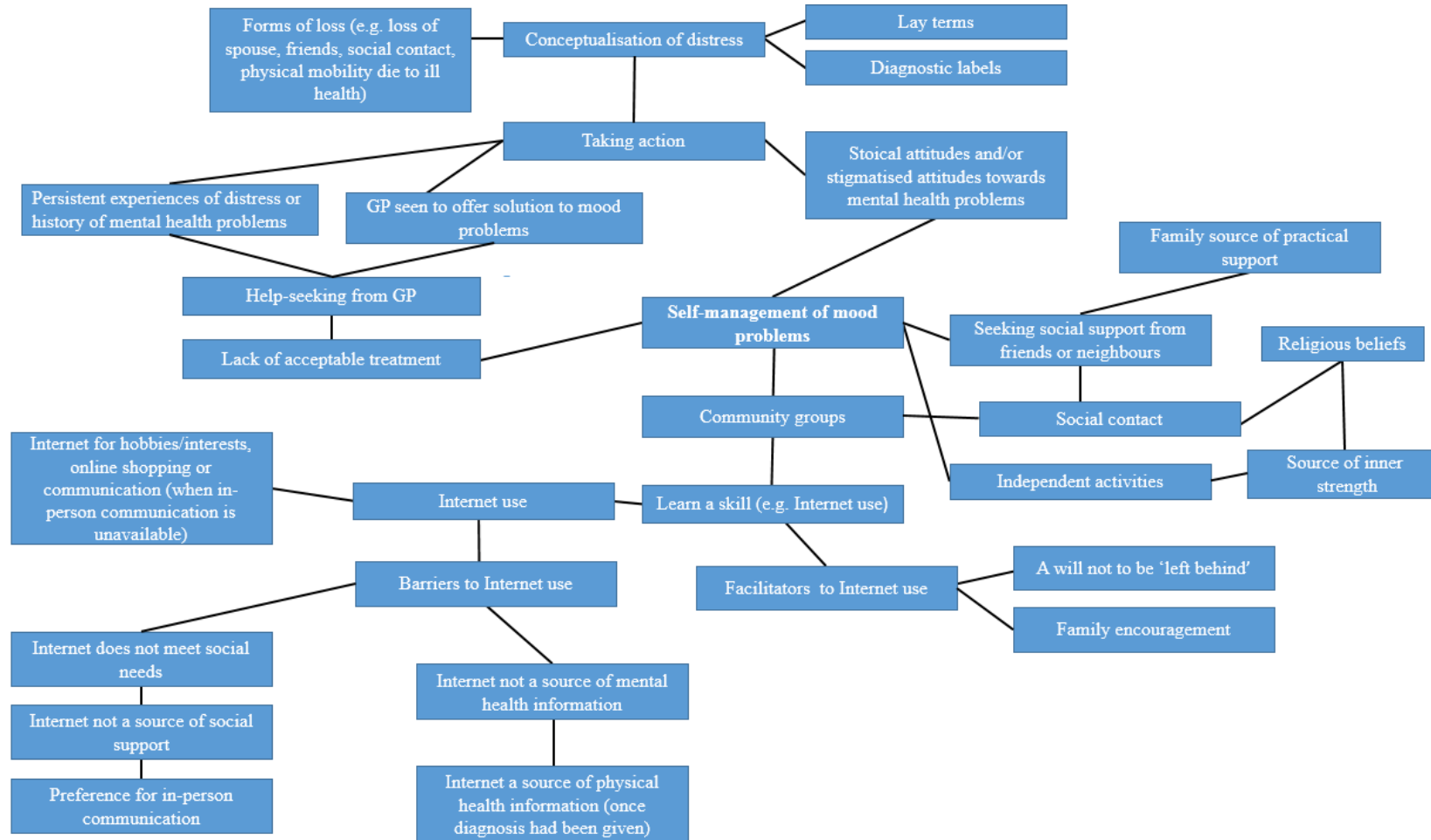|			*when I deal with the bank or the building society I like to see the person face to face."* (Nigel)
Using the internet as a health resource	The internet was an unacceptable source of health information as it provided information which could have been irrelevant to some participants' health needs. A diagnosis of a physical health problem, made by a healthcare professional, was needed before the internet was used as a source of health information. Some participants reported that the internet was inappropriate for information about distress as such problems were *"personal"*.	Information irrelevant to health needs	*"Will not look illnesses on there because it can make you worse than when you bloody started, you're a bit paranoid really aren't you, you see of these things and say I've got that"* (Frances) *"Have to take it with a broad pinch of salt though, because you know you could diagnose yourself with all sorts."* (Leslie)
		Need of a diagnosis	*"I like to know what is coming, like with this operation, it is a bowel resection, and I want to know what is going to happen and why, so yes I do look."* (Kathleen) *"I did google an operation I had and I watched the operation before I had my operation and the surgeon said "you did what?" and I said well I wanted to know what was going to happen."* (Carol)
		Health information for physical illnesses	*"I've got Irritable Bowel Syndrome, I Googled that to know what it was as well as what they told me at the hospital all those sort of things I've got erm what is it? Erm Angina so I Google that you know?"*(Helen) *"It is alright sending people to the internet like to [Brenda], they've said just check such and such thing on the internet, like exercises for a bad back and things like that, more what you'd call physical I guess but not stuff like that."* (Leslie)
		Distress as 'personal'	Interviewer: *"Would you ever use Google to look up things about low mood, distress or mental health problems?"* Kathleen: *"It is … sometimes if I can see like physical problems with friends I'll have a look and think how can this be handled? But I don't go into mental health in-depth because it's personal."* (Kathleen)

Views on accessing social support via the internet	The internet did not meet participants' social needs. Participants preferred in-person communication when seeking social support. Participants also perceived that they would struggle to form friendships online. Participants also discussed the anonymity of online forums.	Not meeting social needs	*"I like meeting people like walking football or like a group of people because that would get you out of yourself and gives you something to look forward to sort of thing and that social aspect but I couldn't do [the internet], no."* (Leslie)
		Preference for in-person communication	*"I just find in times of stress that you, you do need, well I do anyway and perhaps a lot of other people do, the contact of another person to talk with rather than a computer, the computers can only bring so much comfort and erm you can't beat, that can't take the place of a human and the contact with another human being."* (Peter) *"I'd want to talk to someone. I do think there is a difference in communication I think you're more likely to, to open up if you do have any problems if you speak face-to-face."* (Janet)
		Struggle to form friendships online	*"Thing is you see, when you've spent a life without that it is very difficult at this age to start and think about making friends like that because you're so used to that personal, face-to-face contact."* (Nigel)
		The anonymous nature of online forums	*"I mean, those forum things, no it could anybody on the them, just telling you to pick up yourself, pick yourself up and behave yourself and just get on with it, you know, no, never done it."* (Carol) *"I know there is a person on the other side but you know, but you don't know who it is."* (Elizabeth) *"[Online forums] should be moderated … I am not a qualified person, so how do you know that these people at the other end of the computer are a qualified person? They can put anything that they want on there and they can put signs and I've done this, this and this but you don't know."* (Irene)
Facilitating internet use	This theme highlighted factors which encouraged	Not wanting to be 'left behind'	Interviewer: *"What are your opinions on the internet?"* Robert: *"Well it is getting better but I think, it was like a red rag to a bull erm, I use old telephones and letters and cheques, they talked about stopping doing cheques and the*

	participants to want to learn how to use the internet and ways in which participants learnt how to engage with the resource		*reaction was you can't stop doing cheques, you know, but eventually you think no, be sensible, you've got to do something about it and learn.”*(Robert) Interviewer: *“What made you want to [learn how to use the internet]?”* Janet: *“I needed, I felt I needed to keep up with what was going on I didn't want to end up like my parents you know well my Mother anyway where she hadn't a clue how to tune a radio in or anything like that erm automatic washing machines she couldn't use one of those so I thought to myself I need to know I don't want to be left behind as some sort of [laughs]”*(Janet)
		Comparison to family's internet use	*“[Gina] was a whizz on it she could make then do had stands but, and [Robbie] can and [Nina] can, so I just feel as though I need to you know, I don't want to get left behind.”*(Peter) *“My wife is alright on it, she erm is used typing and she's alright, but me I'm still [points one finger at a time], so I came here and this group helps.”*(Nigel)
		Family members aiding learning	*“My son lives in [Wales] just moved [city] way now, erm, he'll help when he's there and [Brenda] will ask him over the phone now and again about [the internet].”* (Leslie) *“The children tried to teach me, but they aren't there and if things went wrong I had to wait for them to come again.”* (Diane)
		Computer groups	*“We'd rather come [to computer group] before committing ourselves to anything online so that is why we come here, very, very, helpful.”* (Leslie) *“Erm basically it increases your confidence because sometimes you're ready to throw it at the wall, because you're in a rush or if you lose any information in any shape or form but erm I think the thing with the groups is that, it is good in the sense that it is teaching you things, but the essential part of it is that you're getting used to computers, that is the essential part of it.”* (Owen)

Appendix 11d

Distress

Positive attitude towards mental health

Negative attitude towards mental health

Experience with healthcare system

Seek help from GP

Community groups

Religion

Social support

Scheduling

Individual activities

Attitude towards treatment

Need for acceptable

Neighbours

Friends

Hobbies

Internet

Internet and social support

Internet only for physical ailments

Barriers of internet use

Facilitators of internet use

Appendix 11e

Forms of loss (e.g. loss of spouse, friends, social contact, physical mobility die to ill health)

Conceptualisation of distress

Lay terms

Diagnostic labels

Taking action

Stoical attitudes and/or stigmatised attitudes towards mental health problems

Persistent experiences of distress or history of mental health problems

GP seen to offer solution to mood problems

Family source of practical support

Help-seeking from GP

Self-management of mood problems

Seeking social support from friends or neighbours

Religious beliefs

Lack of acceptable treatment

Community groups

Social contact

Internet for hobbies/interests, online shopping or communication (when in-person communication is unavailable)

Internet use

Learn a skill (e.g. Internet use)

Independent activities

Source of inner strength

Barriers to Internet use

Facilitators to Internet use

A will not to be 'left behind'

Internet does not meet social needs

Family encouragement

Internet not a source of mental health information

Internet not a source of social support

Preference for in-person communication

Internet a source of physical health information (once diagnosis had been given)

Patient and Public Involvement Request Form

This form is intended to more efficiently support you in incorporating PPI into your research. The details are intended to act as signposts in thinking about some of the issues to consider.

If you have any questions or if it would helpful to talk through some of the issues I'd be very happy to do that. I am Adele Higginbottom and I can be found in room 0.55. My work days are Tuesday, Wednesday, and Thursday

When inviting a patient or member of the public to a meeting, some of the things you need to consider are how far they may have travelled, refreshments, lunch, comfort breaks etc.

Please return this form to Adele Higginbottom (a.higginbottom@keele.ac.uk)

Name:	Alice Moult
Title of Project:	How Older Adults Self-Manage Low mood: A Qualitative Study

Please provide a summary (in lay language) of the overall aims of the project, and what the nature of patient and public involvement will be. Please include the following details:

1. **What are the aims of the overall project?** Provide a lay summary, please consider the following headings (could include; population, intervention (e.g. tens machine), design, timeline, expected start date.

> **Research Summary**
> **Aims**
> To assess the various self-management strategies older adults with low mood engage with.
> To assess the role of the Internet is supporting the self-management of low mood.
> **Population**
> The participants will all be over 65 years old or over and self-identify as experiencing low mood.
> **Design**
> The research will be done through interviews, Internet transcripts and storyboards. The Internet transcripts will be pieces of text taken from what people have written on an online forum and used as a basis for discussion. There will be one storyboard made up of a sequence of drawings, with some dialogue. The storyboard will depict an older adult engaging with the Internet.
> Older adults will be recruited via local community groups around Staffordshire.
> The interviews will ask the participants which self-management strategies they engage with when they have a low mood. An interview guide (questions that are going to be asked in the interview) will be derived from past research regarding self-management strategies. After being asked about which self-management strategies they use to alleviate their low mood,

they will then be shown the Internet transcript and storyboard to generate discussion about online forums and the Internet. The participants would then be asked to complete their own storyboards of why they do/ don't or would/wouldn't engage within an online forum as a self-management strategy.

Timeline

The interviews will hopefully start in September 2016 and it will take me 6 months to conduct all of the interviews. The research process as a whole will last until September 2018.

Expected Start date

Data collection: September 2016.

2. **What is the aim of patient and public involvement in the project?**

1) I aim to receive feedback on my research questions and methods to see if there are any ways I could improve upon them

2) In the future I aim to share my findings with a PPI group to get their opinions and advice and I aim to create a dissemination plan with PPI input

3. **What research tasks will be undertaken and what sort of roles are you considering for PPI?**

The role of PPI would be to give advice and feedback throughout the research process

4. **How many individuals do you need to fulfil the PPI aims?**

Five - six individuals would be needed to fulfil the PPI aims

PPIE Meeting: Self-management strategies older adults use when suffering from a low mood.
4th February 2016
11.00am to 12.30pm

Attendance
John (JM), Robert (RT), Theresa (TG), Carol (CW), Heather Burroughs (HB), Alice Moult (AM).

Discussion on Research Questions
The meeting began with AM explaining the PhD project idea; which was exploring the self-management strategies older adults use when suffering from a low mood. AM explained that the research had two aims; to explore the various self-management strategies older adults with low mood engage with, and to explore how older adults use the Internet to manage their low mood.

AM then moved on to explain why the research would be focusing on low mood rather than depression. HB explained that there are considerable barriers to recruiting depressed older adults from primary care. The PPIE members thought that the research should also include older adults who experience symptoms of anxiety as they believed anxiety and depression go *"hand in hand"*. The PPIE group also thought that older adults would not self-identify as depressed or anxious due to stigma, but the group did believe that older adults would see themselves as experiencing 'distress.' PPIE members thought the term distress was an umbrella term which could allude to symptoms of depression and anxiety (e.g. low mood and stress).

AM asked the PPIE group about their thoughts on self-management as a research topic, the group thought that self-management was a good research area, they believed that individuals should take more accountability for their health, especially as there is a funding crisis within the National Health Service (NHS).

The use of the Internet as a self-management strategy was then discussed. The PPIE group thought that it would be vital for the research to explore why older adults do, or do not, use the Internet, as they believed that this information could be useful for healthcare professionals.

Methods
AM then stated that she would like to use storyboards within the interviews. AM asked the PPIE group's opinion on getting participants to create their own storyboards; the group thought this would deter older adults from taking part in the research. The PPIE members suggested that using a pre-created storyboard would be a good way to create discussion. AM showed two storyboards she had already created, one which depicted a positive encounter within an online forum and another which depicted a negative encounter. The PPIE members thought the storyboards would be a good way to stimulate discussion on why, or why not, an older adult would use the Internet and online forums as a source of support or information. In general the PPIE group suggested that the images within the storyboards should be hand-drawn and that the colour scheme should be black and white. PPIE members suggested the

characters should be a male and a female and gave advice on the characters' physical appearances.

In terms of Storyboard One they believed that Catherine was a suitable name for the character. The PPIE group suggested that Catherine should have gone through a distressing experience that was relatable to other older adults, such as a bereavement. PPIE members thought that feeling alone and stressed about the future may perhaps be a motivation to use an online forum. The PPIE group suggested that the 'story' should show Catherine signing up to an online forum and receiving helpful advice on how to deal with her grief which helps to improve her mood. The PPIE group proposed the first frame within the storyboard should show Catherine in her home with a computer and that the second frame should show her signing onto an online forum. PPIE members suggested that the third frame should show a computer screen with smiling faces in the background.

In terms of the second storyboard, the PPIE group thought that Peter was an appropriate name for a male character and proposed that Peter should be suffering from low mood, not stress. The 'story' of the storyboard was discussed; Peter would be feeling low, he decides to go to his GP who diagnoses Peter with depression and offers him medication. Peter does not wish to take the medication; the PPIE group particularly thought this reflected older adults' views on taking medication for mental health problems. The GP then gives Peter a leaflet which suggests going online. Peter signs into an online forum and other online forum users tell Peter is was 'his fault' he was feeling this way and that he should 'pull himself together', Peter does not feel better and is worried about going back to see the GP.

PPIE members thought that the Storyboard Two should include four frames to include enough detail. The PPIE group thought the first frame should show Peter using a telephone to arrange a GP consultation and that the second frame should illustrate Peter with a GP who offers him an information leaflet with a picture of a computer on it. PPIE members suggested that the third frame should show Peter on a computer with a hand pointing out of the screen towards him and that the last frame should indicate that Peter's mood had not improved and illustrate Peter looking worried with a faded image of a GP in the background.

AM also showed the PPIE group a transcript from an online forum. PPIE members also thought that this would be a good way to stimulate discussion within the interview. The transcript includes a member of an online forum describing that they are feeling low and four replies from other members within the forum. The group thought the discussion within the transcript from the online forum was realistic and thought it would encourage participants to verbalise their experiences and perceptions of the Internet within the interview.

AM then thanked the group for their comments and informed them that their feedback had been invaluable in making improvements to the study.

Appendix 12c
PPIE Meeting: Self-management strategies in distressed older adults
26th March 2016
10.00am to 12.00pm

Attendance
John (JM), Robert (RT), Theresa (TG), Alice Moult (AM)
Project Update

AM introduced the project and the project aims. AM described how the focus of the project had changed from 'low mood' to 'distress' in light of the last meeting.

Storyboards
AM showed the group the storyboards which incorporated feedback from the previous meeting. The only suggested change was to modify the wording in Storyboard One, frame three from 'Catherine's mood had improved' to 'Catherine's mood improves.' The PPIE group agreed with AM that the storyboards were suitable to be used within the interviews.

Poster
AM showed PPIE members the poster than would be used to advertise the study. The PPIE group gave advice on how to modify the poster. PPIE members thought that the poster should have slips that potential participants could rip off and take with them, they thought that slips would be more suitable as potential participants would not have to write down AM's contact details. In regards to the aesthetics of the poster, the PPIE group recommended that the poster should include a picture of a Cherry blossom tree to make it more visually appealing.

Information Leaflet

AM showed the PPIE group the study's information leaflet. The PPIE group liked the layout of the information leaflet but, similar to the poster, suggested including a picture of a Cherry blossom tree. The PPIE group also recommended that the information leaflet should state that the study is being conducted to aid mental health research as this may motivate some older adults to take part in the study. PPIE members also suggested that allowing participants 3 months to withdraw their data after the interview was inappropriate, AM explained the ethical implications.

Topic Guide
AM showed the participants her proposed topic guide and read each question out to the members. The group did not modify the wording of the questions but highlighted that the topic guide asked if participants engaged in social activities, but did not include a question asking what activities they do on their own; they believed this should be integrated into the topic guide.

The PPIE group also commented upon the structure of the topic guide. PPIE members thought that some older adults could use the Internet as a self-management strategy of distress, but

proposed that the interview needed to explore other self-management options before the Internet is introduced as not every older adult may use the Internet.

AM thanked the group for their comments.

PPIE Meeting: How Older Adults Self-Manage Distress

27th July 2017

10am – 1pm

Attendees: Robert (RT), John (JM), Katie (KT), John (JT), John (JH), Alice Moult (AM)

AM opened the PPIE meeting by detailing her PhD research, which is exploring the self-management strategies older adults employ with a particular focus on the role of the Internet. AM explained the aim of this meeting was twofold; to discuss some of the data and to create a dissemination plan of the findings.

Data Analysis

AM showed the PPIE group a map of the data. The group suggested that as the data highlighted that participants used an array of self-management strategies this shows how subjective managing distress is. The group also discussed that feelings of distress are extremely personal and unique to each individual.

AM then showed the group 18 data extracts that corresponded to the map of the data. Examples of data extracts included:

"There isn't a lot of help for people we need a lot more help on how to use it. I really don't know what an App is nobody explains what an App is. I know that the fonts on the iPhone are not big enough but my husband tried yesterday and he said he can't get it to work." (Barbara)

AM thought that this quote demonstrated a lack of help for older adults who have usability issues in terms of not knowing how to use technology or the Internet. The PPIE group agreed.

"Think it is because with knitting and sewing or anything like that I can watch tele and do that as well but if you've got your computer it is all your computer." (Helen)

AM thought the quote shows that the Internet can be perceived as a barrier to other activities that the participant enjoyed. The group agreed and thought that if the participant enjoyed knitting or sewing they should keep engaging with that activity to alleviate feelings of distress.

The PPIE group agreed with AM's interpretation of each of the 18 data extracts.

After seeing the map and extracts of the data the PPIE group particularly discussed the importance of face-to-face contact with friends for older adults experiencing distress. The PPIE members also discussed that participants were raised in a society with no access to the Internet and believed this was why participants self-managed by seeking face-to-face social contact.

The PPIE members also highlighted that the findings show the need for more computer group classes for older adults. From the data AM presented to the group, PPIE members discussed that using the Internet could be useful for older adults who suffer from physical health problems which prevents them from leaving their houses.

Dissemination Plan

AM explained to the group that she has presented her research at various conferences and is currently writing a paper for an academic journal. AM explained that she aims to disseminate the findings to third sector, the PPIE group suggested targeting the following charities; the Beth Johnson Foundation, Age UK and North Staffs Carers.

Appendix 13a Published work

How older adults self-manage distress – does the internet have a role? A qualitative study

Alice Moult[1*] , Heather Burroughs[1], Tom Kingstone[1,2] and Carolyn A. Chew-Graham[1,3]

Abstract

Background: Anxiety and depression are common in older adults, but often under-recognised by GPs. Rather than perceiving themselves as suffering from anxiety or depression, older adults are more likely to self-identify as experiencing low mood, stress or distress. Older people may also feel responsible for managing their own mood problems. The Internet has the potential to support the self-management of distress through accessing health information or social support.

Methods: This study was approved by Keele University's ethical review panel. Older adults who self-identified as experiencing distress were recruited from community groups in the West Midlands, England. To generate data, 'think-aloud' methods (including storyboards and an extract from an online forum) were embedded within semi-structured interviews. Thematic analysis, incorporating constant comparison methods, were used for data analysis.

Results: Data saturation was achieved after 18 interviews. All participants reported having access to the Internet, but only a few described using the Internet to obtain general information or to conduct online purchases. Most participants described barriers to Internet use which included: a lack of interest, knowledge and confidence, a fear of technology and no trust in social media sites. Facilitators of Internet use included family encouragement and attending community groups which taught computer use. Female participants reported valuing the social contact provided by attending such groups. The Internet was seen as a source of health information once a GP had diagnosed a physical problem, but was not considered a source of information about distress or mood problems. Participants did not use the Internet to access social support and described a preference for face-to-face communication.

Conclusions: GPs need to understand how an individual patient utilises the Internet. GPs should explore the self-management strategies already employed by older adults experiencing distress and understand that directing these older people to online support might not be acceptable. Encouraging distressed older adults to attend computer group classes might be useful as this permits face-to-face social contact, and may help to facilitate Internet use in the future.

Keywords: Older adults, Internet, Self-management, Distress, General practitioners

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Background

Older adults have been typically defined as anyone who is 65 years old and above [1, 2], research has shown that anxiety and depression are common, but often unrecognised and untreated in individuals within this age group [3]. Older adults may not present mental health problems in primary care settings due to a myriad of patient-level barriers to care such as stigma, or an attribution of symptoms of mental health problems to the ageing process or physical comorbid conditions [4–8]. A lack of detection by General Practitioners (GPs) may also prevent older adults from receiving a diagnosis of a mental health problem [9]. If recognised by a GP, the management options offered may not be acceptable to older people [10].

Older adults are more likely to perceive themselves as experiencing low mood, stress or distress, rather than depression or anxiety [11]. Distress, depression and anxiety are related but distinct constructs [12]. Distress has been conceptualised as 'the effort people must apply to maintain their psychosocial homeostasis and social functioning when experiencing stress' [13]. Stress is often triggered by a range of life events such as bereavement or receiving a diagnosis of a physical health problem [14]. Distress can be comprised of symptoms including feeling low, worrying, irritability, poor concentration and sleep problems [13]. Depression includes all symptoms indicating distress, however may be identified by additional symptoms such as anhedonia, thoughts of self-harm, suicidal ideation and pervasive negative thoughts about self. In terms of anxiety, distinguishing symptoms from distress include irrational fears and avoidance behaviours [15]. Therefore, distress overlaps with depression and anxiety as an individual reaching the diagnostic criteria for these mental health problems is likely to have experienced distress [12].

Patient and practitioner barriers to help-seeking may result in older adults managing their own mood problems [16]. Self-management is defined as 'taking increased responsibility for one's own health, behaviour and well-being' [17]. Effective self-management encompasses the ability to monitor one's own health problems and to have the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life [18]. Policy initiatives support GPs encouraging older adults to self-manage both physical and mental health problems [19, 20].

To self-manage symptoms of depression and anxiety, younger adults employ several self-management strategies [21]. Some of these self-management strategies include using the Internet as a source of health information, or as a means of accessing social support [22–25]. Younger adults accessed social support through the Internet by engaging in social media sites [26], or within online forums [27]. Online forums are discussion sites where people can anonymously hold conversations in the form of posted messages. The anonymity afforded by online forums may lead to people being more open about their emotions [28]. Older adults could use the Internet to self-manage distress, however there is a lack of research which explores this. The Internet could be a source of information about distress, or be used in a way that enables distressed older adults to access social support. We report a study which explores the role of the Internet, particularly online forums, in how older adults self-manage distress.

Methods
Study design

A qualitative approach was adopted to explore the role of the Internet in how older adults self-manage distress. Ethics approval was obtained from Keele University's ethical review panel (ERP1279). Written consent was obtained from all participants.

Sampling strategy and recruitment

Recruitment to this study, which aimed to explore the role of the Internet in how older adults self-manage distress, was conducted through existing community groups in the Midlands, England. Stigma, or an attribution of symptoms of mental health problems to the aging process or physical illnesses, may prevent older adults from seeking help from healthcare services for their mood problems [4–8]. Recruiting from community groups enabled access to older adults who may not have presented their distress within primary care settings.

Inclusion criteria were used to ensure the sample consisted of individuals who were 65 years or older and who self-identified as distressed. To recruit distressed older adults, information sheets and flyers were given out within community groups (by AM). Distress was described on the information leaflets and flyers as feeling 'low,' 'stressed,' 'anxious' or 'depressed'. The information sheets and flyers also stated that participants had to currently self-identify as distressed, or have been through an experience of distress within the past twelve months. Participants were also asked to describe their experiences of distress within the interview. A purposive sampling strategy was operated to ensure the sample consisted of a mixture of participants from various demographic backgrounds (see Table 1). AM tried to encourage snowball sampling [30] to recruit older adults who did not attend community groups. Older adults who attended the community groups were given additional information leaflets and were asked to pass them onto friends who might be interested in participating in the study.

Data generation

Interviews were conducted (by AM) between September 2016 and March 2017. Interview topic guides were developed with the relevant literature and members of a research advisory group made up of older adults with mood problems; this ensured the wording of the prompts were acceptable to study participants. Semi-structured interviews were used to collect the data as they were sufficiently structured to address dimensions of the research question, but also permitted participants to offer new meanings to the topic under study. Embedded within the semi-structured interviews were 'think aloud' methods [29]. To ensure the 'think aloud' methods were suitable for potential participants, they were also created with advice from a research user group. Participants were first asked to read and reflect upon a transcript taken from an online forum (see Additional file 1). The transcript was taken from an open-access online forum which aimed to provide support for people experiencing depression. This was the only open-access online forum found by AM in which an individual described being an older person experiencing a mood problem. This older person received advice from several other users within the online forum. By showing participants the transcript from an online forum, this aimed to elicit discussion on using the Internet as a self-management strategy of distress. Participants were also asked to read and reflect upon two separate 'storyboards' as 'think aloud' activities. One 'storyboard' depicted an older adult having a positive encounter within an online forum (see Additional file 2). The second 'storyboard' depicted an older person having a negative encounter with an online forum (see Additional file 3). The storyboards also aimed to stimulate discussion around the Internet as a self-management strategy of distress. Contrasting the transcript from an online forum, the storyboards give some context into how a distressed older adult may come to use online forums.

Interviews were digitally recorded, transcribed and anonymised. Data collection and analysis were simultaneous and during this process the topic guide was modified to explore emerging areas of interest. Thematic analysis, incorporating constant comparison techniques, were used to analyse the data [30]. This method of analysis captured developing and recurrent themes within and between transcripts. Data analysis was conducted by four researchers (AM, HB, TK, CCG) from various disciplinary backgrounds, this increased the trustworthiness of the analysis [31]. Transcripts were transcribed and analysed independently by AM. Emerging codes and themes were discussed as a team until a consensus was achieved. Recruitment ceased once data saturation was reached.

Results

All participants were recruited through community groups, the study did not manage to recruit any older people through snowballing methods. All participants were given a choice of a preferred venue in which to be interviewed (within the community group building or at home). Each participant chose to be interviewed within a private room at the building where the community groups were held. Interviews lasted between 44 and 92 min (mean 63 min).

Sample characteristics

Eighteen older adults were interviewed (11 females, 7 males) with a mean age of 77.5 years (range 65–91). All participants reported having Internet access within their own homes (Table 1).

Participant	Gender	Aged Between	Retired	Marital Status
1	Female	85–91	Yes	Widowed
2	Female	65–74	Yes	Married
3	Female	75–84	Yes	Divorced
4	Female	85–91	Yes	Widowed
5	Female	75–84	Yes	Widowed
6	Female	65–74	No	Married
7	Female	75–74	Yes	Married
8	Female	85–91	Yes	Married
9	Female	75–84	Yes	Married
10	Female	65–74	Yes	Married
11	Female	65–74	Yes	Married
12	Male	65–74	Yes	Married
13	Male	95–91	Yes	Married
14	Male	75–84	Yes	Married
15	Male	65–74	Yes	Married
16	Male	65–74	Yes	Widowed
17	Male	75–84	No	Widowed
18	Male	85–91	Yes	Married

Table 1 Participant demographic profiles

Presentation of themes
Key themes presented in this paper include: familiarity with the Internet, increasing familiarity, the Internet as a medical encyclopaedia and meeting social needs on the Internet. Illustrative data is given and identified by a participant number. It is also noted if the data was generated during the 'think aloud' activities.

Familiarity with the internet

All participants were familiar with the concept of the Internet. One participant described accessing the Internet in the following way:

"Yeah, we have Internet on our phones, iPad and computer yeah, everything. I've kept myself up to date but sometimes I have to send for the grandchildren [laughs] Can't do this, sometimes I get mixed up on my phone, its so small!" [Participant 10]

Although some participants had access to the Internet through a range of devices, only a small number of participants were familiar in using the resource. These participants used the Internet as a source of general information:

"You need to be told erm erm oh things like […] what is the weather like where you are, you know, oh it is sun-shining or it is raining." [Participant 3, generated from Storyboard 2]

A few participants reported using the Internet to conduct online purchases, which supported a sense of autonomy:

"I love Amazon because I can't get out and shop without someone taking me and I get tired and very confused quickly so I end up buying the wrong thing, but on Amazon I can sit quietly and do it." [Participant 11]

Participants who engaged with the Internet used the resource for practical purposes.
Most participants were unfamiliar in using the Internet, particularly as a source of social interaction (e.g. using social media platforms or online forums):

"Never been on one, never been on a chat forum so I can't comment really." [Participant 10]

Some participants reported a lack of knowledge about what the Internet might offer them:

"I still have my computer in the corner since last Christmas and I've hardly used it since, I think you can take that as an answer (laughs) I'd never ever resort to the Internet because it's, because it's an unknown country, it is Greek to me." [Participant 13]

Due to a lack of familiarity in knowing how to use the Internet, participants preferred to self-manage by utilising alternative resources. The use of the word "resort" also alludes to a sense of fear, which is also echoed by Participant Fifteen:

"The older you are because you're not au fait with this technology you are behind, you're in a different world and we're frightened of it." [Participant 15]

The source of fear seems rooted in many participants' senses that the Internet is an "unknown country" or a "different world" – a territory they are not familiar with.
Many participants did not perceive older adults as a generation of Internet users and described how the Internet was unavailable to them when they were younger, as reported by Participant Six:

"I think if we'd have been raised with them, I mean my son is a computer man because it is the jobs and the daughter-in-law is and grand-children, that is their jobs, and that is how you learn today, but we never did, and I think that is why I'm not interested."
[Participant 6]

Increasing familiarity
Although most participants were unfamiliar with using the Internet, some acknowledged factors which could encourage Internet use. One participant described that her family and computer group classes, specifically for older adults, contributed to her learning how to use the Internet:

"Well after my Son-in-law got this computer, which was a big thing, the children tried to teach me but they aren't there and if things went wrong I had to wait for them to come again but then at my local school erm the council were putting some computer courses on during the day, mostly for older people, so I went to erm one and I learnt there that was a 6 week course and then there was one or two courses following on which were helpful." [Participant 4]

To learn how to use the Internet computer group classes were important, especially as some participants did not wish to solely depend on family members to teach them. Computer group classes increased a few participants' confidence when engaging with the Internet:

"Coming here has helped, we're more confident with it now, things don't scare me anymore now with it from coming here, yeah it doesn't scare me because coming here helps." [Participant 12]

An increase in confidence helped participants to overcome a fear of engaging with the Internet. One participant described that although she did not currently attend computer group classes, she would like to participate in the future:

"I'd love to go to a computer class! Because I would like to learn about it but they are all in the evenings and I don't go out very much in the evenings and elderly people don't go out very much in the evenings." [Participant 3]

Attending computer group classes facilitated engagement with the Internet as such classes provided the support to learn and to increase participants' familiarity with the Internet. Male participants valued attending computer classes for the purpose of learning a skill. Female participants also appreciated the social contact permitted by attending computer group classes:

"More social, yeah, that is what that computer place is, I mean some of them are really into it and interested but not me […] I don't really want to know, I talk there." [Participant 6]

Computer classes served both an educational and social role for participants.

The internet as a medical encyclopaedia

Some participants perceived that the Internet provided a wide-array of health information that was irrelevant to their needs:

"It gives you too much information, far too much information and you don't need all of that information, you don't need to be told that you are this, you are that, you are the other." [Participant 3]

Access to a wide-range of information could have resulted in an older adult perceiving that they are suffering from an illness they did not have:

"Won't look up nothing on the Tinternet, will not look up illnesses on there because it can make you worse than when you bloody started, you're a bit paranoid really aren't you? You see all of these things and say I've got that." [Participant 5]

Participants suggested that a diagnosis should be made by a healthcare professional before the Internet would be used as a source of health information:

"I like to know what is coming like with this operation, it is a bowel resection, and I want to know what is going to happen and why, so yes I do look. It is probably better to have a diagnosis before looking things up because you can give yourself everything so I wait to be told what it is so then I'll Google." [Participant 11]

Some participants reported using the Internet as a source of health information for physical illnesses and treatment options; this enabled participants to be prepared for what the treatments might entail. However, most participants suggested that the Internet was not an appropriate source of health information about distress, Participant Twelve reflected upon his wife's physical illnesses when discussing this:

"It is alright sending people to the Internet like to [my wife] they've said just check such and such thing on the Internet, like exercises for a bad back and things like that, more what you'd call physical I guess but not stuff like that." [Participant 12, generated from Storyboard 2]

Unlike physical health problems, some participants perceived distress as "shameful":

"Like having your leg off or you know tuberculosis or erm, you know, sort of diabetes, I mean people will brag about having things like that but not mental health, no, somehow it has become shameful." [Participant 1]

The concern regarding stigma drove many participants to assert that they were not experiencing a mental health problem:

"I think most older adults would be in denial of stuff like that, I wouldn't see myself as having a problem like anxiety or stuff, they don't think that they'd have a problem so they'd just get on with life." [Participant 15]

Most participants wanted to manage their mood problems on their own. By not seeking help from healthcare services, participants are less likely to receive a diagnosis of a mental health problem. Even if participants sought help from healthcare services, distress may not warrant a clinical diagnosis and a diagnosis was needed before the Internet was used as a source of health information.

Meeting social needs on the internet
A majority of participants described their concerns with social media sites, associating them with argumentative behaviours:

"There is a lot of rows and […] a lot of unpleasantness going on Facebook and Twitter and stuff so that is my only objection to it, so no I won't use it." [Participant 11]

One participant noted that people may use social media to upload material which might be upsetting to them:

"I know people who have said that they've done Facebook and then people have put something on which would upset me quite a bit, normally to do with animals and I thought no I don't want to see that." [Participant 2, generated from transcript taken from online forum]

Seeing upsetting material, or argumentative behaviours, on social media platforms may add to some participants' feelings of distress. Many participants had no personal experience of using social media platforms. Negative perceptions of social media sites stemmed from hearing their friends' experiences with using such platforms:

"[My friend] told me this, she said she did [Facebook] to keep in touch with her daughter, but she said that there was a lot of negative things on, so I won't be involved for that reason nothing else." [Participant 11]

Hearing negative stories about social media contributed to why participants associated social media with negative online content.
Online forums in particular were not seen as a means of accessing social support. Many participants reported that it would be unlikely that older adults would engage with such platforms:

"I think whatever you find on the computer, there is certain people that would use it, but […] erm I wouldn't and a lot wouldn't, nine out of ten wouldn't, I wouldn't even think of it." [Participant 18, generated from transcript taken from online forum]

Some participants described that they would not engage with online forums as they did not know the other online forum members, as described by Participant Five:

"I know there is a person on the other side but you know, but you don't know who it is. People are far better, to go and talk to a person that is actually sitting there."
[Participant 5, generated from Storyboard 1]

Not knowing who the other online forum members were prevented some participants from trusting the other members:

"It isn't trustworthy you get cranks in everything don't you [laughs] that is why I don't go on because talking to a complete stranger." [Participant 10, generated from transcript taken from online forum]

This lack of trust suggested that online forums did not meet participants' social needs. Instead, participants preferred face-to-face communication when discussing their distress, as described by Participant Five:

"I think that one, Person Two, that is typical of people my age, we do get mood swings and we've just got to fight through it! You're better off speaking to a friend rather than this, rather than talking to a machine as I always say [laughs]" [Participant 5, generated from transcript taken from online forum]

A preference for face-to-face communication permitted in-person social contact with friends. Participants viewed in-person social contact as important as it resulted in building and maintaining social networks and permitted access to social support.

Discussion

To the best of our knowledge, this is the first study which explores older people's views on using the Internet to manage distress. Each participant had access to the Internet within their home, but few engaged with the resource. A small number of participants reported using the Internet to obtain general information, or to conduct online purchases. Many participants alluded to a lack of knowledge about the Internet, or a fear of engaging with the resource, and did not perceive themselves as a generation of Internet users.

To overcome the unfamiliarity of using the Internet, participants reported the benefits of attending computer group classes which are specifically designed for older adults. Goll, Charlesworth, Scior and Stott [32] found that negative life events (e.g. physical health problems and bereavements) have been shown to reduce an older person's interest in attending group activities. However, attending computer group classes have been linked to a reduced number of depressive symptoms reported by older people as they felt empowered by learning how to use the Internet [33]. This study supports this finding as male participants particularly valued attending computer group classes to learn a skill. Female participants also appreciated the face-to-face social contact afforded by attending such groups.

Younger adults have been reported to seek mental health information online [24]. In contrast, this study suggests that older adults were reluctant to seek information through the Internet for their mood problems. In line with Aref-Adib et al's [24] findings, this study confirms that older people do seek physical health information online. Yet, the present findings stress the importance of receiving a diagnosis before physical health information was sought online; past literature did not identify the importance of this [24]. Participants did not perceive the Internet as a source of information about their mood problems. Unlike physical illnesses, participants perceived distress as "private" which prevented them from seeking help from healthcare services and possibly receiving a diagnosis of a mental health problem. To add to that, symptoms of distress may not warrant a diagnosis of a mental health problem and a diagnosis was needed before the Internet was seen as a source of health information.

When self-managing distress, participants described a preference for face-to-face communication as this permitted in-person social contact with friends. Younger adults use social media platforms and online forums as a means of accessing social support [25, 26]. This study found that older adults associate social media sites with arguments and upsetting material, this prevents older people from engaging with such platforms as a means of accessing social support. Moreover, seeing upsetting material and argumentative communication could add to an older person's feelings of distress. Seraj [27] suggested that the anonymity afforded by online forums encouraged individuals to discuss their emotions. Participants in this study did not perceive such anonymity positively and suggested that online forums were untrustworthy due to their anonymous nature.

Strength and limitations of the study

The study's sample was diverse in certain aspects and captured both male and female older adults who had a wide age range. The study recruited from community groups which permitted access to participants who may not have presented their distress within primary care settings. However, all participants were recruited through community groups. Distressed older adults who do not attend community groups may have had different experiences of using the Internet. Another limitation of this study is that the sample did not capture older adults who did not have access to the Internet, which is a barrier to Internet use in itself. Although all participants had access to the Internet, the type of Internet access (e.g. high speed broadband) was also not explored.

Conclusions

The findings infer that GPs should explore self-management strategies already being employed by distressed older adults as directing these older people to the Internet may not be acceptable. In order to overcome unfamiliarity, and to facilitate Internet use in the future, older adults should be encouraged to attend computer group classes. Through computer group classes, third sector services could explore the ways in which older adults could use the Internet to support mental health (e.g. by being a source of information or a means of accessing social support).

Additional files

Additional file 1: Transcript from online forum. This file shows the transcript from an online forum which was used as a 'think aloud' activity. (DOCX 15 kb)

Additional file 2: Storyboard one. This file shows the first storyboard that was shown to participants and used as a 'think aloud' activity. (DOCX 467 kb)

Additional file 3: Storyboard Two. This file shows the second storyboard that was shown to participants and used as a 'think aloud' activity. (DOCX 545 kb)

Abbreviations

GP: General Practitioner

Availability of data and materials

The datasets generated and analysed during the current study are not publicly available due to ethical concerns, anonymised datasets are available from the corresponding author on a reasonable request. The materials used as 'think aloud' methods are available [see Additional files 1, 2 and 3].

Authors' contributions

AM, CCG and HB contributed to the design of the study. AM conducted the interviews and transcribed each interview. All authors (AM, HB, TK and CCG) made substantial contributions to the data analysis process and the writing of successive drafts of the manuscript. All authors have read and approved the final draft.

Consent for publication: Not applicable.

Competing interests

Professor Carolyn Chew-Graham is a Section Editor for BMC Family Practice.

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Appendix 13b Conference presentations

Oral presentations

- The Society for Academic Primary Care Annual Conference (2018)
  - **How do older adults self-manage distress and does the Internet have a role? A Qualitative study**
- The British Society of Gerontology (2017)
  - **The role of a Public and Patient Involvement and Engagement (PPIE) group in a qualitative study exploring how older adults self-manage distress**
- Primary Care and Health Sciences Postgraduate Conference, Keele University (2017)
  - **Older adults and the self-management of distress**
- Primary Care Mental Health conference (2017)
  - **The impact of a Public and Patient Involvement and Engagement (PPIE) group upon a qualitative study exploring how older adults self-manage distress**
- The Society for Academic Primary Care Regional Conference (2016)
  - **How older adults self-manage distress: The impact of a Public and Patient Involvement and Engagement group**

Three minute 'elevator pitches'

- Primary Care and Health Sciences Postgraduate Conference, Keele University (2018)
  - **Exploring self-management strategies in older adults who are distressed: a qualitative study**
- The Society for Academic Primary Care Annual Conference (2017)
  - **How older adults self-manage distress: A Qualitative study**
- Primary Care and Health Sciences Postgraduate Conference, Keele University (2016)
  - **Exploring self-management strategies in older adults who are distressed: a qualitative study**

Poster presentations

- Lived Experience of Distress event (2018)
  - **How do older adults manage distress and does the Internet have a role?**
- Turning Heads: Changing Minds, Keele University's Postgraduate conference (2018)
  - **How do older adults manage their distress? A qualitative study**
- Primary Care Mental Health Conference (2018)
  - **Managing distress in older adults: what support do older adults want? A qualitative study**
- CHAD Health and Social Inequalities Symposium (2017)
  - **Can the Internet offer a solution to the inequalities in managing distress in older people? A Qualitative study**
- New Horizons in 3D (Delirium, Dementia and Depression): Clinical Research in Older Adults (2017)
  - **PPIE impact in a qualitative study exploring how older adults manage distress**

- The Society for Academic Primary Care Regional Conference (2017)
  Self-management of distress in older adults – does the Internet have a role? A Qualitative study (Winner of best poster presentation)

Appendix 13c Publication plan

- **Paper 1**

<u>Proposed title:</u> How older adults understand and manage distress: A qualitative study

<u>Content:</u> A focus on how older adults conceptualise and manage their mood problems and the implications this may have for GPs.

<u>Target journals:</u> BMC Family Practice, British Journal of General Practice

- **Paper 2**

<u>Proposed title:</u> The impact of Public and Patient Involvement and Engagement (PPIE) on a qualitative study exploring how older adults self-manage distress

<u>Content:</u> A focus on how PPIE shaped this study's research questions, methods, findings and dissemination plan.

<u>Target Journals:</u> BMC Family Practice, Health Expectations