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**Examining the impact of a social prescribing service
on the health and well-being of individuals living with
and beyond cancer: A mixed-methods study**



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Declaration

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Summary

Background: Early diagnosis and improved access to treatments, has meant that survival from cancer has improved by 1% per year as reported by the National Cancer Registry of Ireland (NCRI) in 2013 (NCRI, 2013). There are currently over 150,000 cancer survivors in Ireland (DOH, 2017). Cancer survivors experience continuing symptoms such as pain, fatigue, anxiety, depression and cognitive difficulties following treatment (Shneerson et al., 2015). These symptoms can impact on survivors' performance of daily activities or occupations, thus preventing them from engaging in activities of importance to them (Player, MacKenzie, Wills & Loh, 2014). Social prescribing is a community-based service that supports individuals with health needs and chronic conditions to access activities, services and supports in their community (Lester et al., 2007). Social prescribing may offer accessible, community-based support to individuals living with cancer and enable them to engage in a variety of activities, services and initiatives that may reduce the impact of their diagnosis on their health and well-being (Macmillan Social Prescribing Service, 2018).

Methodology: The aims of this study were to examine the impact of social prescribing on the quality of life, mental health, activity participation levels and fatigue levels of individuals living with and beyond cancer, and to explore the experiences and perceptions of individuals living with and beyond cancer following engagement in social prescribing. To achieve these aims a mixed methods approach was utilised. This consisted of a pre-post quantitative design and individual semi-structured qualitative interviews.

Four outcome measures were identified as suitable for evaluating the quality of life, mental health, activity participation levels and fatigue levels of participants:

1. The European Organisation for Research and Treatment of Cancer Quality-of-Life Questionnaire Core-30 (EORTC QLQ-C30) (Aaronson et al., 1993)
2. The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)
3. The Frenchay Activities Index (FAI) (Holbrook & Skilbeck, 1983)
4. The Multidimensional Assessment of Fatigue (MAF) (Belza, 1995)

This study obtained ethical approval from St. James' Hospital Ethics Committee. Data collection was conducted through four primary recruitment pathways; St. James's Hospital Oncology Day Ward and Outpatients Clinics, local cancer-support services, local community centres and local primary care teams and GP practices.

Results: Forty-three participants were recruited to the study and completed pre-intervention measures. Sixteen participants were lost at follow-up. Twenty-seven participants completed self-reporting questionnaires at post-intervention follow-up and engaged in a qualitative interview at the same time point. Descriptive statistics and inferential statistics were carried out on the data set using SPSS. Significant results were observed from baseline to ten-week follow-up in functional quality of life ($p = <0.001$), depression ($p = 0.025$), participation in leisure and work activities ($p = 0.001$), total activity participation levels ($p = 0.005$) and distress related to fatigue ($p = 0.045$).

Cancer survivors reported a lack of follow-up care post-treatment to manage persistent symptoms and identified barriers to activity participation following cancer treatment, including health-related challenges and lack of information regarding suitable activities and support services. Social prescribing was considered an acceptable intervention to support individuals, particularly post-treatment, in identifying and attending both cancer-specific and community-based support services and social and leisure activities. Cancer survivors identified the friendly and helpful personality of the link worker to be a motivating factor in activity engagement. Cancer survivors highlighted the benefits of peer-support within cancer-specific services that offer activities including yoga and mindfulness classes, which included peer support and feelings of understanding. Individuals who had previously engaged with cancer services identified the benefits of attending activities within community centres and with non-cancer populations, as this enabled them to feel a return to “normal living”.

Conclusion: Cancer survivors can experience continuing symptoms, particularly psychosocial symptoms, post-treatment which can have negative impacts on their participation in daily activities and their quality of life. Cancer survivors report a need for follow-up care post-treatment and support increasing activity participation. Social prescribing had statistically significant impacts on the functional quality of life, presence of depressive symptoms, activity participation levels and distress related to fatigue. Furthermore, it was considered an acceptable intervention by cancer survivors by offering reassurance related to cancer symptoms, information regarding local resources, activities and supports, and supporting individuals to access these resources through ongoing support and regular contact. In addition to the absence of a control group, limitations of this study include a moderately small sample size for a mixed-methods study, and challenges conducting research in ‘real-life’ settings. This study concludes with recommendations to advance current policy and areas that would benefit from further research.

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List of Abbreviations

DOH	Department of Health
EORTC QLQ-C30	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30
FAI	Frenchay Activities Index
HADS	Hospital Anxiety and Depression Scale
HRQOL	Health Related Quality of Life
HSE	Health Service Executive
MAF	Multidimensional Assessment of Fatigue
MSP	Macmillan Social Prescribing
OPD	Out Patients Department
OT	Occupational Therapist
PIL	Participant Information Leaflet
QOL	Quality of Life
SP	Social Prescribing
UK	United Kingdom
WHO	World Health Organisation

1. Introduction

1.1 Background and Need

In Ireland, cancer survivorship rates have increased – in the past decade, the percentage of people who survive five years post-diagnosis has risen from 45% to 61% (Department of Health, 2017). There are currently more than 150,000 cancer survivors in Ireland and it is estimated that by 2020, 1 in 20 people will be a cancer survivor (Department of Health, 2017). There has been some debate around the use of the term ‘cancer survivor’ and a definition of when a person with cancer becomes a ‘survivor’ (Hewitt, Greenfield & Stovall, 2006). According to the National Cancer Strategy 2017-2026, cancer survivorship is determined to begin at the time of diagnosis and continue until end of life and therefore that is the definition that shall be used throughout this review (Department of Health, 2017).

Cancer survivors experience continuing symptoms such as pain, fatigue, anxiety, depression and cognitive difficulties following treatment (Shneerson et al., 2015). These symptoms can impact on survivors’ performance of daily activities or occupations, thus preventing them from engaging in activities of importance to them (Player, MacKenzie, Wills & Loh, 2014). This can affect survivors’ quality of life and overall health and wellbeing (Silver & Gilchrist, 2011; Shneerson et al., 2015). With economic and time constraints affecting the provision of post-treatment services, it is becoming difficult for hospital-based services in Ireland to meet the needs of cancer survivors (Naidoo, Hayes, Teo, Calvert, Horgan & O’Connor, 2013).

Social prescribing is a community-based service that supports individuals with health needs and chronic conditions to access activities, services and supports in their community (Lester et al., 2007). Social prescribing enables healthcare professionals to refer individuals to a link worker, who has knowledge and links to voluntary and third-sector organisations that can support individuals and meet the needs of individuals in the community (Bickerdike, Booth, Wilson, Farley & Wright, 2017). Social prescribing has emerged as an answer to burdened healthcare systems by stimulating the growth of stronger links between primary healthcare services and voluntary sector support (South, Higgins, Woodall & White, 2008).

A variety of social prescribing models have been recorded in the literature; some initiatives are provided by the voluntary sector in community centres, others are

provided by health service commissioners in primary care and GP practices, and others still represent a partnership between the primary health and voluntary sectors in community wellbeing hubs (Dayson & Bennett, 2016a; Dayson & Bennett, 2016b; Macmillan Social Prescribing Service, 2018). Despite the variety of available models, the process of social prescribing appears to be relatively similar across projects (Bickerdike et al., 2017). A social prescribing “link worker,” (also known as a community navigator, facilitator, co-ordinator or connector) meets with an individual to establish their activity preferences and interests. The link worker identifies opportunities to engage in preferred activities and supports the individual in attending the activity, including accompanying the individual to their chosen activity (Keenaghan, Sweeney & McGowan, 2012; Kilgarriff-Foster & O’Cathain, 2015). There are a wide variety of activities that individuals may be referred to through a social prescribing project, including (but not limited to) exercise-based activities; arts groups such as painting or dance groups; counselling; computer technology classes; green activity/ecotherapy; volunteering; housing support; and self-help/peer support groups (Bickerdike, et al., 2017; Keenaghan, Sweeney & McGowan, 2012). There is emerging evidence that social prescribing may provide benefits to a range of health and wellbeing outcomes, including improved quality of life and emotional wellbeing (Dayson & Bashir, 2014; Chatterjee, Camic, Lockyer & Thomson, 2017; Moffatt, Steer, Lawson, Penn & O’Brien, 2017).

There appears to be no published studies within the current literature that explore the impact of social prescribing for individuals living with and beyond cancer, however, a summary evaluation report published in 2018 by the Macmillan Social Prescribing Service in the UK shows promising results. The service aimed to address the health and wellbeing needs of individuals with cancer by supporting access to community and voluntary services, improving quality of life and well-being and reducing demand on health services. The findings of the evaluation were positive. Early findings from this social prescribing service for individuals living with and beyond cancer suggest that social prescribing could support cancer survivors to access community-based activities and services that may be beneficial to their health and wellbeing and may reduce some of the difficulties associated with a cancer diagnosis. However, further research is warranted to determine the potential impact of social prescribing for individuals living with and beyond cancer and to gather the perspectives of service-users.

1.2 Aim and Objectives of the Research

The overall aim of this research study was to explore the impact of social prescribing on quality of life, mental health, activity participation levels and fatigue of individuals living with and beyond cancer. The objectives of this study are:

- To examine the impact of a social prescribing service on activity participation levels, mental health and quality of life of individuals living with and beyond cancer
- To explore stakeholders' perspectives and experiences of social prescribing and activity engagement
- To explore the acceptability of a social prescribing service for individuals living with and beyond cancer and those who refer into the service

1.3 Definition of key terms

The following definitions of relevant terms are used throughout this dissertation.

Social prescribing: a community-based non-medical intervention that links individuals with activities, services and supports (AKA community assets) to improve health and well-being (Keenaghan et al., 2012).

Link worker: a community health worker or volunteer who meets with individuals to discuss their needs and direct them to appropriate community/voluntary sector sources of support in their community (Bickerdike et al., 2017).

Cancer survivorship: begins at the time of diagnosis and continues until end of life (Department of Health, 2017).

Cancer survivor: see Cancer survivorship

Out-referral: a term commonly used within existing social prescribing literature which refers to the activities/services/community assets that service users are referred to by the social prescribing link worker

1.4 Overview of Study's Design

A mixed-methods design was chosen to meet the aims for this research study.

Mixed methods research combines qualitative and quantitative approaches to explore or answer a research question (Creswell & Plano Clark, 2011; Tashakkori & Teddlie, 1998; Denscombe, 2008). Using a combination of methods enables the researcher to

answer questions that either method alone could not answer in isolation. Mixed methods research has been found to suit the complex nature of the majority of public health issues and social interventions, which is relevant to the phenomenon in this research study (Baum, 1995; Steckler et al., 1992).

The study utilised a convergent parallel research design. In concurrent parallel research, all data collection occurs during a one phase period, and both qualitative and quantitative strands are equally prioritised (Creswell, 2014). Each strand is collected and analysed separately, and finally compared and integrated in the discussion phase.

The data for this study was collected across a 12-month period from July 2018 to July 2019. Purposive sampling, a type of non-probability sampling whereby participants are deliberately chosen due to a specific feature of interest, was utilised. Four primary recruitment channels were utilised to obtain the sample for this study, including the hospital oncology & haematology department; local primary care services and GP practices; community cancer support services; and voluntary sector community centres.

The quantitative strand of the study utilised a one-group pre-test post-test quasi-experimental design. Four standardised measures were identified and used:

1. The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core-30 (EORTC QLQ-C30) (Aaronson et al., 1993)
2. The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)
3. The Frenchay Activities Index (Holbook & Skilbeck, 1983)
4. The Multidimensional Assessment of Fatigue (Belza, 1995)

The qualitative strand of the study utilised a qualitative description approach. This approach seeks to describe individuals' experiences of a phenomenon in a rich, straight manner, and was therefore deemed suitable to explore the phenomenon of social prescribing as experienced by cancer survivors. Semi-structured individual interviews were conducted to collect detailed accounts of participants' thoughts, attitudes, beliefs and knowledge surrounding social prescribing (Patton, 2002).

Threats to the validity and reliability of the study were considered throughout, and methods to combat these threats were taken where possible, including the use of an audit trail and a reflective journal.

1.5 Overview of the Thesis

In this thesis, an outline of current literature and the rationale for this research study will be presented in Chapter Two. In Chapter Three, the methodology used for conducting the study is outlined. Chapter Four presents the results of the quantitative strand of the study. Following this, the qualitative findings are presented in Chapter Five. Chapter Six provides a discussion which synthesises the findings of both the quantitative and qualitative findings of this study with current literature.

1.6 Conclusion

The incidence of cancer survivors is increasing in Ireland due to early diagnosis and more effective treatments (National Cancer Registry Ireland, 2013). However, following treatment, many cancer survivors report persistent symptoms such as pain, fatigue, anxiety and reduced activity participation.

Social prescribing is a community-based intervention that supports individuals in identifying and accessing activities, social supports and services within their own community.

The aim of this research was to explore the impact of social prescribing on the quality of life, mental health, activity participation and fatigue levels of individuals living with and beyond cancer. A mixed-methods study was undertaken to achieve this aim.

2. Literature Review

2.1 Introduction

This chapter explores the literature relevant to social prescribing and the impact of living with and beyond cancer. By reviewing the literature and presenting current knowledge in these areas, gaps in research are identified, thus providing a rationale for the present study (Aveyard, 2010). This review is organised into four main sections. First, the literature search process is outlined. Next, social prescribing initiatives are described and previous studies are explored within both international and Irish contexts. Following this, cancer as a condition is presented, including the impact of cancer and cancer treatment on the health and well-being of individuals with a cancer diagnosis. Finally, the potential benefits of social prescribing for individuals living with and beyond cancer are outlined, based on existing evidence.

2.2 Search Strategy

Prior to initiating a literature search, a clearly defined topic and questions to guide the review were established. Defining a topic and questions at the outset of the review determined eligibility criteria, search strategy and analysis of the studies included. Furthermore, explicitly outlining search parameters in advance reduced potential selection bias (McDonagh, Peterson, Raina, Change & Shekelle, 2013).

2.2.1 Inclusion and exclusion criteria

Inclusion and exclusion criteria were considered when developing the search strategy. Studies included those published in English where social prescribing for adults was examined. No publication year restriction was set for literature surrounding social prescribing. This allowed the researcher to understand how social prescribing developed in the early 2000s. Literature had to be freely-available or accessible through the library catalogue and databases in Trinity College Dublin. For publications exploring the impact of cancer and its treatment upon health and well-being, studies published within the past 15 years were included. Exclusion criteria were applied to paediatric cancer care literature or literature focusing on adults with a previous diagnosis of paediatric cancer.

2.2.2 Bibliographic databases

A preliminary review of the literature was conducted in July 2018 and subsequent reviews took place on an ongoing basis until July 2019. To source the necessary literature, the library catalogue and databases in Trinity College Dublin were searched. Health research platform EBSCOhost was used to access major health databases to retrieve studies. The databases consulted are listed in Table 2-1.

Table 2-1 Bibliographic databases

EBSCOhost	Other
AMED – The Allied and Complementary Medicine Database	Cochrane Database of Systematic Reviews
CINAHL	Pubmed
MEDLINE Complete	
PsycARTICLES	
PsycINFO	

Key concepts related to the topic were extracted to identify search terminology, for example:

What is the impact of social prescribing on the health and wellbeing of adults living with cancer?

Each search concept was examined to find as many related search terms as possible, ensuring maximum search yield. Thesauri and indexes of all relevant databases were searched to gather related subject terms. Variant forms of the same term were also assessed, e.g. social prescribing/social prescription. In cases like this, truncation was employed, e.g. 'social prescri*' (Table 2-2). Specified search terms were then entered both singularly and in varying combinations into each database to retrieve related information.

Table 2-2 Search terms

Social prescribing	Health and wellbeing	Adults living with cancer
'social prescri**'	'health'	'cancer'
'community referral'	'wellbeing'	'survivorship'
'community participation'	'physical health'	'oncology'
'health promotion'	'mental health'	
'arts on prescription'	'psychosocial'	
'exercise on prescription'	'psychological'	
'non-traditional provider'	'quality of life'	
'lifestyle support'	'health behaviours'	

2.3 Social Prescribing (SP)

Social prescribing (SP) is a community-based service that links individuals with health needs and chronic conditions to activities, services and supports in their community (Lester et al., 2007). There remains a lack of consensus on the definition of social prescribing, however the Social Prescribing Network defines it as, 'enabling healthcare professionals to refer patients to a link worker, to co-design a non-clinical social prescription to improve their health and wellbeing,' (University of Westminster, 2016, p.19). Several quantitative and qualitative studies have found benefits of social prescribing to include increased feelings of self-confidence, reductions in social isolation, anxiety and depression and increased positive health behaviours including weight loss, healthier eating and increased physical activity (Chatterjee, Camic, Lockyer & Thomson, 2017; Moffatt, Steer, Lawson, Penn & O'Brien, 2016).

Community-based third-sector organisations often have no direct links to primary care services and GPs and patients often require support and guidance to access these resources (Grant et al., 2000). Social prescribing has emerged as a potential mechanism for bridging the gap between primary care health services and community

supports (Brown, Friedli & Watson, 2004). Community and voluntary supports can include exercise programmes, arts-based initiatives, self-help and support programmes, volunteering opportunities, further education services and skill-development groups (Keenaghan et al., 2012; Kimberlee, 2013).

Social prescribing is a relatively novel approach that began to receive attention in the early 2000s as a potential bridge between primary health care services and the voluntary and community sector (South, Higgins, Woodall & White, 2008). Due to increasing pressure on health service resources in the UK, it was envisioned that voluntary and community organisations could play an increasing role in supporting primary care services (Coid et al., 2003; Department of Health, 2004; Secretary of State for Health, 2006). Voluntary and community organisations have the potential to supplement statutory health services by responding to local needs and filling services gaps (Ward, 2001; Milne et al., 2004; Secretary of State for Health, 2006). National organisations can provide health information and support services and community-based initiatives generate access to local activities such as self-help groups and social gatherings like breakfast clubs or walking groups. Due to the frequency and variety of voluntary organisations, it has been suggested that every patient presenting in the UK National Health Service could be provided with support by at least one organisation (Crombie & Coid, 2000).

Social prescribing may serve to strengthen links between healthcare providers and community, voluntary and local authority services for the promotion of public health (Friedli, Jackson, Abernethy & Stansfield, 2009). Social prescribing may also provide a path to reducing social exclusion for isolated and vulnerable populations in general, including those in disadvantaged areas, those with enduring mental health problems and those living with long-term chronic illness (Keenaghan, Sweeney & McGowan, 2012; Gask, Rogers, Roland & Morris, 2000; Bates, 2002; Friedli, Jackson, Abernethy & Stansfield, 2009).

2.3.1 Models of social prescribing

Several models of social prescribing have been described in the literature. In 2007, Brandling and House proposed that six models of social prescribing existed based on the level of support that was provided to service users. These models were developed based on workshops held in the Bromley Primary Care Trust in 2002, although it is not stated who the stakeholders were within these workshops (Brandling & House, 2007). The models included an information-only service with no face to face contact; an information service with telephone support only; primary care referrals to a social

prescribing service if the individual highlights non-clinical issues in an appointment; a GP practice based generic referral worker who provides triage and signposting; a GP practice based specialist referral worker who may provide direct advice in addition to referral and signposting; and finally a non-primary care based service situated in the community which offers one to one support.

In 2013, however, Richard Kimberlee argued that this set of social prescribing models did not accurately represent the current landscape of social prescribing and instead put forth his own review of existing social prescribing models. Kimberlee suggested that based on a review of literature and the interviews and focus groups he conducted, there was no single, agreed understanding of what social prescribing involved or what interventions could be described as social prescribing. Through discussions with social prescribing providers, healthcare practitioners and local authority employees in Bristol, Kimberlee proposed four models of social prescribing:

- 1) Social Prescribing as Signposting
- 2) Social Prescribing Light
- 3) Social Prescribing Medium
- 4) Social Prescribing Holistic

Social Prescribing as Signposting describes social prescribing projects that refer individuals to appropriate groups and organisations that may support the individual to address their health and wellbeing needs. These projects may be based in the GP practice but share no formal or regular links with the practitioners. Individuals may be referred to activities such as the gym, cooking groups, peer support or counselling opportunities.

Social Prescribing Light is described by Kimberlee as the most common form of SP. These projects work with vulnerable patients and refer them to a specific programme to address a specific need or to encourage them to reach a specific goal e.g. exercise on prescription, prescription for learning and Arts on prescription.

Social Prescribing Medium is described through an example project based in Devon whereby the health facilitator works closely with the GP and provides both signposting support and advice on exercise, nutrition, diet etc. The project aims to address certain needs or behaviours as identified by the GP rather than addressing the individual's needs in a holistic way.

Finally, Social Prescribing Holistic is described as a flexible model often achieved once a project has developed beyond a lower level of SP over time. They develop

organically through a partnership between GP practices and community organisations and direct referral routes from the GP are in situ. Practical, emotional and social support is offered on a one-to-one basis and health facilitators may act as advocates for individuals with other services or departments. Activities are often readily available for individuals to participate in within the social prescribing service, enabling individuals to engage in taster sessions and peer support to get involved. This model involves the promotion of patient self-management and resilience and supports individuals to seek solutions and develop self-management techniques.

2.3.2 The process of social prescribing

Whilst there are a variety of social prescribing models available, the process of social prescribing appears relatively similar across projects (Bickerdike, Booth, Wilson, Farley & Wright, 2016). Typically, social prescribing is provided by a facilitator, herein referred to as a “link worker,” who meets with service users to establish their activity preferences. Where required, the link worker may accompany individuals to their chosen activity, which has been reported by some service users as a valuable support (Keenaghan, Sweeney & McGowan, 2012; Kilgarriff-Foster & O’Cathain, 2015). Depending on the service, the timeline of this process may vary, however one study reported that individuals were typically seen within four weeks (Grayer, Cape, Orpwood, Leibowitz & Buszewicz, 2008). Non-engagement rates have been reported as higher amongst individuals who wait longer to be seen for an initial appointment (The Care Forum, 2012). Kimberlee (2013) argues that a holistic social prescribing model will meet with a service user as many times as they require and should be dependent on need, however, not every model of social prescribing may provide this level of support.

Across the majority of social prescribing models, the primary care team are usually the main source of referral (Keenaghan, Sweeney & McGowan, 2012; Polley, Fleming, Anfilogoff & Carpenter, 2017). In some contexts, healthcare professionals based in the hospital or on social care teams may also refer participants to the social prescribing service and in others still, individuals are able to self-refer to the service. The relationships between the primary care team, the social prescribing facilitator and the voluntary and community services have been highlighted as crucial to the optimal functioning of social prescribing programmes (Edmonds, 2003; Constantine, 2007; Friedli et al., 2009; White & Salamon, 2010).

2.3.3 The role of the social prescribing facilitator

Nearly all models of social prescribing involve a facilitator who supports people in accessing local community-led initiatives (Evans & Buck, 2018). Several names have been used to describe this facilitator role, including community link worker; community navigator; care navigator; health advisor; health trainer; social prescribing co-ordinator and community care co-ordinator (Polley et al., 2016; Polley, Fleming, Anfilogoff & Carpenter, 2017). The role of the facilitator has been highlighted repeatedly as integral to the success of a social prescribing service (Brandling & House, 2007; Keenaghan, Sweeney & McGowan, 2012). Brandling and House (2007, p.15) described the social prescribing link worker as, “someone with highly developed interpersonal, communication and networking skills, with a motivating and inspiring manner to encourage clients to make brave decisions or take up new opportunities.”

Facilitators are usually employed by community organisations and tend to have a generic or community health background rather than having specific clinical qualifications, although training and knowledge varies between projects (Keenaghan, Sweeney & McGowan, 2012; Bickerdike, Booth, Wilson, Farley & Wright, 2017). Some facilitators have been found to have good knowledge and existing networks with local services in place (South et al., 2008; White, Kinsella & South, 2010; Woodhall & South, 2005). Meanwhile, others receive some basic training and make use of a directory of resources (Grayer et al., 2008). While healthcare professionals may be unable to maintain a working knowledge of local community initiatives and services, an advantage of the facilitator role is that they can (and should) develop a continuous knowledge of these resources (Polley, Fleming, Anfilogoff & Carpenter, 2017). Facilitators may be situated within a GP surgery, in the local community such as a community centre, or a mixture of both.

Individuals attending a social prescribing service may be referred to a variety of activities and services based on their needs and preferences (Bickerdike, Booth, Wilson, Farley & Wright, 2017). These activities include exercise and other physical activities; arts & creativity groups such as photography, dance, drama, etc.; luncheon clubs; counselling; computer and technology classes; books on prescription/bibliotherapy; green activity/ecotherapy; time banks; volunteering; housing support; welfare and debt advice; adult education and literacy; and self-help/peer support groups (Bickerdike, Booth, Wilson, Farley & Wright, 2017; Keenaghan, Sweeney & McGowan, 2012).

2.3.4 The development of social prescribing

Social prescribing is still a relatively new initiative but has been gaining popularity in recent years (Pescheny, Pappas & Randhawa, 2018). Social prescribing initially emerged as a health promotion initiative in the area of mental health in the United Kingdom (UK) (Keenaghan, Sweeney & McGowan, 2012). Collaboration between the Bromley by Bow community centre and the Bromley by Bow Partnership (a set of three GP practices) in London has been hailed as one of the first models of social prescribing, with origins dating back to the 1990s (Brandling & House, 2009; Polley, Fleming, Anfilogoff & Carpenter, 2017; Stocks-Rankin, Seale & Mead, 2018). Interest in social prescribing as a model for increased collaboration between healthcare professionals and the community and voluntary sector has expanded within the last decade, however (Polley, Fleming, Anfilogoff & Carpenter, 2017).

In 2005, research by the Mental Health Foundation in the UK highlighted the need for an alternative solution to the mental health difficulties faced by attendees in GP practices beyond medication prescription. Over three quarters of GPs who participated in the study reported that they had prescribed an antidepressant in the previous three years despite believing an alternative treatment may have been more appropriate. Though it was acknowledged that both medication and psychological therapies had a role in supporting individuals with enduring mental health difficulties, it was also felt that social prescribing could provide alternative supports to GPs and their patients, based on a broader, holistic approach to health and wellbeing (Friedli, Jackson, Abernethy & Stansfield, 2009).

Social prescribing began to feature more prominently in UK policy and publications subsequently. In 2006, social prescribing was highlighted in a UK White Paper as a mechanism for promoting health, independence and access to local services (Department of Health, 2006). From 2008 onwards, emerging literature began to suggest that social prescribing could facilitate links between primary care and the community and voluntary sector, but more research was required to determine clarity around the efficacy of social prescribing and to build a stronger evidence base (South, Higgins, Woodall & White, 2008; Friedli, Jackson, Abernethy & Stansfield, 2009; Stickly & Hui, 2012). By 2013, growing evidence was emerging that social prescribing could be effective: evidence from pilot projects undertaken in the UK suggested that real changes could be identified after 18-24 months (Dayson, Bashir & Pearson, 2013). Outcomes included improved health and quality of life, increased patient satisfaction

and a reduction in the use of medical services such as primary care, A&E departments and hospital resources (Dayson, Bashir & Pearson, 2013).

Following a series of evaluative reports, the UK government has begun to place greater funding into social prescribing schemes and initiatives. Most recently, the Department of Health and Social Care and NHS England have committed to vastly expanding social prescribing services in the UK and to implement social prescribing in all local health and care systems nationwide (Department for Digital Culture, Media and Sport, 2018).

2.3.5 Social Prescribing in Ireland

In 2012, a report containing recommendations on the development of social prescribing services in Irish primary care teams was published (Keenaghan, Sweeney & McGowan, 2012). This report provided an overview of evidence from national and international research related to social prescribing and the activities to which people are commonly referred. It also listed examples of existing programmes based in both Ireland and the UK. In Ireland, initiatives such as the National GP Exercise Referral Programme, the Green Prescription Programme in Donegal, the Waterford Healing Arts Trust and the Health Options Project Erris in Castlebar, Co. Mayo were highlighted. Recommendations for the development and implementation of a social prescribing practice in Ireland were outlined.

The following year in 2013, a pilot evaluation of social prescribing services across six areas in Donegal was initiated. The initiative was funded by the National Office for Suicide Prevention and the aim of this scheme was to promote positive mental health in the six areas involved. The results of this pilot found a significant positive impact on the wellbeing, anxiety, depression and community involvement levels of participants and visits to GPs were reported to have significantly decreased after three months (Health Service Executive, 2015). Following a review of the literature, it appears that the Donegal Social Prescribing Scheme is the only scheme in Ireland to have published an evaluation report on the impact of their service.

2.3.6 Critique of the literature

Although initially established for individuals with mental health difficulties, social prescribing initiatives for individuals with other needs are beginning to emerge, including one study which evaluated the impact of social prescribing on adults with long-term chronic conditions such as diabetes, chronic heart conditions such as

coronary heart disease and pulmonary conditions such as chronic obstructive pulmonary disease (Moffatt, Steer, Lawson, Penn O'Brien, 2017). The impact of social prescribing for individuals living with cancer has yet to receive significant attention in the literature, although a social prescribing initiative has been set up in Bromley by Bow, UK, by Macmillan Cancer Service.

2.4 Living with and beyond cancer

With advances in early detection and improvement in cancer treatments, the number of people living with and beyond cancer has increased globally. More people are experiencing cancer, not as an acute or life-limiting 'incurable' disease, but as a life-changing and chronic condition (Hewitt, Greenfield & Stovall, 2006; Pavlic et al., 2009). In Ireland, cancer survivorship rates have increased – in the past decade, the percentage of people who survive five years post-diagnosis has risen from 45% to 61% (Department of Health, 2017). There are currently more than 150,000 cancer survivors in Ireland and it is estimated that by 2020, 1 in 20 people will be a cancer survivor (Department of Health, 2017). There has been some debate around the use of the term 'cancer survivor' and a definition of when a person with cancer becomes a 'survivor' (Hewitt, Greenfield & Stovall, 2006). According to the National Cancer Strategy 2017-2026, cancer survivorship is determined to begin at the time of diagnosis and continue until end of life and therefore that is the definition that shall be used throughout this review (Department of Health, 2017).

2.4.1 The impact of cancer on health and wellbeing

The increase in survival rates following cancer diagnosis has prompted increased attention to the quality of life and psychosocial consequences of cancer and its treatment (Stanton, 2012). Quality of life is a construct determined by both objective factors and an individual's assessment of their own general well-being, including elements such as their goals, expectations, standards, concerns, and experiences, in relation to their own culture and value systems (Galic, Glavic & Cesarik, 2014; Padmaja, Vanlalhruii, Rana, Tiamongla & Kopparty, 2017). Women diagnosed with breast cancer were found to have a lower quality of life (QOL) than the general population (Maly, Liu, Liang & Ganz, 2015). People can experience symptoms and challenges in the years following (or during continuous) treatment and these can be difficult to manage (Jefford et al., 2008). In Ireland, 1 in 4 cancer survivors have physical and/or psychological consequences following treatment (Department of Health, 2017). Additionally, cancer survivors can experience issues related to

social/emotional support, health habits, their spirituality, body image and fatigue (Shneerson, Taskila, Gale, Greenfield & Chen, 2013). Cancer survivors have expressed a need for support in managing the impact of cancer on their lives, as they can be unprepared for these changes, feel vulnerable, lose confidence and struggle to access support (Foster et al., 2015; Armes et al., 2009; Corner et al., 2007).

2.4.2 The impact of cancer on psychosocial health

The impact of cancer on the health of survivors is significant and associated with several long-term psychosocial challenges (Hewitt, Greenfield & Stovall, 2006). Some of the psychological consequences of cancer may be particularly severe and result in persistent mental health difficulties (Macmillan Cancer Support, 2013). For example, depression and depressive symptoms have been found to occur frequently in cancer patients (Irwin, 2013). Around one third of UK-based individuals diagnosed with breast, prostate or colorectal cancer or non-Hodgkin lymphoma within five years previous reported experiences of anxiety or depression (Department of Health, 2012). More than one in eight of those individuals reported moderate to extreme levels of anxiety or depression. Additionally, the presence of symptoms related to anxiety and depression have been linked to an increased risk of unmet supportive care needs in individuals with melanoma (Molassiotis et al., 2014). Psychosocial problems have been noted to affect an individual's ability to self-manage and may cause an increased reliance on other people or health and social services (Macmillan Cancer Support, 2011).

Stress has been identified as a major psychological issue for cancer patients, from their initial diagnosis, through treatment and prognosis, and beyond (Kang, Park & McArdle, 2012). Studies indicate that up to 30% of individuals with breast cancer report high stress levels due to diagnosis and treatment (Kang, Park & McArdle, 2012; Yang, Brothers & Andersen, 2008). Individuals with cancer can experience stress due to feelings of uncertainty, the severity of their condition, physical difficulties, medical treatments, psychosocial challenges and family issues (Kreitler, Peleg & Ehrenfeld, 2007). Although initial stress may decline over time for most patients, many others continue to experience high stress for years, even following successful completion of treatment (Bleiker, Pouwer, Ven Der Ploeg, Leer & Ader, 2000). Stress is a significant factor in the reduction of quality of life, both physical and psychological, in individuals with cancer (Kang, Park & McArdle, 2012; Kreitler, Peleg & Ehrenfeld, 2007).

Some positive impacts of a cancer diagnosis on the psychosocial health of survivors have been noted in the literature, particularly in relation to individuals' motivation to enact healthy lifestyle changes following diagnosis. A study conducted in 2004 found

significant increases in physical activity, vegetable intake and supplement use among colorectal survivors two years post-diagnosis (Satia et al., 2004). Furthermore, a more recent qualitative study undertaken in the UK suggested that successful lifestyle changes were often brought on by a cancer diagnosis (Dowswell et al., 2012). Another study found that survivors of colorectal cancer have a desire to make changes in their lifestyle and are ready to participate in action-oriented programmes throughout their cancer journey (Dennis, Waring, Payeur, Cosby & Daudt, 2013). There is increased acknowledgement that healthy lifestyle choices can help to protect against some short-term and long-term consequences of cancer and its treatment (Davies, Thomas & Batehup, 2010). Therefore, it seems there may be opportunities to support change in the lifestyles of cancer survivors and that this may be beneficial to their overall health and reduction of cancer symptoms.

2.4.3 The impact of cancer on physical health

Cancer survivors face many physical challenges due to both the nature of the cancer itself and some of the side effects of treatment (Macmillan Cancer Support, 2013). Some of the most common physical challenges associated with cancer include fatigue, pain and biological changes related to surgery (Hewitt, Greenfield & Stovall, 2006). Many cancer patients have been found to reduce their activity levels during treatment as a result of physical challenges and do not resume activity at pre-diagnosis levels (Irwin et al, 2013; Blanchard et al., 2003).

Fatigue is typically described as feeling tired, weak or exhausted, sometimes without any evident cause, and it affects most people during and after their cancer treatment (Hofman, Ryan, Figueroa-Moseley, Jean-Pierre & Morrow, 2007). Cancer survivors of any diagnosis experience fatigue more often than the non-cancer population and it is a common and debilitating symptom (Smith et al., 2013). Fatigue is one of the most common symptoms reported by adults with cancer (Barsevick et al., 2013). Fatigue can impact severely on an individual's abilities to function in everyday life and at worst may leave them bedridden (Bower, 2014). It can have a profound negative impact on an individual's quality of life and ability to function and may lead to decreased physical function (Kenzik, Morey, Cohen, Sloane & Demark-Wahnefried, 2015). Although fatigue can have a profound effect on many individuals with cancer, there are interventions that have been found to reduce its impact. For example, an in-depth review of 22 studies showed that aerobic exercise, such as walking or cycling, can significantly reduce fatigue (Cramp & Byron-Daniel, 2012).

2.4.4 Unmet needs of individuals with cancer

Studies have identified the existence of unmet supportive care needs among cancer populations (Armes et al., 2009; Beesley et al., 2014; Burg et al., 2015). Some of the most frequently expressed unmet needs include psychological and emotional distress, uncertainty about the future, physical problems including pain and fatigue, and social problems such as employment and financial issues (Armes et al., 2009; Beesley et al., 2014; Burg et al., 2015; Hamama-Raz, 2012; Harrison, Young, Price, Butow & Solomon, 2009; Luker, Campbell, Amir, & Davies, 2013; Pisu, Martin, Shewchuk, & Meneses, 2014; Smith et al., 2007). Many individuals experience long-term challenges as a consequence of cancer that may be considered mild or moderate and therefore do not require major interventions, however these people are known to visit health professionals more frequently than the general population (Elliott et al., 2011; Santin, Mills, Treanor & Donnelly, 2009). They may also present a higher risk of health deterioration to the point of requiring inpatient care (Macmillan Cancer Support, 2013). There is potential for social prescribing to act as a gateway to address some of the unmet needs of individuals living with and beyond cancer. Activities such as yoga, mindfulness and low-cost counselling, all of which may be referred to through social prescribing, could provide support to individuals dealing with psychological and emotional distress as a result of cancer (Bower et al., 2018; Miller & Hopkinson, 2008). Activities such as exercise programmes may support individuals with fatigue, as exercise has been linked to a reduction in fatigue symptoms (Cramp & Byron-Daniel, 2012; Pinto, Dunsiger & Waldemore, 2013).

As outlined above, the impact of cancer diagnosis, treatment and survivorship on individuals is multi-faceted and experienced to varying degrees. Cancer survivors may require support for individuals to receive support at multiple levels to address the unmet needs and challenges of cancer, from diagnosis through treatment and beyond. While the more severe impacts of cancer warrant greater input and support from specialist healthcare professionals, there is potential for mild or moderate symptoms and challenges to be addressed in alternative ways.

2.5 Social Prescribing for Cancer Survivors

The level of disruption to an individual's life as a result of a cancer diagnosis varies, and some people are able to cope and are supported to manage their cancer (Foster et al., 2016). However, many people will need some level of support to overcome the difficulties associated with a cancer diagnosis. It is important that these people are

identified and offered the appropriate level of support when needed, and to identify what the different levels of support may be (Foster, Calman, Richardson, Pimperton & Nash, 2018).

Social prescribing may offer accessible, community-based support to individuals living with cancer and enable them to engage in a variety of activities, services and initiatives that may reduce the impact of their diagnosis on their health and well-being. As outlined above, the literature on social prescribing has focused predominantly on health promotion in socioeconomically deprived communities and to support the mental health of individuals in the community. During this literature search, information could be found on only one social prescribing service in the UK (and none in Ireland) that has been designed specifically to support individuals living with and beyond cancer (Macmillan Social Prescribing Service, 2018). There is an apparent lack of focus in the literature on the potential for social prescribing to address the unmet needs of cancer survivors and to support this population.

2.5.1 Social Prescribing services for Cancer Survivors

There appears to be no published studies within the current literature that explore the impact of social prescribing for individuals living with and beyond cancer, however, the UK-based Macmillan Cancer Service published a summary evaluation report in 2018 regarding the outcomes of a social prescribing pilot programme conducted in Bromley by Bow in London (Macmillan Social Prescribing Service, 2018). The service was designed to address the health and wellbeing needs of individuals with cancer by promoting awareness of the value of community and voluntary services, improving quality of life and wellbeing, supporting integration of care and reducing demand on health services. The aims of the service evaluation were to determine the extent to which the service was achieving these outcomes.

A review of evidence collected across a two-year period was analysed. Service users who attended for face to face support sessions were asked to complete three different outcome measures to assess changes in their health related quality of life: the Work and Social Adjustment Scale (WSAS), the Measure Yourself Concerns and Wellbeing (MYCAW) tool and the Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS) (Mundt, Marks, Shear & Greist, 2002; Paterson, Thomas, Manasse, Cooke & Peace, 2007; Tennant et al., 2007). In addition to these outcome measures, consultations were held with key stakeholders in the service. This included telephone interviews with all three Macmillan Social Prescribing (MSP) staff; a focus group conducted with ten MSP steering group members; an e-survey, telephone interviews

and a focus group conducted with ninety service users; nine telephone interviews and eighteen e-surveys with referrers into the MSP service; and telephone interviews with nine services that clients were referred onto by MSP.

The findings of the evaluation were positive. In total, 531 clients were signposted or referred to at least one service and thus were able to access support they may not have done otherwise. Participants reported in focus groups and interviews that they were satisfied with the services they went onto access and found them useful. Participants reported improved quality of life and well-being following engagement with the social prescribing service and felt they had increased their knowledge of relevant supports in their area. Additionally, the majority of clients consulted reported that since accessing a cancer-specific social prescribing service, they were more aware of their health and wellbeing, the aspects they could change and how they could go about causing that change.

The findings of the MYCAW tool were both clinically and statistically significant and found that after engaging with the service, clients felt less concerned about nine out of ten domains, including emotional wellbeing, physical activity, socialising, finance, work, physical concern, diet/nutrition, care/extra support and treatment options. Socialising, emotional wellbeing and physical activity were found to have the greatest changes in participants' concern levels.

Healthcare professionals were also invited to provide their opinions and experience of working with the social prescribing service. They reported that the service promoted greater knowledge of local services and that while they had already valued the voluntary sector, they were now better able to access the supports available. Social prescribing was found to bridge the gap between GPs' and healthcare professionals' knowledge of local services and support. In particular, healthcare professionals reported that the cancer-specific nature of the service was valuable as MSP staff were familiar with the various effects a cancer diagnosis and treatment can have on individuals. Healthcare professionals also felt that clients were more likely to be referred on to appropriate services that were relevant to them because the service was cancer-specific as opposed to a more generic social prescribing service.

As the service appears to be the first of its kind, the initial findings from the study are promising. There is both statistically and clinically significant evidence supported by qualitative findings that a cancer-specific social prescribing service may improve a range of areas of health and wellbeing for individuals living with and beyond cancer. However, these findings were based on a small sample and therefore should be

interpreted with caution. Further research is required to determine whether a social prescribing service would be of benefit to cancer survivors and what form this benefit may take, be it psychosocial, physical or across a range of domains of health and wellbeing. Additionally, further research is required to identify the optimal time in a cancer survivor's journey, from diagnosis to post-treatment, to engage in social prescribing.

2.5.2 Benefits of social prescribing activities for cancer survivors

As discussed previously, cancer survivors can face various challenges as a result of their diagnosis, including fatigue, stress, and mental health difficulties such as depression or depressive symptoms. Social prescribing may offer a supportive pathway to accessing resources, services and activities that could address some of these challenges. Some of the activities commonly referred to by social prescribing, such as exercise, yoga, tai chi and mindfulness, have been found to have a positive impact on cancer survivors' health and well-being.

Social prescribing services may refer individuals to exercise classes and increased exercise activity has been identified as a beneficial activity for cancer survivors across several studies. Exercise has been found to have a positive impact on cancer-related fatigue, physical functioning, individuals' quality of life and overall cancer-specific survival (Cramp & Byron-Daniel, 2012; Pinto, Dunsiger & Waldemore, 2013; Mishra, Scherer, Snyder, Geigle & Gotay, 2012; Lahart, Metsios, Nevill & Carmichael, 2015; Wu et al., 2016). It has also been found to lead to improvements in cancer-related psychosocial variables such as social functioning and mental health (as measured by the Short Form 36 Quality of Life assessment) (Morey et al., 2009; Ware & Sherbourne, 1992). Guidelines regarding aerobic and strength exercise for patients with cancer have been published, although most cancer survivors do not meet these recommendations (Schmitz et al., 2010; Crawford, Holt, Vallance & Courneya, 2016; Ottenbacher et al., 2015). On the contrary, cancer survivors often reduce their levels of physical activity following a cancer diagnosis (Huy, Schmidt, Vrieling, Change-Claude & Steindorf, 2012; Williams, Steptoe & Wardle, 2013). Social prescribing may offer an opportunity for individuals living with and beyond cancer to access exercise classes and programmes and to increase their physical activity throughout their cancer journey.

A cancer diagnosis can negatively impact on individual's psychosocial health, leading to increased levels of stress, psychological distress and mental health challenges. Activities and supports such as meditation, progressive muscular relaxation and guided visualisation, have been found to be effective in addressing some of the fears and

anxieties associated with cancer (Miller & Hopkinson, 2008). Furthermore, there is a growing evidence base for the effectiveness of mindfulness interventions in cancer survivorship, with randomised controlled trials identifying beneficial effects on a variety of outcomes (Shennan, Payne & Fenlon, 2011; Ledesma & Kumano, 2009). Mindfulness interventions are typically delivered through classes held once a week over a 6 to 8-week period and participants are encouraged to practice the skills they develop in class at home (Haydon et al., 2018). Mindfulness interventions have been shown to reduce stress, anxiety, depressive symptoms and fear of recurrence in cancer survivors (Bower et al., 2015; Carlson et al., 2013; Hoffman et al., 2012; Wurtzen et al., 2013; Lengacher et al., 2016; Henderson et al., 2012; Lengacher et al., 2014). Further evidence suggests that mindfulness interventions can promote greater quality of life and well-being in cancer survivors (Hoffman et al., 2012; Johannsen et al., 2017). Some trials have found that mindfulness interventions can have a positive impact on cancer-related fatigue, sleep disturbance and pain, however, further research is required as results in the literature are mixed (Haydon et al., 2018; Bower et al., 2015; Lengacher et al., 2016; Johannsen et al., 2017; Reich et al., 2017). Nevertheless, there is promising evidence that suggests cancer survivors may benefit from participation in mindfulness interventions. Similarly, to physical activity, mindfulness has been cited as a common onward referral from social prescribing schemes and therefore it is possible that social prescribing may encourage cancer survivors to participate in mindfulness interventions.

Other forms of activity which include an emphasis on relaxation or mindfulness, such as yoga and tai chi, also have evidence of improving health and wellbeing among cancer populations. A Cochrane review completed in 2017 by Cramer et al., found that there was moderate-quality evidence for the effectiveness of yoga in improving health-related quality of life and reducing fatigue and sleep disturbances in women with breast cancer. Several studies have also identified the benefits of Tai Chi and Qigong in the improvement of quality of life, cancer-related fatigue, stress and mood in cancer survivors (Larkey et al., 2015; Oh et al., 2010; Oh et al., 2012; Oh et al., 2014). As such, it could be beneficial for cancer survivors to receive support from a social prescribing service to increase uptake in activities such as yoga, Tai Chi and Qigong.

2.6 Summary

Social prescribing is a community-based service that links individuals with health needs to activities, services and supports in their community. As of yet, the majority of social prescribing studies have been conducted with individuals with mental health

challenges. With the increase in cancer survival rates, increased attention has been placed on the quality of life of people living with and beyond cancer. Cancer survivors are faced with a plethora of challenges to both their physical and mental health and require support to overcome and address many of these challenges. Early findings from a social prescribing service for individuals living with and beyond cancer suggest that social prescribing could support cancer survivors to access community-based activities and services that may be beneficial to their health and wellbeing and may reduce some of the difficulties associated with a cancer diagnosis. However, further research is warranted to determine the impact of social prescribing for cancer survivors and to establish best practice for service delivery to this population. Questions remain regarding when (and if) it is best for cancer survivors to receive support by way of social prescribing and how best this support may be delivered, if appropriate. This study aims to provide further insight into the impact of social prescribing on cancer survivors, particularly within an Irish context. The methodology of this study will therefore be outlined in the next chapter.

3. Methodology

3.1 Introduction

The aim of this research study is to explore the impact of a social prescribing service on the mental and/or physical health of individuals living with and beyond cancer. To frame this exploration, a convergent parallel mixed methods design was employed. This chapter identifies the aims and objectives of this study. The chosen research design is described and the rationale for its selection is presented. Details of the methods used in this convergent parallel study are also described, including the quantitative and qualitative tools used. Details of data collection and analysis are discussed and the ethical considerations of this study are presented.

3.2 Research aims and objectives

The aim of this research study is to explore and evaluate the impact of a social prescribing service on the quality of life, mental health, fatigue and activity participation levels, of individuals living with and beyond cancer. The qualitative and quantitative objectives of this study are outlined as follows:

3.2.1 Research objectives

- To examine the impact of a social prescribing service on activity participation levels, mental health and quality of life of individuals living with and beyond cancer
- To explore stakeholders' perspectives and experiences of social prescribing and activity engagement
- To explore the acceptability of a social prescribing service for individuals living with and beyond cancer and those who refer into the service

3.3 Research Design

A mixed-methods design was selected for this research study. Mixed methods research combines qualitative and quantitative approaches to explore or answer a research question (Creswell & Plano Clark, 2011; Tashakkori & Teddlie, 1998; Denscombe, 2008). Many different terms have been used to describe mixed methods research, including integration, synthesis, quantitative and qualitative methods, multimethod and mixed methodology, but recent writings tend to use the term mixed

methods (Bryman, 2006; Creswell, 2014; Tashakkori & Teddlie, 2010). This research study complies with the four characteristics of mixed methods research, as outlined by Denscombe (2008):

- The use of both quantitative and qualitative methods within one research project
- The use of pragmatism as the philosophical underpinning for the study
- The identification of the priority and sequencing assigned to quantitative and qualitative data collection
- The specification of the relationship between quantitative and qualitative data, emphasising methods of triangulation

3.3.1 Rationale for mixed methods design

Mixed methods research facilitates the combination of both qualitative and quantitative approaches within a single study, which may enable the researcher to answer questions quantitative or qualitative methods alone cannot answer (Creswell, Fetters & Ivankova, 2004; Creswell, 2014; Matthews & Kostelis, 2011). While quantitative methods use numerical data, qualitative research asks questions such as “why?” and “how?”. Using a combination of methods enables the researcher to answer questions that either method alone could not answer in isolation. For example, while quantitative data can describe or identify a phenomenon (e.g. individuals with cancer may find it difficult to participate in leisure activities), qualitative data could be used to explain the phenomenon (e.g. individuals with cancer may find it difficult to participate in leisure activities due to difficulties managing their fatigue).

Mixed methods research is suitable when one data source is insufficient, for example, when one type of data will not provide a complete account of a situation (Creswell & Plano Clark, 2011). In this study, quantitative information is required. For example, individuals with cancer are known to experience symptoms such as fatigue and nausea. Therefore, quantitative measures in this study can be used to investigate how many symptoms they experience, what these symptoms are and whether these symptoms have changed following participation in a social prescribing service. However, the qualitative strand enables the researcher to explore how these symptoms affected the individual and the role social prescribing may have played in managing those symptoms.

Mixed methods research may also help to reduce the disadvantages of using either quantitative or qualitative methods alone (Matthews & Kostelis, 2011). Quantitative

data collection has been criticised as it does not depict individual experiences and processes or provide an understanding of context (Creswell, 2014). For example, an individual may report that they have been experiencing high levels of stress or worry in the past week but lack the opportunity to identify specific sources of their stress e.g. returning to work. Meanwhile, qualitative data has been acknowledged to face challenges in reflexivity and transferability and may be influenced by bias in interpretation and analysis (Malterud, 2001). By using a mixed methods approach, the strengths of each approach are emphasised and the weakness can be compensated for (Corcoran, 2006; Creswell, 2014).

There are several other justifications for the use of mixed methods in this study (Bryman, 2006). Mixed methods research has been found to suit the complex nature of the majority of public health issues and social interventions, which is relevant to the phenomenon in this research study (Baum, 1995; Steckler et al., 1992). Triangulation is another common reason for employing mixed methods (Bryman, 2006). Triangulation is an approach used to increase the validity of research and involves using data collected from several sources. This means that results can be mutually corroborated (Creswell & Plano Clark, 2011). Triangulation is achieved in this study through the collection of two different types of data: qualitative and quantitative. These findings and results can be mutually corroborated to gain a clearer understanding of the phenomenon and of participants' experiences in a social prescribing service.

Addressing different research questions is an additional justification for mixed methods, which applies to this study (Bryman, 2006). Some questions can be answered solely quantitatively, others require qualitative information and some require a combination of both. The inclusion of these different research questions enables the research aims to be addressed. Explanation (using one method to clarify the findings of another) and illustration (using qualitative data to explain quantitative results) are both relevant in this study. In this study, the information obtained from interviews enabled explanation of data from the quantitative measures. Allowing a diversity of views to be included is another basis for using mixed methods research. This means that the perspectives of the researcher and participant can be combined and also enables the relationship between variables and meanings to be revealed (Bryman, 2006).

There are also challenges involved when using mixed methods research designs. Developing and implementing the research design can be a lengthy process so it is important to ensure there is sufficient time to implement a mixed methods study (Matthews & Kostelis, 2011). Other challenges related to the skills of the researcher.

Researchers who choose to use mixed methods must be familiar with both quantitative and qualitative data collection procedures and analysis techniques. It is preferable if the researcher has experience in both methods (Creswell & Plano Clark, 2011).

On consideration of this information, it was established that a mixed methods approach would be appropriate in the context of this research study as it would provide a sufficient framework to guide the research process. The complexity of this data collection process was chosen as one data source was unlikely to allow for an adequate exploration of the research objectives. Therefore, a quantitative approach was selected to gain objective, numerical data to evaluate the impact that social prescribing had on participants' health and well-being (Creswell, 2014; Domholdt, 1993). Qualitative data was gathered to gain an in-depth understanding of the participants' experiences and perspectives of social prescribing and to explore the contextual elements of the research question (Creswell, 2014).

3.3.2 The process of selecting a mixed methods research design

Cresswell and Plano Clark (2011) identify four key decisions which should be made to select an appropriate mixed methods research design. These decisions define the various ways that the quantitative and qualitative strands of the study relate to each other. The decision-making process for this study is described through these key decisions:

1. Determine the level of interaction between the strands

The level of interaction determines the extent to which the qualitative and quantitative strands either interact with or remain independent of each other. The data in this research was collected separately within the same time period. Both strands were analysed separately, however, the findings of both strands will be compared in the discussion section of this research study. Therefore, there is an independent level of interaction between the strands until the interpretive phase of this study.

2. Determine the priority of qualitative and quantitative strands

In this research study, the qualitative and quantitative data strands operate on an equal level of prioritisation and importance, as both play an equally important role in addressing the research problem.

3. Determine the timing of the qualitative and quantitative strands

Timing relates to the time phase in which the data sets are collected and the order in which the results of the two data sets are used. A concurrent timing approach was

adopted for this study; both quantitative and qualitative strands were implemented during a single phase of the research study. Data was collected across a 12-month period from July 2018 to July 2019 (the study began in July 2018 as there was a research assistant post attached, enabling gathering of the data across a 12-month period).

4. Determine where and how to mix the qualitative and quantitative strands

Mixing relates to the interrelation of the quantitative and qualitative strands of the research. In this research study, the strands are mixed at the level of interpretation. The qualitative and quantitative strands are collected and analysed separately. The findings are then combined to draw conclusions through comparison and synthesis in the discussion section of this study.

3.3.3 Convergent parallel research design

A convergent parallel mixed methods research design was selected for this study. In concurrent parallel research, all data collection occurs during a one phase period and both strands are equally prioritised (Creswell, 2014). Each strand of data is collected and analysed separately and then compared and integrated in the discussion phase, as presented in Figure 3-1 (Creswell, 2014):

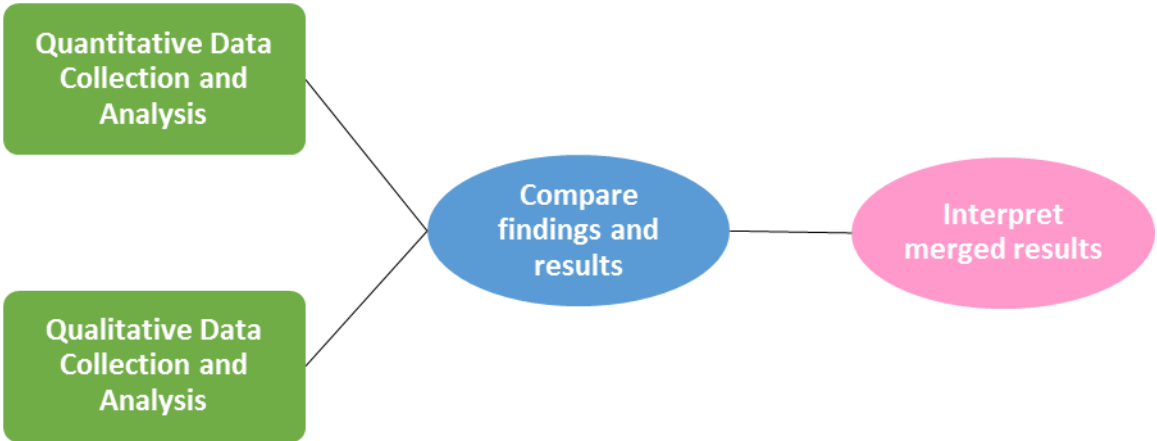


Figure 3-1: Convergent parallel research design (Creswell, 2014)

There are four main steps in the convergent parallel design. Firstly, both quantitative and qualitative data are collected. In the second step, each dataset is analysed separately using typical quantitative and qualitative analysis procedures. Thirdly, the two sets of findings are merged. This can be done in a number of ways, for example, by identifying content represented in both types of data and comparing or synthesizing results or by transforming one type of data into the other (e.g. turning codes into numbers and using statistical analysis). Finally, the merged results are interpreted and the extent to which the quantitative and qualitative results combine to answer the research question is discussed (Creswell & Plano Clark, 2011).

The purpose of the convergent design is “to obtain different but complementary data on the same topic,” (Morse, 1991, p. 122). In doing so, the differing strengths of quantitative methods (large sample size, trends, generalisation) and qualitative methods (small sample, details, in depth) may be combined at an equal level to best understand the research problem (Creswell and Plano Clark, 2011). This research design enables the researcher to compare and contrast quantitative statistical results with qualitative findings for corroboration and validation purposes (Creswell and Plano Clark, 2011; Pope & Mayes, 2013).

There are challenges that may arise when using the convergent parallel design. Merging the two sets of results can be difficult and therefore the quantitative and qualitative strands of this study were designed to relate to similar concepts, enabling comparison of the data sets. Having different sample sizes can also be a problem for merging data, however, in this study the quantitative and qualitative samples were the same size and composed of the same individuals, which enabled more fluid data comparison (Creswell & Plano Clark, 2011).

3.4 Sampling and Data Collection

This section describes the sampling methods used and the methods of data collection. All data was collected during a 12-month period from July 2018 to July 2019. The sampling processes for this study are described below, followed by descriptions of procedures specific to the quantitative and qualitative strands.

3.4.1 Planning Data Collection

This study sought to recruit adults with an existing or previous diagnosis of cancer to engage with a social prescribing service based in the Dublin 8 area.

3.4.1.1 Geographical Inclusion & Exclusion

Following liaison with oncology consultants in St. James' Hospital and the existing social prescribing service based within Dublin 8, it was determined that inclusion for the study would need to be limited to a pre-determined catchment area geographically aligned to the social prescribing service. This was to reduce the amount of travel participants would need to complete to engage with the study and therefore increase accessibility. Furthermore, it was anticipated that identifying community assets within each postcode area would take time and resources. To maximise the link worker's ability to adequately support participants and maintain service capacity, it was decided to limit the catchment areas for inclusion within the study to those living within the Dublin 6, 6W, 8, 10 and 12 postcode areas (see figure 3-2).

Later in the data collection process, however, due to challenges with recruitment, it became clear that an expansion to eligible inclusion areas would enhance the study. After further liaison with the social prescribing link worker and researcher supervisor, it was participants living within the Dublin 1, 2, 7, 20, 22 and 24 postcodes were also eligible for inclusion in the study. This was based on the link worker's pre-existing knowledge of community assets within these areas and their relative proximity to the social prescribing service.

Dublin Postal Districts

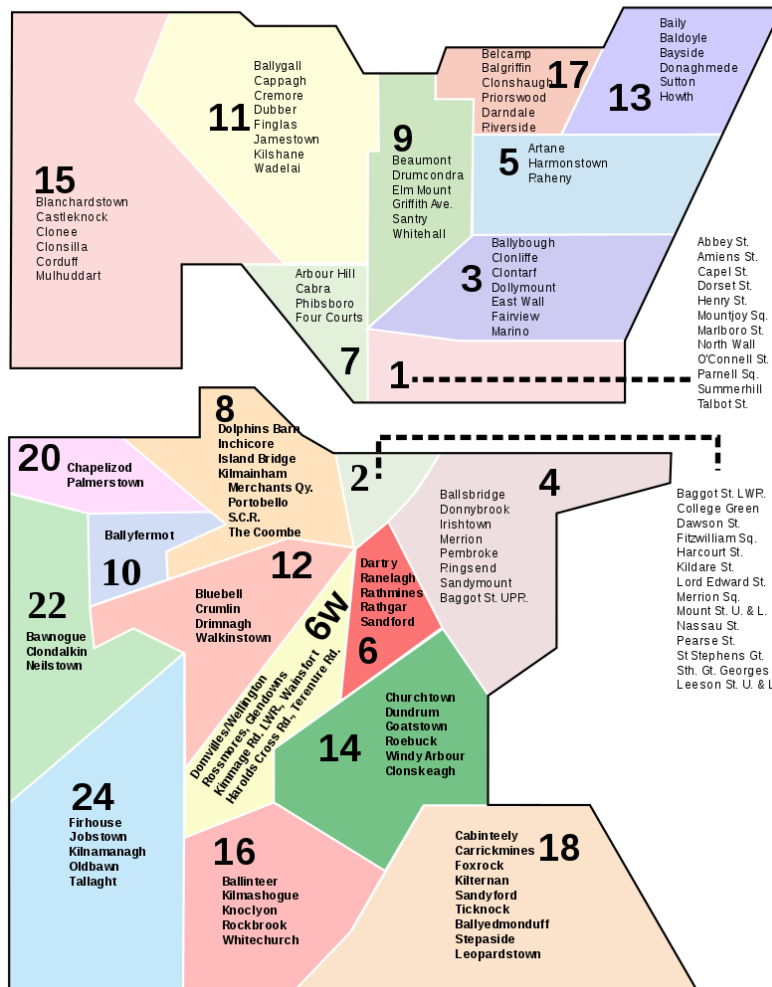


Figure 3-2: Map of Dublin Postal Districts

3.4.2 Purposeful sampling

Purposive sampling, a type of non-probability sampling, was used in this study and applied to both questionnaires and interviews. Purposive sampling reflects an approach whereby participants are deliberately chosen due to some characteristic or feature of interest, (Tashakkori & Teddlie, 2003). Purposive sampling is most widely used in qualitative research but has been found to be an appropriate form of sampling for mixed methods studies (Palinkas et al., 2015).

In this study, homogenous sampling, a purposive sampling technique, was used in the selection as research questions addressed were specific to the characteristics of a particular group of interest, i.e. adults with an existing or previous diagnosis of cancer who lived within the catchment area of the social prescribing service. Inclusion and

exclusion criteria were defined to carefully select and exclude potential participants from involvement in the study, making eligibility for participation clear during recruitment (Table 3-1). A clear outline of criteria can also justify sampling, reducing researcher bias which is often a limitation in purposive sampling (Macnee & McCabe, 2008).

Please note, as discussed above, the inclusion criteria was expanded six months into the study due to recruitment challenges. Initially, only participants living within Dublin 6, 6W, 8, 10 and 12 were eligible for inclusion. This expanded to include Dublin 1, 2, 7, 20, 22 and 24. The final inclusion criteria is reflected in the table below.

Table 3-1: Inclusion and exclusion criteria for the study

Inclusion	Exclusion
Adults with any diagnosis of cancer, including haematological cancers such as lymphoma	Received a paediatric diagnosis of cancer
Pre or post treatment for diagnosis	Received a diagnosis of cancer greater than 10 years ago
Willing to commit time to engage with the service and in a new activity	Lived outside of the designated postcode areas (Dublin 1, 2, 6, 6W, 7, 8, 10, 12, 20, 22 and 24)
Able to speak, read or write in English	
Living within the Dublin 1, 2, 6, 6W, 7, 8, 10, 12, 20, 22 and 24 postcode areas	

To enable comparison and corroboration across data sets, the individuals who participated in the quantitative sample were the same individuals who participated in the qualitative sample (Creswell and Plano Clark, 2011).

3.4.3 Sample Size

As this was an exploratory study, it was difficult to calculate an exact sample size prior to initiating the study, however in 2015, 10,985 individuals attended the medical oncology department in St. James' Hospital (1216 were people with newly diagnosed cancer and 9769 were return patients) (St James' Hospital, 2015). However, it was anticipated that not all of these individuals would be eligible for inclusion, and/or interested in participating in the study. The existing social prescribing service based within the local community centre began in February 2017 and had received 38 referrals over a period of eight months. Based on these numbers, and potential participants from other recruitment channels, it was anticipated that the sample size for this exploratory study could be up to 50-60 participants.

3.4.4 Recruitment Processes

Ethical approval was obtained from the St. James' Hospital Research Ethics Committee prior to recruitment (Appendix 8). Four primary recruitment channels were utilised to obtain the sample for this study (Fig 3-3):

1. St. James' Hospital Oncology & Haematology Department
2. Local Primary Care Services and GP Practices
3. Community Cancer Support Services
4. Community Centres

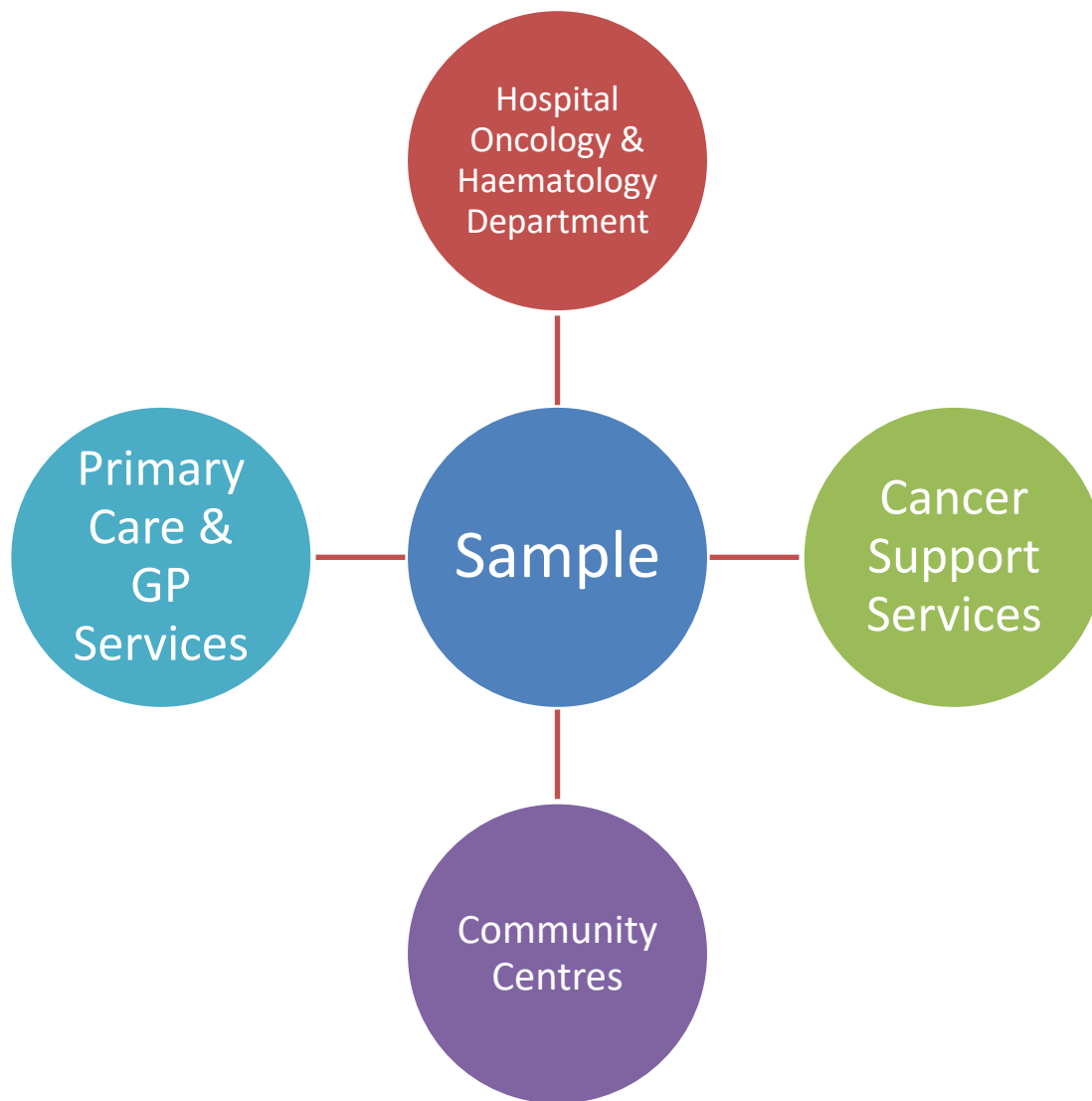


Figure 3-3 Four recruitment channels used to obtain sample

3.4.4.1 St. James' Hospital Oncology Department

The first channel of recruitment for this study was through St. James' Hospital Oncology Department. Consultants working in St. James' Hospital were contacted with information about the study and permission was requested to recruit patients under their care who were interested in participating in the study. Advanced Nurse Practitioners, Clinical Nurse Managers and Clinical Nurse Specialists were also contacted with information regarding the study. The researcher met regularly with nurses working in the Oncology and Haematology Day wards and outpatient clinics to collaboratively identify suitable potential participants. The nurses and administration

staff acted as gatekeepers by distributing leaflets to potential participants, which included information about the study and contact details of the researcher (appendix 5). Additionally, leaflets were distributed throughout the wards at various information points for individuals to peruse. Those who were interested in the study were advised to contact the researcher for more information and/or to indicate their interest in participating in the study. If the researcher was present on the day ward or in the outpatient clinic, the individual could approach the researcher for further information on the day.

3.4.4.2 Local Primary Care Services

The second channel of recruitment for this study was through local primary care services. GP practices that were already engaging in a social prescribing programme in the local community organisation were provided with updated referral forms that now indicated if the individual had a previous diagnosis of cancer and if they were interested in participating in a research study. An additional 26 GP practices were contacted with information about the study and of these, two practices contacted the researcher and agreed to refer any individuals they felt would be suitable. The researcher contacted two primary care teams based within the communities within the inclusion criteria of the study to disseminate information. Both teams responded positively and agreed to distribute participant information leaflets to interested individuals, who were then advised to contact the researcher for further information.

3.4.4.3 Community Cancer Support Services

The third channel of recruitment was through local community cancer support services. Two community cancer support services based in and near St. James' Hospital were contacted with information about the study. Both services agreed to distribute the information leaflets for the study to potential participants and to display the leaflets at their information desks, as appropriate.

3.4.4.4 Community Centres

The final channel of recruitment for this study was through local voluntary sector community centres. Five community centres were contacted and agreed to advertise and distribute participant information leaflets to interested individuals who could subsequently contact the researcher for more information.

3.5 Quantitative strand

The quantitative data in this research study was collected using four patient-reported outcome measures (Dawson, 2009). Quantitative data involves the collection of numerical data through standardised instruments, which have previously been tested for reliability and validity to ensure objectivity and eliminate bias (Denscombe, 2008; Gerrish & Lacey, 2006).

The quantitative strand of this study used a one-group pre-test-post-test, quasi-experimental design to measure the health-related outcomes of social prescribing (Allen, 2017). Quasi-experimental designs are designs that do not meet all of the criteria for experimental design, i.e. one or more control groups plus an experimental group, random assignment of subjects in both control and experimental groups, pre-test of groups, post-test of groups to identify the impact of intervention and controlled manipulation of independent variables (Allen, 2017).

In a one-group pre-test-post-test design, there is a single group of participants given the same treatment or intervention, and assessments are conducted both prior to and after the intervention has been implemented. The effect the intervention is determined by analysing the difference between the first assessment of the dependent variable and the second (Allen, 2017).

Quantitative data was gathered to provide objective, numerical data to evaluate the impact of social prescribing on the health and well-being of cancer survivors and to provide complementary data to validate and integrate with the qualitative findings (Creswell, 2014; Domholdt, 1993).

The researcher met with individuals at a date and time chosen by the individual. Participants were offered the choice of several locations, including their own homes if this was their preferred option, however all individuals opted to meet within the Trinity Health Sciences' Facility. At this meeting, the researcher first reviewed the participant information leaflet (appendix 5) and the consent form (appendix 6) with the participant. The participant was given the opportunity to ask any questions about the study at this point. The individual then signed the consent form in the presence of the researcher before proceeding to complete the health-related outcome measures (appendices 1-4). Additionally, participants were asked to complete a short demographic questionnaire designed by the research team (appendix 9).

Once the measures were complete, participants then engaged with the social prescribing link worker for their first meeting. Further information about the social

prescribing intervention provided to participants within this study is provided in section 3.8.

After ten weeks had passed, participants attended a second meeting to complete the outcome measures again. The purpose of this was to measure the changes to participants' health-related quality of life, physical and/or mental health and activity participation following involvement in the social prescribing service. The qualitative strand of this study also took place during this second meeting with the researcher.

The health-related outcome measures used in this study and the reasons for choosing them are described in the following sections.

3.5.1 The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core-30 (EORTC QLQ-C30)

The European Organisation for Research and Treatment of Cancer developed the Quality of Life Questionnaire Core-30 (EORTC QLQ-C30) self-report questionnaire as a measure of cancer-related quality of life and the impact of disease and clinical treatment on individual's daily lives (Aaronson, et al., 1993). A description of the EORTC QLQ-C30 and discussion of its psychometric properties are provided below. Please see Appendix 1 for a copy of the EORTC QLQ-C30.

3.5.1.1 Description of the EORTC QLQ-C30

The QLQ-C30 includes nine multiple-item subscales and six single-item subscales, resulting in 15 sub-domains measured by 30 items. Each item has four response categories – “not at all,” “a little,” “quite a bit,” and “very much.” The final quality of life subscale is rated from 1 (“very poor”) to 7 (“excellent”). These sub-domains are grouped into three domains; Global Quality of Life, Functional Quality of Life and Symptoms. In addition to this, an EORTC Summary Score may be calculated, comprising all 15 sub-domains. Higher scores indicate a greater quality of life, except within the Symptom scale, where a higher score indicates a greater presence of symptoms, and therefore a lower quality of life.

A list of the scales and corresponding number of items has been provided in Table 3-2.

Table 3-2: EORTC QLQ-C30 Scales and Items

Measures	Scales/Items	Item Range*	Number of Items
Global health status/QOL	Global health status/QoL (revised)	6	2
Functional scales	Physical functioning (revised)	3	5
	Role functioning (revised)	3	2
	Emotional functioning	3	4
	Cognitive functioning	3	2
	Social functioning	3	2
Symptom scales	Fatigue	3	3
	Nausea and vomiting	3	2
	Pain	3	2
Symptom items	Dyspnoea	3	1
	Insomnia	3	1
	Appetite loss	3	1
	Constipation	3	1
	Diarrhoea	3	1
	Financial difficulties	3	1

QoL = Quality of Life

* Item range refers to the difference between the maximum and minimum response to individual items.

3.5.1.2 Psychometric Properties of the EORTC QLQ-C30

A number of studies investigating the validity (measuring what is intended to be measured), reliability (measuring with sufficient precision) and sensitivity (ability to detect changes) of the QLQ-C30 have found the tool to have strong psychometric properties relevant to different cancer-patient populations (Aronson, et al., 1993; Niezgoda & Pater, 1993; Ringdal & Ringdal, 2000).

Bjordal et al. (2000) evaluated the reliability and validity of version 3.0 of the EORTC QLQ-C30 in a study involving 622 head and neck cancer patients from 12 countries. More specifically, the internal consistency reliability, construct validity, and responsiveness were assessed. Cronbach's alpha coefficient (a measure of internal consistency) was used to assess the scales of the questionnaire and a score higher than 0.70 was achieved for all scales, which is considered to indicate acceptable internal consistency.

The construct validity of the EORTC QLQ-C30 was also assessed via a known-groups approach to assess the differences in the scales and single items between patients who had recently been diagnosed, patients with recurrent disease, and disease-free patients (Bjordal et al., 2000). The known-groups approach is a typical method used to support construct validity and is provided when a test can discriminate between a group of individuals known to have a particular trait and a group who do not have the trait, or who have differing levels/severities of that trait (Portney & Watkins, 2008). In this case, there was a statistically significant difference across groups for the following domains of the EORTC QLQ-C30: role functioning, emotional functioning, social functioning, fatigue, pain, appetite loss, insomnia, and general QoL, demonstrating construct validity. In addition, sensitivity was demonstrated by a change in scores of the questionnaire over time.

Lastly, an estimate for the minimally important difference was provided by Osoba et al., (1998) based on a sample of patients with breast and small-cell lung cancer. An anchor-based approach was taken, using global ratings of change as measured by a subjective significance questionnaire, as an anchor. The mean change in scores for patients who indicated a small difference, either positive or negative, was 5 to 10 points (Osoba et al., 1998). A "moderate" change reported by patients had corresponding changes of about 10 to 20. Similar findings were reported in a study by King, et al. in 1996. The two studies combined have resulted in a mean difference of 10 points being widely accepted as the minimal clinically important difference for the EORTC QLQ-C30 (King et al., 1996; Osoba et al., 1998).

3.5.2 Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS) is a 14-item self-administered data collection tool that was designed to assess anxiety and depression in medical in-patients (Zigmond & Snaith, 1983). A description of the HADS and discussion of its psychometric properties are provided below. Please see Appendix 3 for a copy of the HADS.

3.5.2.1 Description of the HADS

The HADS is a pen-and-paper task which invites individuals to self-rate their mental health over the last week. Each item is measured on a 4-point Likert response scale (e.g., for item, "I enjoy the things I used to", the rating ranges from "0, definitely as much" to "3, hardly at all"). Subscale scores are constructed by summation, whereby increasing scores indicate increasing levels of anxiety or depression: scores less than 8 are categorised as normal, scores of 8-10 as borderline case, and scores of 11-21 as clinical case (Zigmond & Snaith, 1983).

3.5.2.2 Psychometric Properties of the HADS

In 1989, it was recommended for use in cancer studies by Maguire & Selby, and more recently Herrmann et al. (1997) reviewed international psychometric and clinical data from the HADS and concluded that the instrument's psychometric properties were 'good'.

HADS-A and HADS-D have both demonstrated good internal consistency ($\alpha = 0.89$ for HADS-A; $\alpha = 0.86$ for HADS-D), good specificity and sensitivity to change, moderate inter-correlation and a distinct two factor structure in general practice populations (Hermann, 1997; Olsson, Mykletun & Dahl, 2005). Internal consistency has been reported to be between 0.80 and 0.93 for anxiety and between 0.81 to 0.90 for depression (Hermann, 1997). It is quick and easy to administer, making it well accepted amongst patients (Hermann, 1997; Johnston et al., 2000).

The sensitivity of the anxiety scale ranged from 61 to 84% in samples of metastatic cancer or other cancer types (Hopwood, Howell & Maguire, 1991; Le Fevre, et al., 1999; Razavi et al., 1992). High reliability (Cronbach's $\alpha > 0.8$) has been demonstrated in a variety of cancer samples (Bjellanda, Dahlb, Haugc & Neckelmannd, 2002; Carroll, et al., 1993; Le Fevre, et al., 1999; Moorey et al., 1991; Watson et al., 1999).

This measure has been validated with a variety of cancer populations, including breast, lung, testicular, prostate, laryngeal and head and neck cancer (Berglund, Petersson,

Eriksson, Wallenius & Roshani, 2007; Castelli, Bincaschi, Caldera & Torta, 2009; Johnston, Pollard & Hennessey, 2000; Katz, Kopek, Waldron, Devins & Tomlinson, 2004; Love, Grabsch, Clarke, Bloch & Kissane, 2004; Hartung, et al., 2016; Singer et al., 2009).

3.5.3 Frenchay Activities Index (FAI)

The Frenchay Activities Index (FAI) is a 15-item self-report tool designed to assess the frequency at which individuals perform Instrumental Activities of Daily Living (IADLs) (Holbrook & Skilbeck, 1983). A description of the FAI and discussion of its psychometric properties are provided below. Please see Appendix 2 for a copy of the FAI.

3.5.3.1 Description of the FAI

Individuals are asked to describe their participation within the last 3 and 6 months across three activity domains: domestic, leisure/work and outdoors. Scores are rated on a four-point ordinal scale from 0 to 3. The scores are compiled into a single summary score (with a range of 15-60 points), with a higher score indicating more frequent activity participation.

3.5.3.2 Psychometric Properties of the FAI within a cancer population

The FAI was originally designed for use with stroke patients but has since been validated with a cancer population (Purcell & Fleming, 2011). Excellent internal consistency ($\alpha = 0.83$), criterion and construct validity have been indicated in stroke populations (Schuling, de Haan, Limburg & Groenier, 1993) and excellent test-retest reliability ($r = 0.96$) is indicated in community-dwelling populations (Turnbull et al., 2000). An advantage of the FAI is that it is quick to administer, taking approximately 5 minutes to complete when administered in an interview format (Segal & Schall, 1994).

3.5.4 Multidimensional Assessment of Fatigue (MAF)

The Multidimensional Assessment of Fatigue (MAF) is a 16-item self-report measure of fatigue (Belza, 1995). A description of the MAF and discussion of its psychometric properties are provided below. Please see Appendix 4 for a copy of the MAF.

3.5.4.1 Description of the MAF

The MAF measures fatigue across four dimensions: severity, distress, frequency and change within the past week, and impact on various activities of daily living (household

chores, cooking, bathing, dressing, working, visiting, sexual activity, leisure, shopping, walking and exercise). The MAF was developed to provide a Global Fatigue Index based on the first 15 items. Items are scored using a numerical rating scale ranging from 1-10. Items 1 (degree) and 4-14 (interference) have anchors of “Not at all,” to “A great deal,” item 2 (severity) has anchors of “Mild,” to “Severe,” and item 3 (distress) has anchors of “No distress,” to “A great deal of distress.” Items 4-14 (interference with activities) provide respondents with the opportunity to indicate if they do not engage in an activity due to reasons other than fatigue, which excludes the item. Items 15 and 16 are scored on a 4 point ordinal scale, with item 15 (frequency) ranging from “Hardly any days,” to “Every day,” and item 16 (change) ranging from “Decreased,” to “Increased.”

3.5.4.2 Psychometric Properties of the MAF within a cancer population

The MAF has been found to detect fatigue changes in patients with cancer-related fatigue (Meek et al., 2000; Roscoe et al., 2002; Winstead-Fry, 1998). A systematic review of studies that have used the MAF found that the tool was reported to be easy-to-use and had strong reliability and validity (Belza et al., 2018). Another review found the MAF was reported as one of only 4 fatigue measures that could detect change over time (Whitehead, 2009). Within a cancer population (n=212), the MAF was found to have excellent test-retest reliability, ($\alpha = 0.88$) and excellent internal consistency (Cronbach’s Alpha = 0.93). The MAF has also shown sensitivity in detecting fatigue changes in patients with cancer-related fatigue over time (Meek et al., 2000).

3.6 Qualitative Strand

Qualitative methods were used to explore the personal experience of engaging in social prescribing as an individual living with and beyond cancer. Semi-structured interviews took place 10 weeks following initial engagement with the social prescribing service.

3.6.1 Qualitative Methodology

A qualitative descriptive design as described by Sandelowski (2000), was chosen for this mixed-methods study. Qualitative description research seeks instead to provide a rich description of the experience depicted in easily understood language (Sullivan-Bolyai et al., 2005). The researcher seeks to discover and understand a phenomenon, a process, or the perspectives and worldviews of the people involved (Bradshaw, Atkinson & Doody, 2007). It has been identified as a suitable qualitative approach within mixed methods inquiries and relevant within healthcare research as it allows the

service users' perspectives and evaluations to be represented (Neergaard et al., 2009). Semi-structured interviews with open-ended questions are typically used in qualitative description research and were similarly employed here (Neergaard et al., 2009).

Qualitative description differs from other forms of qualitative methodology as it involves neither thick description (ethnography), theory development (grounded theory) nor interpretative meaning of an experience (phenomenology), but rather a rich, straight description of an experience or event. In the analytical processes and presentation of data, researchers remain close to the data, and the final product is a description of participants' experiences in a manner similar to their own language (Sandelowski, 2000; Sullivan-Bolyai, Bova & Harper, 2005). Thematic analysis is a common approach used in qualitative description (Miles et al., 2014). Further information about the qualitative analysis process is outlined below in section 3.7.2.

3.6.2 Qualitative Data Collection

Qualitative data for this study was obtained through semi-structured interviews, utilising open-ended questions. The aim of individual interviews is to collect detailed accounts of participants' thoughts, attitudes, beliefs, and knowledge pertaining to a particular phenomenon (Patton, 2002). Semi-structured interviews allow interviewers flexibility in questioning to expand upon areas of interest and to maintain an openness to the phenomenon (Holloway, 2005). An interview guide is used, which lists topics for discussion, and the interviewer is free to ask any questions about these topics and build a conversation about them (Patton, 2002). The development of the interview guide and process for interviewing participants are outlined below.

3.6.3 Development of the Interview Guide

The interview guide was developed by initially writing down the larger research questions and aims of the study and outlining broad areas of knowledge that might be relevant to answering these questions.

Though it would have been beneficial to pilot the interview guide with an individual who has received a cancer diagnosis and/or engaged in social prescribing, due to limited access to individuals within either group, the researcher was unable to complete a pilot interview. This is a limitation of the study and should be considered when interpreting results. In an attempt to combat this limitation, the researcher engaged in discussion with the research supervisor; an advanced nurse practitioner in oncology working within the hospital; and a social prescribing link worker, to develop the interview guide.

The interview guide was refined and further developed through regular discussion between the researcher and research supervisor.

The interview guide used listed several topics to be covered in the interview including the physical and/or mental health impact of social prescribing, discussion around activities attended by the participant and why (or why not) and recommendations for the improvement of the social prescribing service in the future. Each section contained further probes based on potential responses. A copy of the interview guide is included in Appendix 7.

3.6.4 Context and Environment of the Interview

As with the pre-test data collection point, participants were invited to identify a preferred location for the facilitation of the post-test data collection and interview. Though given alternative options, all participants chose to meet the researcher within the Trinity Centre for Health Sciences. The interview was held within a quiet environment and distractions were minimised where possible. Participants were offered water, biscuits and tea prior to the interview and were informed they could take a break at any point during the completion of the post-test measures or the interview. The interview was completed after participants had completed the post-test measures to reduce the risk of the interview influencing the answers given in the post-test measure.

3.7 Data Analysis

In mixed methods research with a convergent parallel design, the quantitative data is analysed using quantitative methods and the qualitative data using qualitative methods. However, methods of mixing both types of data are also required (Creswell & Plano Clark, 2010). All methods of data analysis are described in this section.

3.7.1 Quantitative Data Analysis

Quantitative data analysis was carried out using the Statistical Package for Social Science (SPSS) version 22 (SPSS 22). All possible responses in the health-related outcome measures were assigned a numerical code so the data could be analysed using SPSS (Pallant, 2010). Initial descriptive statistics using frequencies, means (SD), medians (IQR) and percentages were calculated. Inferential analysis was used to examine differences in participants in mental health and quality of life before and after attending social prescribing service.

The data collected in this study did not meet all assumptions for the use of parametric methods in quantitative analysis, therefore, non-parametric methods were used. In order to use parametric methods of quantitative analysis, the recommended sample size to complete both the pre- and post-test measures should be greater than 30 (Pallant, 2016). The sample size of participants who completed both pre and post-quantitative measures for this study was therefore too small ($n=27$) to conduct parametric analysis methods and non-parametric methods were used. They are outlined below.

3.7.1.1 The Wilcoxon Signed-Rank Test

The Wilcoxon Signed-Rank Test is a non-parametric test that can be used to compare two sets of scores that come from the same group of participants, as is the case in this study (Pallant, 2016). This test permits the investigation of any change in scores from one time point to another. The Wilcoxon Signed-Rank Test was the most frequently used test in this study as it was used to examine the change in the scores of each of the chosen standardised measures used in the pre- and post-intervention time points. Statistical significance at $P<0.05$ was assumed throughout.

Three assumptions are required of data to ensure the Wilcoxon Signed-Rank test will give a valid result.

The first assumption is that the dependent variable is measured at the ordinal or continuous level. Ordinal variables include Likert scales, e.g. a 7-point item ranging from “strongly agree” through to “strongly disagree.” Each of the standardised measures for this study measure data at the ordinal level and therefore satisfying this assumption.

The second assumption requires the independent variable to consist of two categorical, “related groups” or “matched pairs”, indicating that the same subjects are present in both groups. This indicates that each item has been measured on two occasions on the same dependent variable. 43 participants in this study completed the quantitative measures prior to engaging with the social prescribing service and 27 participants completed the measures ten weeks later (Section 4.2 discusses this in further detail). Therefore, the Wilcoxon Signed-Rank test was completed using the sample of 27 participants, as these subjects were present in both groups.

The third assumption requires the distribution of differences between the two related groups to be symmetrical in shape. For each test, a review of the distribution of

differences was performed to ensure they were symmetrical, therefore satisfying this assumption.

In this study, the Wilcoxon Signed Rank test was used to analyse the pre-intervention and post-intervention scores for each of the standardised measures chosen for quantitative analysis. The results of these analyses are reported in Chapter 4.

3.7.2 Qualitative Data Analysis

Thematic analysis is a common method of analysis used in qualitative description, the methodology guiding the qualitative strand of this study (Miles et al., 2014). To guide the thematic analysis in this study, the framework approach was chosen (Gale et al., 2013). The framework approach is an increasingly popular method in the management and analysis of qualitative data in health research (Ritchie & Lewis, 2003). It is most commonly used in the thematic analysis of semi-structured interview transcripts identifying commonalities and differences in qualitative data, and seeking to draw descriptive and/or explanatory conclusions clustered around themes. Its defining feature is its matrix output in the final stages of data analysis; a spreadsheet of rows (cases) which looks at each individual interview, columns (codes) and 'cells' of summarised data which provide the researcher to systematically reduce the data in order to analyse by case and code.

The Nudist Vivo version 23 (NVivo) programme was utilised as a means of efficiently producing this final spreadsheet. The approach is advantageous for early-stage researchers in its clear step-by-step procedure, guiding stages of analysis from initial data management to descriptive accounts (Smith & Firth, 2011). This provides a clear audit trail from original data to final themes, enhancing confirmability of results.

The approach is not without weakness, however. Experience in qualitative research is essential in appropriately interpreting the data (Gale et al., 2013). Consequently, the researcher sought guidance from the principle investigator throughout the course of data analysis.

3.7.2.1 Step One: Transcription

Good quality audio recordings and verbatim transcripts of each interview were required in the first step of analysis. In the framework approach, analysis focuses on content rather than conventions of dialogue. Therefore, only long pauses, interruptions, and non-verbal communication (e.g. laughter) were noted in transcription. Transcripts were checked for error by listening again to audio recordings and reading transcripts

simultaneously. The researcher completed the transcription of ten interviews independently, however, due to time restrictions, outsourced the task of the remaining seventeen interviews to a professional transcription service.

3.7.2.2 Step Two: Familiarisation

The second step involved the researcher immersing themselves in the original data. The researcher read and re-read all transcripts while also listening to audio recordings at least once to become familiar with the data-set. This was an important step for the interviews that had not been transcribed by the researcher as it allowed for greater familiarisation of the data that would have been gained through transcription. Analytic memos were recorded during this process, outlining initial impressions within the right-hand-side margin of transcripts. This step ensured that all labels developed were both grounded in and supported by the data (Gale et al., 2013).

3.7.2.3 Step Three: Coding

Following familiarisation, the researcher carefully read each transcript line-by-line, underlining interesting segments of text and applying a label or paraphrase, i.e. a 'code', describing what they interpreted in the passage as important. Coding permitted the researcher to classify all data so that it could be compared systematically with all parts of the dataset. Open-coding was utilised. Open-coding refers to anything that may be relevant from multiple perspectives e.g. emotions. It was included to ensure that important aspects of the data were not missed.

Five participant interviews were coded and analysed by hand utilising highlighters and the margins of the page to identify codes. It was at this point that two academic peers were invited to code and analyse three of the anonymised transcripts to promote inter-coder reliability and compare with the interpretation of the researcher.

All twenty-seven transcripts were then coded using NVivo Version 23, including the five already hand-coded by the researcher and peers. This served as a validation check. If there were instances where the codes did not match, the researcher compared and reanalysed the hand codes, software codes and peer-reviewed codes and referred to the original interviews to determine the final code.

3.7.2.4 Step Four: Developing a working analytical framework

Once the first four transcripts were coded, codes were examined and grouped together into categories using a tree diagram and then clearly defined, forming a working

analytic framework. An 'other' code under each category was also included in order to avoid dismissing data that was yet to fit the model.

3.7.2.5 Step Five: Applying the working analytic framework

The working analytic framework was then applied by indexing subsequent transcripts using existing categories and codes. Indexing refers to the systematic application of codes from the final analytic framework to the whole dataset (Gale et al., 2013).

3.7.2.6 Step Six: Charting data into the framework matrix

Once all data had been coded using the framework, the researcher summarised the data in a matrix for each category, where each row represented a participant and each column, a code. A separate sheet was used for each category.

3.7.2.7 Step Seven: Interpreting the data

Themes were drawn from the data-set by reviewing the matrix and comparing and contrasting within and between participants and categories.

3.7.3 Mixed Methods Analysis

In convergent parallel mixed methods studies, integration of the qualitative and quantitative data occurs after all data has been collected and analysed separately. Details on the qualitative and quantitative analysis have been provided above.

There are a variety of strategies identified in the literature regarding the integration of qualitative and quantitative data at the interpretation stage of the study (Stange, Crabtree & Miller, 2006; Creswell & Tashakkori, 2007). This study utilises an integration through narrative approach. This means the qualitative and quantitative finds are described in a series of reports. Within this thesis, the results of the quantitative strand are reported in Chapter 4, and the findings of the qualitative strand within Chapter 5. This is referred to as the contiguous approach to integration, and involves the presentation of findings within a single report or thesis, but with the reporting of quantitative and qualitative findings in different sections (Carr, 2000; Fetters, Curry & Creswell, 2013).

Once the data has been presented, the fit of the data is considered by comparing and contrasting the findings with one another. This may lead to several questions of "fit," most commonly divided into confirmation, expansion and discordance (Fetters, Curry & Creswell, 2013).

- Confirmation: the qualitative and quantitative findings confirm the results of one another, thus providing greater credibility
- Expansion: the findings of the data diverge, expanding the insight into the topic of interest by addressing differing or complementary aspects of the same phenomenon e.g. quantitative data may describe the strength of the phenomenon where qualitative data provides insight into the nature of the phenomenon
- Discordance: the qualitative and quantitative findings are inconsistent, incongruous, contradictory, conflicting or somehow in disagreement with one another.

Further analysis may include seeking potential sources of bias, examining methodological assumptions and procedures, discussing the conflicting results, identifying potential explanation from theory or previous research, and laying out future research options (Pluye et al., 2005; Moffatt et al., 2006). Analysis of both sets of data occurs within Chapter 6 of this thesis.

3.8 The Social Prescribing Service

To increase the trustworthiness of a study, a clear description of the intervention should be provided. A description of the service is provided, followed by information regarding the link worker facilitating the social prescription, and finally an overview of the processes followed throughout this study to provide social prescribing to individuals living with and beyond cancer. Further audit data regarding the number of interactions participants had with the link worker and the frequency of activities attended is provided in Chapter 4.

3.8.1 The Social Prescribing Service

For the purposes of this study, an existing social prescribing service received funding to expand its current capacity to provide social prescribing to individuals living with and beyond cancer participating in the study. The existing service was based within a community centre near St. James' Hospital and had been established in February 2017, approximately 17 months prior to the initiation of the study's data collection phase (July 2018). One link worker worked within the existing social prescribing service two days a week; for the purposes of the study, two additional days per week were allocated to meet the social prescribing needs of participants.

3.8.2 The Link Worker

The link worker involved in this study was a community health worker with over ten years' experience working within the community health sector. They had minimal direct experience working with individuals living with and beyond cancer however undertook learning related to the common symptoms and side effects of cancer once invited to engage in this study. Prior to (and throughout) this study, the link worker worked in a community centre local to the hospital where a social prescribing service had been provided since February 2017 – approximately 18 months prior to the initiation of the study.

3.8.3 Identifying Community Assets

As the existing social prescribing service was based within a community centre offering low-cost activities and services, many of the social prescribing out-referrals (assets service users were supported to access) were to activities within the community centre itself. However, due to the broader inclusion criteria of the study, it was necessary to expand the service's knowledge of activities, services and community assets within each of the areas identified for inclusion within the study.

Prior to meeting with any participants, both the link worker and researcher initiated a process of identifying activities, services and community assets within each of the areas initially identified for inclusion (Dublin 6, 6W, 8, 10 and 12). This was achieved through internet searches; communication with libraries, community centres and local service authorities; and on-foot review of libraries, churches and shops for leaflets/fliers advertising local community assets. A database was kept recording each identified asset by location and type. This was to promote a more efficient social prescribing process for study participants and was hoped to reduce the delay in identifying activities, services and community assets of interest or need to participants.

Throughout the study, the link worker and researcher continued to expand and maintain the database of resources through regular communication with local authorities and renewed and repeated internet searches. As participants identified previously unexplored interests or service needs in initial meetings with the link worker, more specific and well-defined searches were completed to identify further assets that were relevant. As the study's catchment area for recruitment expanded, efforts were made to identify assets within each of the new included communities.

3.8.4 Description of the Social Prescribing Process

To maximise time and reduce the need for participants to travel to more than one location to engage in the study, participants met with the social prescribing link worker immediately after the completion of the pre-test quantitative measures with the researcher.

3.8.4.1 The Initial Meeting

During the initial meeting, the link worker introduced themselves, explained their role, and held a supportive discussion with the participant regarding their current activity levels and other commitments such as work or family. The link worker developed an interest profile of the participant and gathered details about the participant's geographical location and access to travel. If participants had no clear preference regarding activities or services, the link worker provided information on assets already known to the service within the participant's local area.

3.8.4.2 Ongoing Identification of Resources

The aim of the social prescribing service was in fact to not be prescriptive, but individualised. Though a database of assets and activities already identified within each area was utilised to guide discussion and provide a variety of options to participants, if there was nothing available of interest or use to the participant, the link worker endeavoured to identify further options. Again, this was completed through renewed searches and communication with valuable points of contact in the community (e.g. other community health workers or community council officers).

Participants were contacted within 1-2 weeks of the initial meeting with information about activities, services and social groups that were available in their area. The link worker continued to provide follow-up communication with all participants through email, phone or in person, depending on the participant's preference and need.

3.8.4.3 Additional Support

Additionally, participants were given the option of meeting the link worker at their chosen activity (where possible, taking working hours and geography into consideration) and two participants availed of this option.

In 9 cases, the link worker contacted the facilitator of a participant's chosen activity or community asset ahead of time to identify whether the activity would be suitable for them. This was done with the participant's permission and to maximise the likelihood of successful attendance at the activity. Facilitators of guitar classes (P2), yoga (P5), art

classes (P11), personal training (P42), and volunteering associations (P43) were contacted by phone. For the remaining 4 participants, their chosen activities were based within the same community centre as the social prescribing service, and therefore the link worker knew and was able to liaise with the facilitators in person.

To meet the specific health needs of individuals living with and beyond cancer, the link worker liaised with healthcare professionals within the hospital for the benefit of participants who did not know where to find information or receive further support. This was a unique benefit of the relationship between the researcher and healthcare professionals within the hospital, however, and may be a consideration for future social prescribing services meeting the needs of cancer survivors.

For one participant, health advice was obtained from an advanced nurse practitioner regarding contraindications to swimming given a side effect of their diagnosis. In two further cases, the link worker and researcher liaised with a healthcare professional within the hospital to arrange referral to outpatient physiotherapy to support the individuals' health needs.

3.9 Research Trustworthiness

To provide a study of value, the threats that are posed against its trustworthiness should be acknowledged, and the methods put in place to combat these threats should be outlined. The trustworthiness of quantitative scientific research encompasses both validity and reliability of the study. Validity is concerned with the accuracy of scientific findings, where reliability is concerned with the replicability of scientific findings (Hissong, Lape & Bailey, 2015). Meanwhile in qualitative research, the criteria of credibility, transferability, dependability and confirmability should be considered (Lincoln & Guba, 1985). In the below sections, the threats posed to the validity and reliability of the study are outlined, and methods of promoting credibility, transferability, dependability and confirmability are discussed.

3.9.1 Internal Validity

The internal validity of a quantitative study refers to the degree to which the results can be attributed to the independent variables as opposed to external factors; i.e. are researchers observing and measuring what they think they are observing and measuring (Brink, van der Walt & van Rensburg, 2012)? Threats to internal validity

include the impact of historical contamination, participant maturation, repeated testing, subject selection and subject attrition or mortality (Hissong, Lape & Bailey, 2015).

The threats to internal validity present in this study are outlined below, in addition to efforts made to combat them.

3.9.1.1 Maturation of participants

Maturation refers to the natural development or change of the participant over time, which may influence pre-test and post-test measurements (Hissong, Lape & Bailey, 2015). On any given day participants may feel or behave differently depending on whether they are hungry, tired, have had a stressful week or have just returned from holiday. Within a cancer population, the fluctuation of symptoms over time and the natural journey as a “cancer patient”, may also impact the answers provided. Participants have a period of ten weeks between pre-test and post-test, during which a range of life events may occur that could impact the participant and therefore results. The inclusion of a qualitative interview in this study provides the opportunity to explore and capture changes that may have occurred to the participant over the study period, thereby reducing (though not eliminating) the risk of maturation to internal validity.

3.9.1.2 History

Historical contamination refers to the occurrence of an event or environmental change that was not anticipated in the planning of the study, such as an injury or decreased interest in participation (Hissong, Lape & Bailey, 2015). Again, the inclusion of a qualitative interview in this study offers the opportunity to explore or identify events that may have impacted on the study, such as engaging in other treatments or interventions. For example, decreased motivation was reported by some participants in the qualitative interviews as a barrier to engagement in activity.

3.9.1.3 Effects of repeated testing

The nature of the pre-post quantitative strand in this study presents the possibility that subjects will experience a practice effect, and that this will impact the scores given in the post-test phase, as participants will have “practiced” the test (Cunningham, Weathington & Pittenger, 2013). The measures used within this study are self-report measures based on the participant’s experiences within a recent time period and not intended as a “test” of skill or ability, which reduces the risk of a practice effect occurring (Cunningham, Weathington & Pittenger, 2013). Participants are also at risk of the influence of experiment fatigue which reflects general experiences of engaging in an experimental study that may lead to physical and/or mental fatigue. This could be

due to a particular treatment, which may be physical and/or mentally demanding, or simply due to the fact that being part of a research project, which is unusual for most participants, can be tiring.

Within this study, the combination of the interview and post-test phase occurring simultaneously presents the possibility that participants' responses to the post-test measures may be influenced by the opportunities for reflection through interviewing. To reduce this risk, the interview was conducted after the completion of the post-test questionnaires to avoid influencing the answers given. Additionally, participants were offered the opportunity for several breaks throughout both data collection periods (pre and post-test) to reduce fatigue.

3.9.1.4 Mortality and attrition

The impact of participants dropping out of a study or disengaging from their chosen activity is referred to as mortality, or attrition, of subjects (Brink, van der Walt & van Rensburg, 2012). Unfortunately, the nature of a cancer diagnosis carries with it an increased risk of participants experiencing heightened symptoms, illness, or death.

To reduce the impact of mortality and attrition on the internal validity of the study, participants were informed of the post-test aspect of the research both prior to consenting to participate in addition to throughout the study period. Participation in the post-test was made as convenient as possible to the participant by utilising a similar location and structure as the pre-test, though there was additional time required for the interview at the second data collection point (Brink, van der Walt & van Rensburg, 2012).

3.9.1.5 Subject selection

Subjects who volunteer for a study are likely to be different from those who are selected to participate, although there is an element of volunteerism for any subject within a scientific study due to the nature of the consent process (Hissong, Lape & Bailey, 2015). Within this study, participants typically self-referred to the social prescribing service, or were encouraged by a health professional (e.g. nurse, doctor or occupational therapist) to do so. It is possible that these participants may have different experiences than those who did not wish to engage with the study.

3.9.2 External Validity

The external validity is the degree to which the results can be generalised to people, settings, outcomes or treatments (Huebschmann, Leavitt & Glasgow, 2019). External

validity and internal validity often impact one another. Controls put in place to combat threats to internal validity may reduce the relevance of the results to the programme's real-life execution (Hissong, Lape & Bailey, 2015).

3.9.2.1 Replication

In the absence of sufficient records of the study's methods, including the process, context, settings and intervention, studies aiming to replicate the findings cannot be generalised as the results cannot be conclusively attributed to the same methods (Huebschmann, Leavitt & Glasgow, 2019). This threat was recognised and strategies such as an audit trail and a reflective diary were implemented to attempt to reduce this threat.

3.9.2.1.1 *Audit Trail*

The audit trail is a detailed document that records research processes as they occur (Akkerman, Admiraal, Brekelmans & Oost, 2006). An extract of the audit trail maintained for this research can be found in Appendix 11.

Use of an audit trail allows for the pathway taken by the study to be recorded, hence enhancing the reproducibility of the study. It also tracks when key decisions were made, which, with the aid of the reflective journal, allows for the researcher to reflect on the progress of the research and monitor threats to the validity and reliability. The extract of the audit trail shows the researcher's efforts to maintain a balance between organising the practicalities of recruitment and data collection; building awareness of researcher bias through regular supervision and use of the reflective journal; and liaising with the social prescribing link worker regarding participant progress and decisions to be made regarding the study's recruitment processes.

3.9.2.1.2 *Intervention Fidelity*

When exploring the effectiveness of an intervention, it is important to explore, not only whether the intervention made an impact, but how and why it did so (McGee et al., 2018). By exploring the fidelity of an intervention, the internal validity of the research increases as the findings can be more largely attributed to the intervention described (O'Shea, McCormack, Bradley & O'Neill, 2016). It also benefits the reproducibility of the study, hence improving the external validity (O'Shea, McCormack, Bradley & O'Neill, 2016). Monitoring of the intervention also benefits in improving its ability to be generalised to other settings as evidence-based practice.

Efforts were made by both the link worker and the researcher to monitor the frequency with which participants interacted with the link worker (i.e. the amount of social prescribing support they received). Additionally, information was sought on the content, intensity and environment of activities and services that were attended by participants. This was a challenge as neither the researcher nor the link worker attended the activities themselves, though the link worker was more familiar with activities that took place within the same community centre as the SP service. Further information was garnered primarily through verbal discussion with the participants, thus gaining the information second hand. This information is presented in Appendix 14, however due to the nature of social prescribing and the variety of activities attended by participants, intervention fidelity remains a challenge for studies exploring the impact of social prescribing. It is difficult to gather information on every activity participants attend due to the varied nature of their interests.

3.9.2.2 Generalisability

Generalisability refers to the extent that results found within the study sample are likely to be found in the larger population from which the sample was drawn (Hissong, Lape & Bailey, 2015). This may be reduced through methods such as randomly selecting the sample from which the population is drawn, however, random selection was not possible within this exploratory study.

3.9.2.3 Multiple Treatments

Similar to historical contamination, participants are likely to receive multiple interventions and other medical treatments to manage the symptoms and the severity of their cancer through the period of this study. This reduces the ability to generalise the results to other services and locations, where participants may not receive multiple interventions, or the same interventions, as those who have participated in this study (Hissong, Lape & Bailey, 2015).

3.9.2.4 Reactive Effect

When a participant is aware that they are involved in an assessment, they may exhibit reactions, such as anxiety, that may hinder how they respond in the questionnaire or interview (Brink, van der Walt & van Rensburg, 2012). Controlling external factors that lead to these reactions is a means of combatting this.

Attempts were made to standardise the instruments used, the timing, and the environment of data collection.

In selecting a high-quality questionnaire, use of pre-existing, widely used, standardised assessments are preferred as they are often extensively researched and contain administration instructions, which adds to the validity and reliability of studies these measures (Drummond, 1996). For both the pre-test and post-test, the same outcome measures were used as part of the questionnaire. This aimed to reduce the threat to internal validity as standardisation was maintained (Brink, van der Walt & van Rensburg, 2012). The order of these outcome measures also remained the same and the same individual facilitated the measures in both the pre-test and post-test.

In addition to standardising the instrument, efforts were made to standardise the timing of data collection across all participants. Unfortunately, due to external factors including work and family commitments, holidays and hospital appointments, the data collection period for participants varied between 10 and 12 weeks post the initial meeting with the link worker.

The physical environment of data collection was maintained between pre-test and post-test. Though participants were offered the option of meeting the researcher at a place of their own choosing, all meetings with the researcher were held within the Trinity Health Centre in a quiet environment. The questionnaires were conducted in the presence of the researcher in order to allow for participants to clarify any question they did not understand, to avoid misinterpretation and maintain standardisation (Powell, 2014; Hissong, Lape & Bailey, 2015). It also reduced the risk of missing data and allowed the researcher to control factors that could impact the validity and reliability of the study (Powell, 2014).

3.9.2.5 Researcher Bias

The relationship between the researcher and the participant has the potential to influence the reaction or response of the participant, either positively or negatively (Hissong, Lape & Bailey, 2015). The researcher's role in the study was an important aspect to consider to reduce the threats to the reliability and validity of the study, including researcher bias.

Efforts were made to reduce the role of the researcher embodying the role of a second social prescribing link worker, as this may increase the risk of researcher bias and socially desirable responses.

To reduce a biased approach towards participants, a reflective journal was kept by the researcher. This allowed the researcher to reflect on her own experience of the research and was updated after each interaction with participants to maintain similar

interactions throughout. The use of the reflective journal also aided in documenting observations and environmental aspects when conducting the data collection.

The researcher also used careful observation skills by offering appropriate breaks, adapting the environment or providing encouragement to manage participant fatigue, loss of motivation and/or loss of concentration while completing the questionnaire.

3.9.3 Reliability

Like validity, reliability of a study impacts the trustworthiness of its results. Reliability refers to reproducibility of the study; a study is considered reliable if, when it is repeated, similar findings are produced (Keen & Otter, 2014). Reliability is considered particularly important within qualitative research. External reliability addresses the issue of whether two different researchers would arrive at the same final themes and theories within the same study setting; internal reliability refers to the extent to which other researchers, given a set of previously generated codes and constructs, would make them with interview data and field notes in the same way the original researcher did (Hissong, Lane & Bailey, 2015).

3.9.3.1 Participant Fatigue

Cancer-related fatigue is one of the most common symptoms of both cancer and its treatments, as outlined previously. Completion of four questionnaires in the pre-test, followed by engagement in conversation with the social prescribing link worker, may be difficult for some individuals, and answers may be affected if these challenges occur (Hissong, Lape & Bailey, 2015). Similarly, completing four questionnaires and engaging in a qualitative interview may present a challenge to any participant's concentration and energy levels. Careful planning of the questionnaires used, the utilisation of the environment, and the researcher's observations outlined above aimed to reduce this threat to reliability.

3.9.3.2 Test Environment

Changes in the environment from test to test can influence a participant's responses (Hissong, Lape & Bailey, 2015). Busy environments that are noisy or unfit for the purpose of completing both quantitative measures and interviews are likely to impact upon results. As outlined in section 3.9.2.4, both sets of quantitative measures and interviews took place in the same environments, minimising changes in the environment from test to test.

3.9.3.3 Differing Testers

People administering tests differ in a variety of ways, including their degree of enthusiasm, delivery of instructions, voice, personality and ability to handle the situation. The same subject may score differently on a test depending on who administers it. In this study, the same tester administered both the pre and post-test quantitative measures, in addition to the qualitative interviews, to address this challenge.

3.9.3.4 Social Desirability Responses

As this study utilizes both self-report measures and a qualitative interview format, it is possible that participants will attempt to appear “better,” or to offer more socially acceptable answers, for the benefit of the researcher, rather than true self-reflection (Hissong, Lape & Bailey, 2015). This is more likely to occur if a relationship between the researcher and the participant already exists (Hissong, Lape & Bailey, 2015), hence the distant role of the researcher, outlined in Section 3.9.2.5., is important to combat this threat.

3.9.3.5 Researcher status position

Clarifying the role and interaction of the researcher to the participants is an important facet of ensuring external reliability within a qualitative (or mixed methods) research design. This is due to the fact that different researchers will hold different social roles within a studied group, and begin with different knowledge bases about the studied group, therefore challenging the replicability of a study (Hissong, Lape & Bailey, 2015). The role of the researcher (and efforts made to standardise their role) was therefore outlined in 3.9.2.5.

3.9.4 Credibility

Credibility of the study involves confidence in the ‘truth’ of the findings, i.e. whether results of the study are believable (Polit & Beck, 2014). A number of strategies were used to promote credibility and are outlined below.

3.9.4.1 Use of established methods

First, well-established research methods were adopted where semi-structured interviews and questionnaires were used. Interviews and questionnaires are one of the most common methods of data collection within qualitative and quantitative healthcare research, respectively (Gill et al, 2008; Timmins, 2015). Well-validated standardised assessments were chosen for the collection of quantitative data in the study. The

interview guide was designed to explore the perspectives and experiences of the participants throughout each stage of the social prescribing process, while also exploring the participants' view of the changes to their health and well-being in a more subjective and detailed manner than that of the questionnaires. In this way, the strengths of the quantitative and qualitative strands of the study could be optimised.

3.9.4.2 Triangulation

Triangulation is the process of using different data collection techniques to study the same phenomenon. The use of mixed methods is considered to be a form of triangulation e.g. if both quantitative and qualitative data arrive at the same conclusion, there is an increased confidence that the results found are valid (Todd et al., 2004). Triangulation also compensates for the limitations and exploits the benefits of the individual methods used to collect data. The use of standardised quantitative measures, that provide objective information on outcomes, reduces the risk of the researcher unintentionally influencing the participants responses.

3.9.4.3 Honesty

Honesty was promoted in participants. All participants were given the opportunity to withdraw from the study at any stage and were reminded prior to initiating the interviews that there were no 'right' answers to any questions, and that the purpose of the study was to gather their true perspective of social prescribing. In this way, honesty was encouraged, thereby promoting credibility (Shenton, 2004). It should be noted that a trusting relationship between researcher and participant is another means by which to promote honesty and willingness to exchange information between participants, however this had to be carefully balanced with the distant role of the researcher that serves to promote validity within quantitative strands of mixed methods studies (Bradshaw, Atkinson & Doody, 2017).

3.9.4.4 Member Checking

Throughout the interviews, the researcher attempted to provide a summary of their understanding of participants points. This can be used as a means of promoting within-interview member checking where more rigorous methods of member checking may not be possible within a study.

One way of ensuring that a researcher has accurately interpreted the data, analyses, interpretations, and conclusions of a study is by conducting member-checks (Creswell & Poth, 2018). Lincoln and Guba (1985) claim that member-checks are "the most critical technique for establishing credibility" (p. 314). Member-checks within this study

were completed both during interviews and through the examination of transcripts (Creswell & Poth, 2018). Throughout the interview process, the researcher attempted to provide a summary of their understanding of a participants' points. After transcripts had been compiled, they were sent to participants for review. Due to time and resource limitations, it was not possible for participants to review preliminary analyses of descriptions and themes, though this would have been another means of increasing the credibility of the study's findings.

3.9.4.5 Peer Scrutiny

Peer scrutiny was sought throughout the duration of the study through regular supervision with the research supervisor, in addition to frequent consultation and discussion with independent researchers and academic peers.

3.9.5 Transferability

Transferability is concerned with the extent to which findings of a study can be applied elsewhere (Merriam, 1998). To promote replicability and transferability of a study, it is necessary to provide thorough description of the strategies and techniques used to collect and analyse data (Hissong, Lape & Bailey, 2015).

Thick description is a way of achieving transferability of qualitative and mixed methods research. By describing a phenomenon in sufficient detail, others can evaluate the extent to which the conclusions drawn are transferable to other times, settings and situations (Lincoln & Guba, 1985). In this study, descriptions were provided to explain the study context, including information regarding the social prescribing service, the link worker involved, and the processes involved within the social prescribing intervention. Description of the data collection and data analysis processes were provided, including inclusion and exclusion criteria of all participants, data collection methods employed, and the time period in which the data were collected, all outlined within this chapter (Pitts, 1994).

3.9.6 Dependability

Dependability demonstrates that should the study be repeated, in the same context with the same methodology and participants, similar results would be obtained. Since a qualitative researcher's perspective is naturally biased due to their close association with the data, sources and methods, various audit strategies can be used to confirm findings (Bowen, 2009). As noted previously, the use of standardised, objective

measures can be used to reduce the risk of researcher bias influencing the results of the study.

Furthermore, dependability can be increased through external auditing. This process involves introducing an individual external to the project to examine the narrative account and attest to its credibility (Creswell & Miller, 2000). The qualitative raw data were discussed regularly with the research supervisor to promote the validity of the interpretations in terms of themes and codes. Additionally, two academic peers completely external to the study were invited to independently code three anonymised transcripts as a means of peer review. These codes were compared against the researcher's own interpretation of the raw data to promote inter-coder reliability and reduce researcher bias.

In addressing dependability, the researcher described the research design and its implementation in-depth. Additionally, the process of data collection was described in detail in this chapter (Shenton, 2004).

3.9.7 Confirmability

Confirmability is the extent to which the study results are shaped by participants and not that of researcher motivation, bias or interest. The qualitative description approach used in data analysis is known for its transparency as the aim of this approach is to remain as close to the original data as possible (Bradshaw, Atkinson & Doody, 2017). A clear audit trail from raw data to final themes supported by verbatim quotes supports objectivity of results. The desired outcome of the audit trail is that another researcher could arrive at comparable conclusions given the same data and research context. Trustworthiness of interpretations and findings are dependent on being able to demonstrate how they were reached (Mauthner & Doucet, 2003). Confirmability in this study, therefore, was promoted through the methodology chapter and the appendices included in this thesis.

3.10 Ethical Considerations

Ethical behaviour is defined as the representation of a set of moral principles, rules or standards governing a person or a profession (Lichtman, 2013). Full ethical approval was sought and granted by St. James' Hospital Research Ethics Committee for this study. A number of ethical issues were considered and are outlined below, including informed consent, confidentiality, and secure data storage.

3.10.1 Informed Consent

Informed consent is an important element in research involving human participants (Matthews & Kostelis, 2011). The principle of informed consent refers to providing participants with enough information to make an informed decision about whether they will participate in the study or not (Workman & Kielhofner, 2006). In this study, clear and concise information leaflets and consent forms were designed to ensure that they were accessible and easy to understand.

Participant information leaflets contained details about the purpose of the study, what participants would be asked to do and how the information would be used and stored (appendix 5). Participants were provided with contact details for the researcher so they could ask questions or gather further information. Participants were informed that they were entitled to withdraw from the study at any time.

Written consent was obtained in the first meeting with the researcher. On meeting participants for the first time, the researcher reviewed the details of the study with the participants to ensure they understood what they were asked to do and the purpose and methods of the research. Participants were then asked to sign a consent form in the presence of the researcher (appendix 6). Both the participant information leaflet and consent form were designed in compliance with the European Union General Data Protection Regulations (GDPR) (GDPR, 2018).

3.10.2 Confidentiality and anonymity

Confidentiality is broadly defined as (i) not disclosing information provided by an individual to others, and (ii) presenting results in a manner that ensures a participant cannot be identified by anyone other than the research team (Wiles et al., 2008). Participants should have complete anonymity i.e. it should be impossible to link any information back to individual participants (Matthews & Kostelis, 2011). There is a challenge in maintaining participant confidentiality when managing rich accounts in qualitative research (Kaiser, 2009). Internal confidentiality, known as deductive disclosure, can occur when the traits of individuals or groups make them identifiable in report (Tolich, 2004). While confidentiality cannot be guaranteed, several efforts were made to reduce any connection between participant and response. This involved the removal of any information that might link the participant to their respective hospital or Dublin postcode area, e.g. hospital names, street names, major landmarks. Additionally, names of services attended or individuals working in those services or

activities were removed. Finally, participants were provided with numbers in place of their names for alternative identification.

Data storage is another issue related to confidentiality (Matthews & Kostelis, 2011). All data must be protected to maintain the integrity of the research and to protect the identities of participants (Workman & Kielhofner, 2006). Electronic data from this study was stored on a password protected computer in Trinity College Dublin. All hardcopies were stored in filing cabinets in a locked office.

3.11 Chapter Summary

In this chapter, the mixed methods study design has been outlined. The rationale for and processes of data collection and analysis for both phases of the study, qualitative and quantitative, have been described. Ethical considerations were described. The findings from both phases of the study will be outlined in the following chapters.

4. Quantitative Results

4.1 Introduction

This chapter presents the quantitative findings of this study. The recruitment, attrition and demographics of study participants are provided in section 4.2. The analysis of the four outcome measures used in this study are presented in sections 4.3, 4.4, 4.5 and 4.6, respectively.

The aim of this research study was to examine the impact of a social prescribing service on the quality of life, mental health, fatigue and activity participation levels of individuals living with and beyond cancer. The spread of data was analysed to assess normality, however, as the data in this study did not meet the requirements for parametric testing of a sufficiently large sample (Pallant, 2016) non-parametric tests were conducted. To test whether social prescribing had a significant impact on the median scores for participants on any given measure, Wilcoxon Signed Rank Tests were used. The significance level is equal to or less than .05.

4.2 Participant Data

A total of 563 participants met the inclusion criteria for the study and were given a participant information leaflet inviting them to contact the researcher for further information. A total of 43 participants were recruited to the study and completed the baseline measures. This indicates that 520 individuals were invited to take part in the study and declined, however, it is important to note that the level of information offered to individuals varied between sites and interactions.

4.2.1 Recruitment Challenges

Healthcare professionals based within St. James' Hospital acted as primary gatekeepers to the study. Though the researcher attended outpatient clinics regularly, to maintain compliance with GDPR guidelines, they did not complete chart reviews to identify potential participants, nor did they approach individuals without prior consent. Healthcare professionals working within the clinics, including nurses and medical staff, instead were given participant information leaflets and, as and when possible, approached individuals with these leaflets. The researcher endeavoured to be present to answer any further questions individuals may have about the study and to offer further information, however, most of the information was delivered to individuals

second-hand or – when clinics were very busy – through the participant information leaflet alone.

This presented a significant limitation to the level of understanding the individual may have had about the study. It also limited the ability to identify potential reasons why the individual did not want to participate in the study.

In an attempt to increase recruitment, fliers advertising the study and inviting participants to contact the researcher were also placed on notice boards within the clinics, the cancer support services and the GP practices (Appendix 15).

Regarding other recruitment sites, such as GP Practices and Primary Health Care Centres, due to limited buy-in and engagement from these sites, it was not possible to record the number of participants who were referred to the study by healthcare professionals, or to know how many individuals were given leaflets within these practices.

The cancer support service placed fliers on the notice board and the researcher was permitted to speak at the beginning of some activities including yoga and mindfulness, however, the nature of the service is that it is mostly the same individuals attending the service within a certain time period, therefore limiting the effectiveness of this recruitment strategy.

Overall, therefore, participants who were considered to have “declined” the study (i.e. 520) are those who either spoke to a healthcare professional within the acute hospital setting regarding the study (though it is unknown for how long or to what level of detail) or were known to have been given a participant information leaflet by a healthcare professional or administrator. This information was reported to the researcher throughout the study and monitored, however, it is difficult to confidently quantify the level of detail that was offered to individuals regarding the study.

Healthcare professionals advised the researcher that some individuals they spoke to regarding the study reported they were already engaging in activities, felt they were too busy with family or work commitments, were limited by health-related challenges including mobility, or simply had a lack of interest. Future research exploring the reasons why cancer survivors may decline to participate in social prescribing would be of extreme value to identify whether social prescribing is an acceptable intervention for individuals living with and beyond cancer.

Challenges to recruitment and the reduced ability to quantify the level of information delivered to potential participants, nor the number approached, are both considered limitations of the study and are discussed further in Chapter 6.

4.2.2 Recruitment Success

The number of participants recruited from each site is outlined in table 4-1.

Table 4-1 Recruitment sites

Recruitment Site	Frequency	Percentage
Outpatient Oncology Clinics	28	66
Oncology Day Ward	4	9
Cancer Support Service	4	9
Participant Information Leaflets in the Community	3	7
GP Practices	2	5
Primary Care Services	1	2
Hospital Staff Referral	1	2
Total	43	100

The two most successful recruitment sites were based in St. James's Hospital. Most participants ($n=28$) were recruited from the outpatient oncology clinics that were attended several times a week by the researcher, and secondarily, the oncology day ward ($n=4$) in the hospital. Participants were also recruited from a local cancer support service ($n=4$) and through participant information leaflets placed in libraries and community centres ($n=3$). Two participants were referred from GP practices. One participant was successfully recruited by the occupational therapist in a local primary care service and another participant was recruited by a member of hospital administrative staff who was aware of the study. An overview of recruitment and drop-out rates is presented in Figure 4-1.

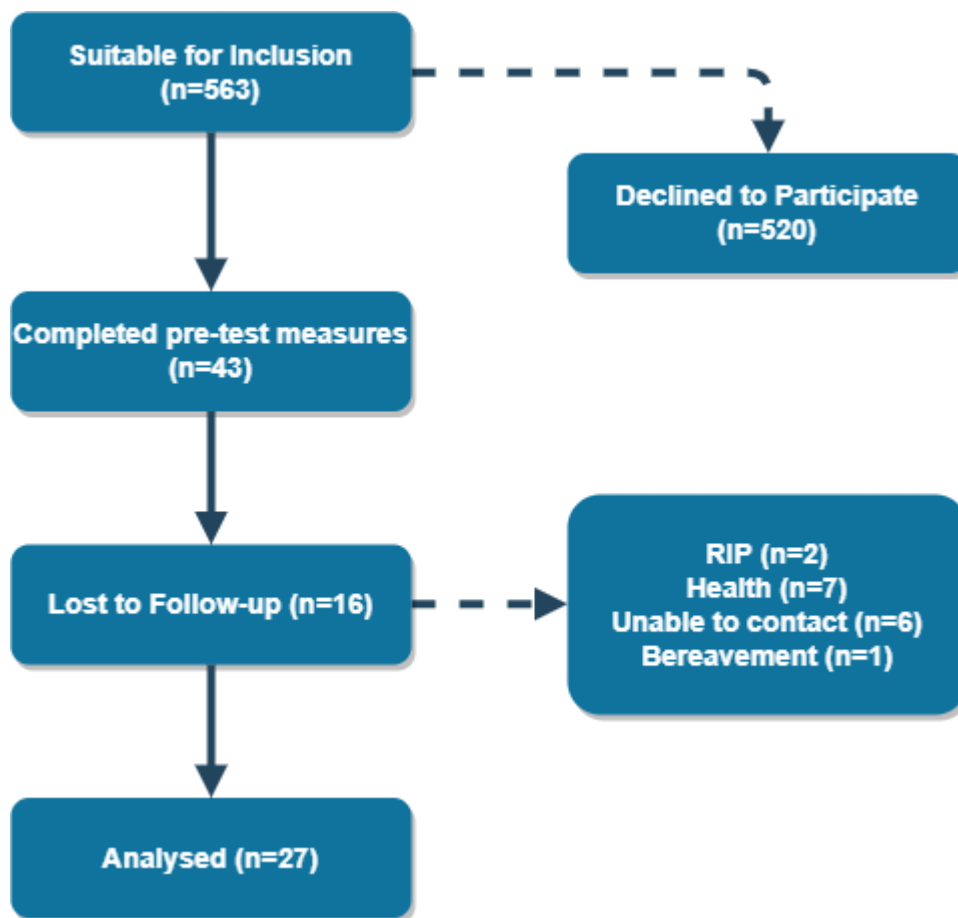


Figure 4-1 Flowchart of recruitment process and attrition rate

Sixteen participants (37%) were lost to follow-up. Two participants passed away during the study, seven withdrew due to health reasons, five participants were unreachable, one withdrew due to family commitments and one participant withdrew due to a family bereavement. A table outlining the reasons for participant drop-out is provided in Appendix 12.

4.3 Demographics

The demographics of the twenty-seven cancer survivors who completed both pre and post intervention measures and follow-up interview will be presented below.

Nineteen (70%) were female and eight (30%) were male. The mean age of the sample was 57 years (SD 16.39). Ages of participants ranged from 23 to 85 and are displayed in figure 4-2.

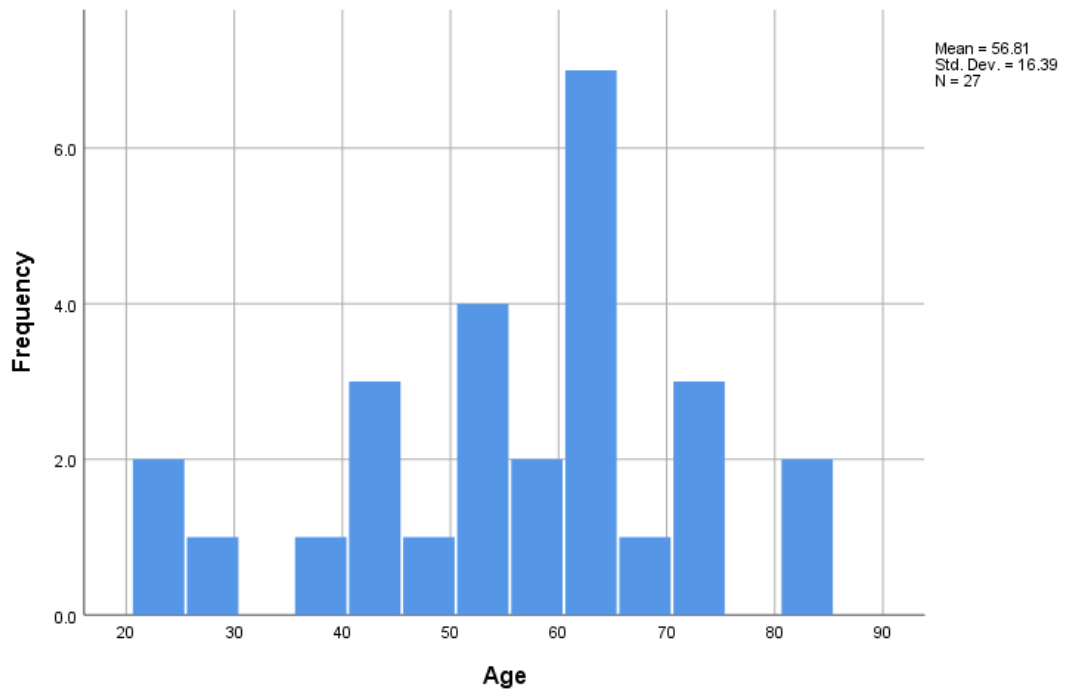


Figure 4-2 Histogram of age

4.3.1 Family and Home life

The majority of participants ($n=15$, 56%) were living with at least one member of their family, while the remainder ($n=12$, 44%) lived alone. Thirteen participants (48%) were married (Figure 4-3).

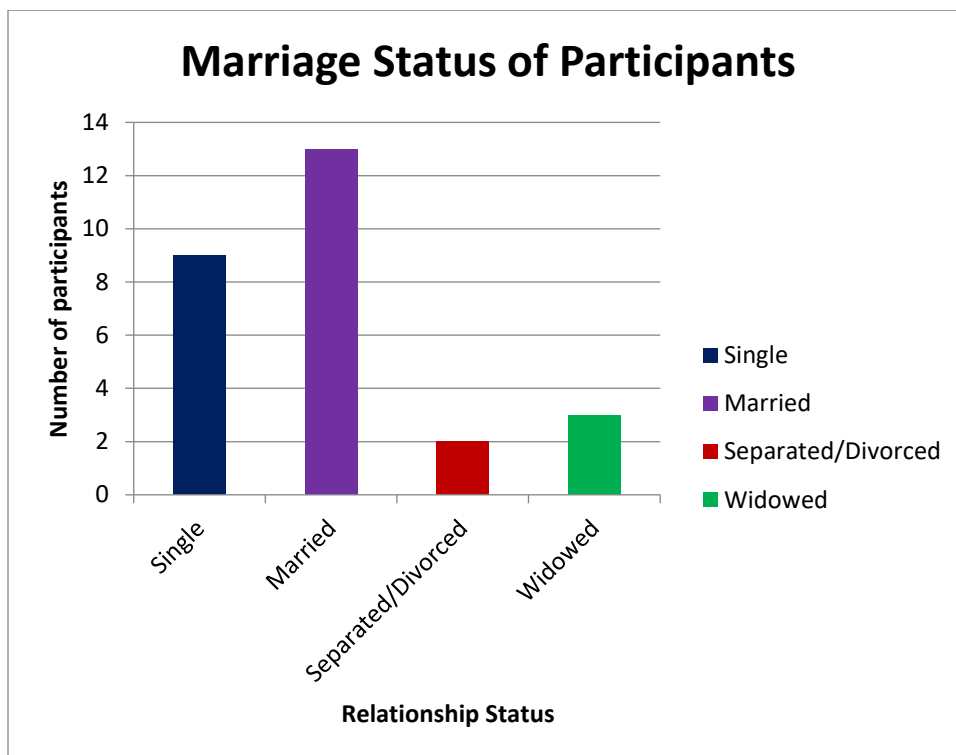


Figure 4-3 Marital status

4.3.2 Education

The majority of participants ($n=12$, 44%) had attended third level education (college or university), while a minority had left education after completing primary school ($n = 4$, 15%).

Table 4-2 Level of education

	Frequency	Percentage
Primary School	4	15%
Junior Certificate	6	22%
Leaving Certificate	5	19%
College/University	12	44%
Total	27	100%

4.3.3 Employment

Nineteen participants were not working at the outset of the study. Nine participants reported they were retired, eight were not currently working due to their cancer and two participants were not working due to other reasons. Three participants were working part-time and five were in full-time employment.

4.3.4 Cancer diagnoses

Nine different cancer types were reported (Figure 4-4). Breast cancer (n = 12, 44%) was the most common type of cancer diagnosis, both overall and among females, while bowel cancer (n = 3, 11%) was the most common among males.

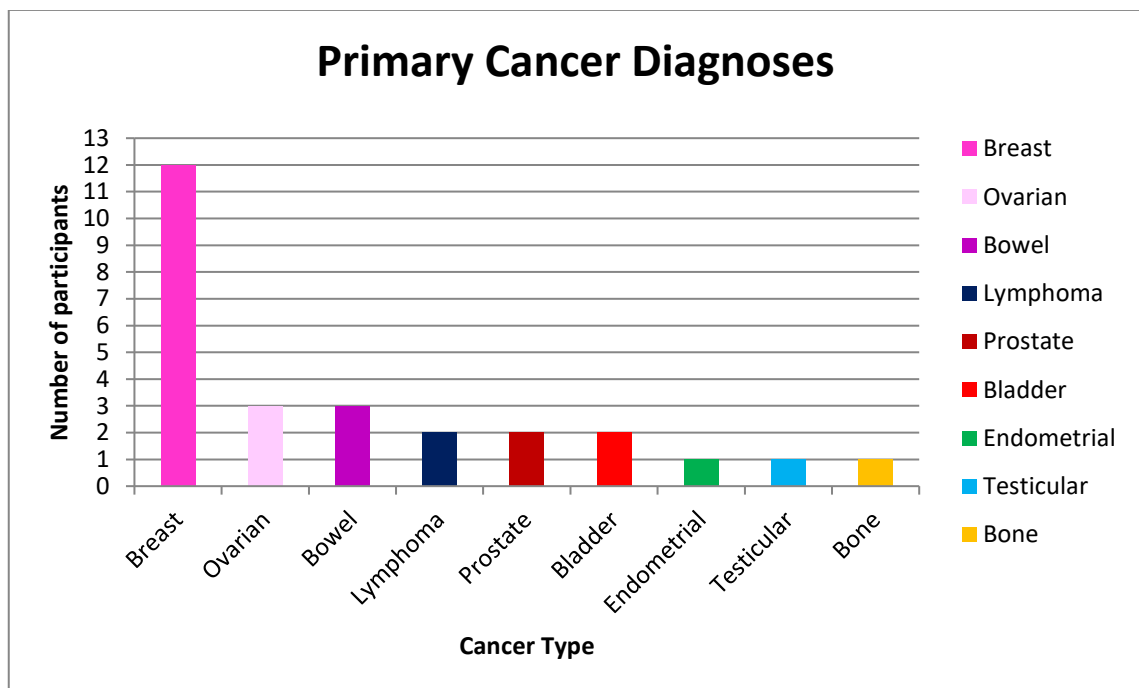


Figure 4-4 Frequency of primary cancer diagnoses

Participants were asked to indicate when they had first received their primary cancer diagnosis (Table 4-3). Most participants (n=8, 30%) had received their cancer diagnosis within the previous year of the initial interview, with a time range of two months up to eight years.

Table 4-3 Time since primary cancer diagnosis

	Frequency	Percentage
<1 year	8	30%
1-2 years	5	18%
2-3 years	5	18%
3-4 years	1	4%
4-5 years	3	12%
5+ years	5	18%
Total	27	100%

4.3.5 Cancer Treatments

Most participants (n=20, 74%) had received more than one type of cancer treatment and several participants (n=6, 22%) had received all four listed treatments: chemotherapy, radiotherapy, surgery and hormone therapy. Chemotherapy was the most common type of treatment received (n=21, 78%), followed by surgery (n=17, 63%), radiotherapy (n=13, 48%) and hormone therapy (n=9, 33%). One participant had yet to begin treatment at baseline.

4.3.6 Activity involvement prior to study

Participants were asked if they were attending any community activities prior to commencement of the study. Twelve participants (44%) reported that they were participating in a community activity (Table 4-4).

Table 4-4 Activities attended prior to social prescribing

Activity Type	Frequency	Percentage
Cancer Support Service	3	11%
Arts, crafts & music	3	11%
Physical activity	2	7%
Volunteering	2	7%
Relaxation-based	1	4%
Education	1	4%
None	15	56%
Total	27	100%

4.4 Intervention Data

It is important to provide information around the number of interactions participants had with the social prescribing link worker, in addition to the types of activities that were attended, and how frequently, to enhance replicability of future studies.

4.4.1 Interactions with the link worker

As noted within the literature review, social prescribing services typically offer up to six sessions or interactions with the social prescribing link worker, either in person or by telephone follow-up (Kimberly, 2013). For the purposes of this study, there was no set limit placed on the number of interactions offered to participants, as it was important to work on the basis of need to establish what level of social prescribing input is optimal for cancer survivors. As such, across the sample of 43 participants who completed the pre-intervention measures, participants interacted with the link worker between 1 and 15 times by phone or in person, with an average of 4.9 interactions.

It should be noted that the participant who received only one interaction unfortunately became unwell early into the study and withdrew before they could be given further input; the participant who had fifteen interactions had been struggling with ongoing mental health difficulties and received a high level of input from the social prescribing link worker as a result, before ultimately withdrawing from the study. Excluding these participants, the number of interactions ranged from 3 to 9 across 41 participants.

Of the sample of 16 participants who withdrew from the study prior to engaging in the post-intervention measures and qualitative interview, the average number of interactions with the link worker was 5.2. The number of interactions per participant lost to follow-up is presented in Appendix 12.

Of the sample of 27 participants who engaged in both the pre- and post-intervention measures and completed the qualitative interview, the average number of interactions with the link worker was 5.3. The number of interactions per participant who completed both pre- and post-intervention measures is presented in Appendix 13.

Therefore, there was no discrepancy in the average number of interactions between individuals who withdrew from the study and individuals who completed both the pre-test and post-test measures.

4.4.2 Engagement with activities and community assets

Participants were asked to record the number of times they had attended an activity. Efforts were made to monitor the frequency of engagement in the chosen activity throughout the social prescribing process, as it was anticipated participants may not have a clear recollection of their attendance at the end of the process when they returned for interview.

It is not possible to know the exact content and intensity of each activity attended by participants as they were not facilitated by the link worker nor the researcher. This is a limitation of the study and reduces the ability for the study to be replicated, however attempts were made to gather this data through discussion with the participants as they attended the activities. This information is presented in Appendix 14.

The information provided is based on the 27 participants who completed both the pre- and post-test measures, as well as the qualitative interview, as this data was confirmed at the final data collection point.

4.5 Outcome Measures

Four outcome measures were used for pre- and post-intervention data collection: the European Organisation for Research and Treatment of Cancer Quality-of-life Questionnaire Core 30 (EORTC QLQ-C30), the Hospital Anxiety and Depression Scale (HADS), the Frenchay Activities Index (FAI) and the Multidimensional Assessment of Fatigue (MAF).

4.5.1 EORTC QLQ-C30

All four category scores of the EORTC QLQ-C30 (Global Health Status, Function, Presence of Symptoms and Summary Score) were analysed using Wilcoxon Signed Rank Tests for significance of score change between baseline and follow-up. These categories include the Global Health Status Score, the Functional Quality of Life Score, the Presence of Symptoms Score and the EORTC Quality of Life Summary Score.

The Global Health Status score summarises global quality of life according to two quality of life scales. The Functional Quality of Life score includes five domains: physical, role, emotional, social and cognitive. The Presence of Symptoms score assesses the presence of symptoms across nine domains: fatigue, nausea/vomiting, pain, dyspnoea, insomnia, appetite loss, constipation, diarrhoea and financial difficulties. The EORTC Quality of Life Summary Score comprises all fourteen sub-domains and the global quality of life score combined.

Increases in the scores of the Global Health Status, Functional and EORTC Summary Scores indicate a greater quality of life; increases in the Presence of Symptoms score indicate a greater presence of symptoms, and therefore a lower quality of life. Table 4-5 displays the results of the Wilcoxon Signed Rank tests that were performed on these categories.

Table 4-5 Comparison of changes in median (interquartile range) of EORTC category scores at baseline and post-intervention follow-up

	Baseline (n=27) Median (IQR)	Post- Intervention (n=27) Median (IQR)	Change in Median	p-value
EORTC Global Health Status Scores	66.67 (33.33)	75 (16.66)	8.33	0.5
EORTC Functional Scores	75 (23.66)	90.33 (15.33)	15.33	<u><0.001</u>
EORTC Symptom Scores	16.05 (17.91)	15.43 (12.96)	-0.62	0.431
EORTC Summary Scores	80.32 (20.16)	85.87 (14.92)	7.26	0.18

A Wilcoxon Signed Rank Test revealed no statistically significant changes between baseline and follow-up in:

- the Global Health Status score of participants ($z = -1.960$, $p = 0.5$)
- the Symptom score ($z = -0.787$, $p = 0.431$)
- the Summary score ($z = -2.375$, $p = 0.18$)

There was, however, a **statistically significant improvement** in the functional quality of life of cancer survivors following participation in social prescribing ($z = -3.485$, $p = <0.001$).

4.5.2 Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) is used to identify levels of anxiety and depression through two subscales: Hospital Anxiety and Depression Scale-Anxiety (HADS-A) and Hospital Anxiety and Depression Scale –Depression (HADS-D), respectively. The scores on both subscales can be classified under ‘normal’, ‘borderline cases’ and ‘clinical case’ levels of anxiety and depression. Scores less than 8 are categorised as *normal*, scores of 8-10 as *borderline case* and scores of 11-21 as *clinical*. Therefore, lower scores on both the HADS-A and HADS-D scales indicate lower levels of anxiety and depression, respectively. Table 4-6 presents the frequencies and percentages of participants within each category for both the HADS-A and HADS-D at baseline and follow-up.

Table 4-6 Frequency of HADS categories at baseline and post-intervention follow-up

	HADS-A Baseline	HADS-A Post- Intervention	HADS-D Baseline	HADS-D Post- Intervention
Clinical Case Category	(n=27) n (%)	(n=27) n (%)	(n=27) n (%)	(n=27) n (%)
Normal	13 (48%)	18 (67%)	22 (81%)	24 (89%)
Borderline	6 (22%)	6 (22%)	4 (15%)	1 (4%)
Clinical Case	8 (30%)	3 (11%)	1 (4%)	2 (8%)

There was a general decrease in levels of anxiety within the sample, with a decrease of clinical cases from eight people (30%) at baseline to three (11%) at follow-up. Additionally, an increased number of participants were within the *normal* category of the HADS-A subscale at follow-up, with a change from 13 (48%) people to 18 (67%).

There was a general decrease in levels of depression across the sample, with an increase in *normal* cases from 22 (81%) to 24 (89%). Although there was an increase of one participant (4%) in *clinical* cases of depression detected at follow-up, those in the borderline category fell from four (15%) people to one (4%).

Table 4-7 presents the changes in median scores of both the HADS-A and HADS-D subscales between baseline and follow-up.

Table 4-7 Comparison of changes in median (interquartile range) of HADS-A and HADS-D subscales at baseline and post-intervention follow-up

	Baseline (n=27) Median (IQR)	Post- Intervention (n=27) Median (IQR)	Change in Median	p-value
HADS-A Scores				
	8 (8)	5 (6)	-3	0.099
HADS-D Scores				
	5 (5)	2 (4)	-3	<u>0.025</u>

While there was not a statistically significant change detected in the HADS-A subscale ($z = -1.648$, $p = 0.099$), there was a statistically significant reduction in median scores of depression detected on the HADS-D subscale between baseline and follow-up ($z = -2.243$, $p = 0.025$).

4.5.3 Frenchay Activities Index

The Frenchay Activities Index assesses the activity participation levels of individuals across three categories: domestic activity, leisure and work, and outdoor activities. An overall Total Activity Participation score can also be calculated, with cut-off scores indicating whether the individual is considered inactive (0-15), moderately active (16-30) or very active (31-45) (Monteiro et al., 2016). An increase in scores indicates greater levels of activity participation. Table 4-8 presents the frequencies and percentages of participants who fell into each category at baseline and follow-up.

Table 4-8 Frequency of FAI Total Activity Participation score categories at baseline and post-intervention follow-up

	FAI Total Activity Participation Baseline (n=27)	FAI Total Activity Participation Post-Intervention (n=27)
Activity Level Category	n (%)	n (%)
Very Active (30-45)	15 (55.6%)	22 (81.5%)
Moderately Active (16-30)	11 (40.7%)	5 (18.5%)
Inactive (0-15)	1 (3.7%)	0 (0%)

In general, there was an increase in total activity participation levels following social prescribing intervention. The number of individuals within the *inactive* category dropped to zero and the number of individuals within the *very active* category increased by 25%, from 15 participants to 22.

Analysis was conducted comparing the medians of FAI scores from baseline to post-intervention follow-up. Table 4-9 presents the medians, interquartile ranges and p-values across all four categories.

Table 4-9 Comparison of changes in median (interquartile range) of the FAI activity participation subscales at baseline and post-intervention follow-up

FAI Subscales	Baseline (n=27) Median (IQR)	Post- Intervention (n=27) Median (IQR)	Change in Median	p-value
Domestic	13 (4)	14 (3)	+1	0.317
Leisure and Work	8 (2)	10 (3)	+2	<u>0.001</u>
Outdoors	11 (2)	11 (2)	0	0.282
Total Activity Participation	32 (6)	35 (6)	+3	<u>0.005</u>

There were improvements in activity participation levels across almost all categories, excluding outdoor activity participation scores ($z = -1.076$, $p = 0.282$) which remained static. The Domestic activity participation scores ($z = -1.00$, $p = 0.317$) increased slightly, but did not demonstrate statistically significant change.

The changes in Leisure & Work participation levels were found to be statistically significant ($z = -3.255$, $p = 0.001$). There was also a statistically significant increase in the FAI Total Activity Participation score ($z = -2.427$, $p = 0.005$).

4.5.4 Multidimensional Assessment of Fatigue

The Multidimensional Assessment of Fatigue (MAF) assesses a responder's level of fatigue across three subscales: fatigue severity, distress related to fatigue, and the interference of fatigue in activities of daily living (ADLs). A higher score across all categories suggests greater levels of fatigue, distress related to fatigue and interference of fatigue in activities of daily living. Additionally, an overall score referred to as the Global Fatigue Index can be calculated, where a higher score indicates a greater presence of fatigue.

Table 4-10 displays the changes in the medians of each of these categories, as calculated by a Wilcoxon Signed Rank test.

Table 4-10 Comparison of changes in the median (interquartile range) of the MAF subscales at baseline and post-intervention follow-up

	Baseline (n=27) Median (IQR)	Post-Intervention (n=27) Median (IQR)	Change in Median	p-value
Fatigue Severity	5 (3.50)	4 (4)	-1	0.109
Distress caused by Fatigue	4 (5)	2 (3)	-2	<u>0.045</u>
Interference of Fatigue in ADLs	3.11 (4)	2 (2.40)	-1.11	0.209
Global Fatigue Index	24.56 (19.80)	17.89 (16.41)	-6.67	0.118

There were improvements across all three subscales of the MAF and within the global fatigue index score. Though the changes for the fatigue severity ($z = -1.603$, $p = 0.109$), interference of fatigue in activities of daily living ($z = -1.257$, $p = 0.209$) and the global

fatigue index ($z = -1.562$, $p = 0.118$) were not statistically significant, there was a statistically significant reduction in the distress related to fatigue subscale ($z = -2.002$, $p = 0.045$).

4.6 Summary

Twenty seven individuals living with and beyond cancer completed four outcome measures to detect if there was a statistically significant change in a range of domains encompassing quality of life, levels of anxiety and depression, levels of activity participation and levels of fatigue following engagement in social prescribing. Statistically significant outcomes were reported in five domains: the EORTC QLQ-C30 Functional Quality of Life subscale, the HADS Depression subscale, the FAI Leisure & Work subscale, the FAI Total Activity Participation score and the MAF Distress Related to Fatigue subscale. While there were not statistically significant outcomes detected in the remaining outcomes, scores generally improved across each of the scales between baseline and follow-up, with the exception of the EORTC Symptom scale and the FAI Outdoor activity participation scale. The next chapter will report on the qualitative findings of this study.

5. Qualitative Findings

5.1 Introduction

The purpose of the qualitative phase of the study was to explore participants' perspectives and experiences of social prescribing and activity engagement, and to explore the acceptability of a social prescribing service for individuals living with and beyond cancer. A profile of participants will be presented, followed by the main themes emerging from analysis of the qualitative interviews.

5.1.1 Participant Profile

Twenty-seven individuals completed the post-test measures and semi-structured interviews exploring their perspectives and experiences of social prescribing and activity engagement. The demographics of these participants were presented in Chapter 4. Contextual information can support the transferability of results.

5.2 Key Themes and Sub-Themes

Three key themes emerged from data analysis and were comprised of a number of sub-themes. An introduction will be provided for each key-theme, followed by a brief explanation of each sub-theme, supported by verbatim extracts. The structure of themes and sub-themes that emerged are presented in Figure 5-1.

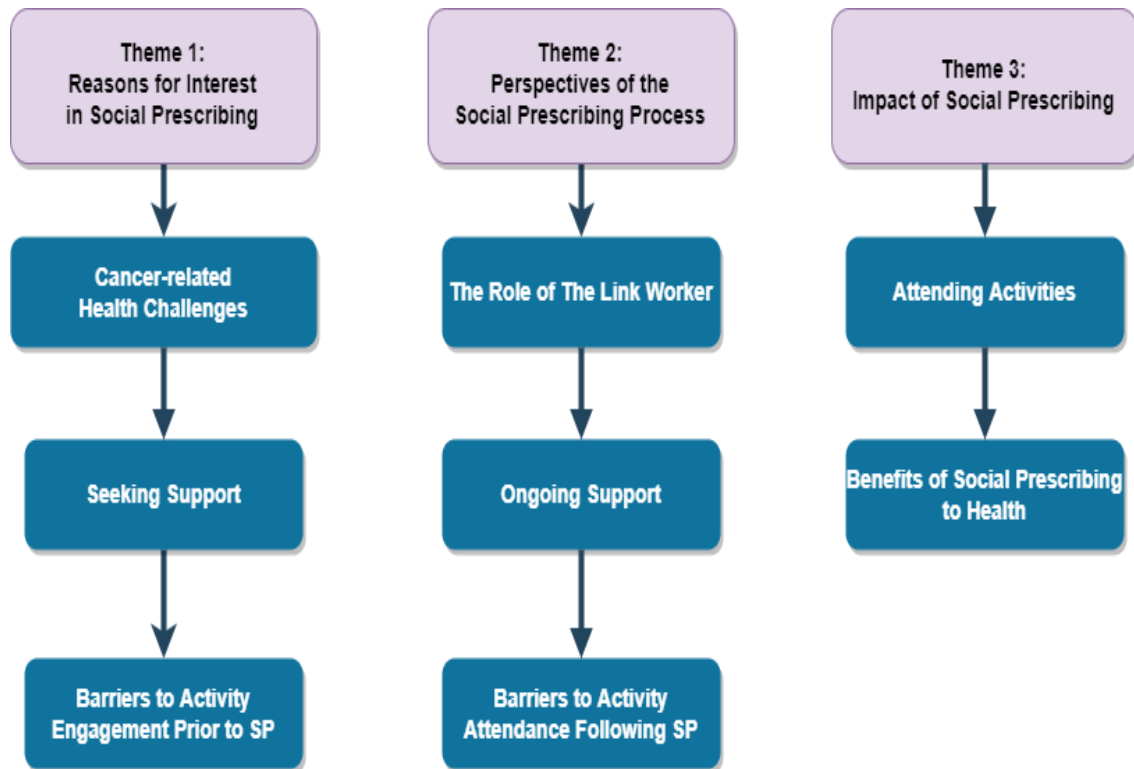


Figure 5-1 Main Themes and Sub-Themes

5.3 Reasons for Interest in Social Prescribing

Cancer survivors reported a variety of reasons for wanting to engage in social prescribing. These included cancer-related health challenges they were hoping to overcome; seeking support to manage their health in the absence of support from the hospital post-treatment; looking for an opportunity to socialise and meet more people; and hoping to overcome previous barriers to activity engagement.

5.3.1 Cancer-related health challenges

Cancer survivors described some of the cancer-related health challenges and continuing symptoms they were experiencing.

Fatigue was the main issue reported by participants. Participants described how they were trying to learn how to manage their fatigue but that it negatively impacted their ability to participate in social leisure activities.

“The fatigue was a big thing. Definitely it’s been like one of the most prominent things in my life, physically, since my diagnosis.” (P43)

“I have a lot of friends but I find it difficult to connect and say ‘let’s meet’ because again that requires previous arrangement and I don’t know, maybe I agree with a friend to meet her in four days and then I’m tired.” (P38)

Some participants reported additional challenges with sleep quality and experiences of insomnia, which they perceived to exacerbate the frequency and severity of their fatigue.

“My biggest learning has been fatigue, I never really understood fatigue before I’ve actually experienced it first-hand. And then insomnia as well that I suffer from doesn’t really help with the fatigue. So again just I suppose having to learn to listen to my body and learn what my abilities are and how much you’re capable of.” (P19)

“I was so tired last night because I hadn’t slept the night before. That’s a different story all together. Sometimes my sleep is shocking.” (P29)

Two participants spoke about cognitive challenges they’d been experiencing since their treatment, particularly in relation to their memory. Experiencing these cognitive and memory challenges negatively impacted their confidence and activity participation as a result.

“It’s a strange one to call because some of the symptoms that I have like memory and stuff like that I don’t know if that’s specifically associated with the treatment or if it’s just because I’m getting old.” (P2)

“An issue I’d have to address would be lack of professional confidence. Because where I was at in my game, in my profession,

versus struggling to even remember stuff now, how could I chair meetings at the executive level I was at?" (P19)

Six participants reported having a history of clinical depression and/or anxiety, or other mental health challenges. One participant suggested that his challenges with depression and anxiety may have been linked to his cancer diagnosis.

"I have had issues with depression and anxiety. Whether that's from the cancer, I don't know but I have no doubt it has a certain role to play in it. I don't think there's any doubt on that." (P43)

Fear of cancer recurrence was reported by participants as having an impact on their quality of life. Participants described feelings of anxiety around symptoms and fearing that common symptoms such as '*a pain or ache*' (P35) might signify a deterioration in their health.

"It just leaves you that if you've a pain or ache, the first thing you think is, 'Oh, is the cancer back?' But it's just your mind." (P35)

"The fear, oh my god, the terror of it coming back. That stayed with me a long, long time after the treatment was finished." (P40)

Participants spoke about how they felt their cancer could sometimes leave them feeling socially isolated and misunderstood. For some, it could be difficult to relate to individuals who had not received a cancer diagnosis. One participant described how they believed talking about cancer with others could cause the person they were speaking with to feel fearful:

"Because I find with the cancer, when you stop and you talk to people, you want to talk about your cancer but it puts fear into people I think. That's the way it was coming across to me." (P37)

5.3.2 Seeking Support

Cancer survivors discussed a perceived lack of support from the hospital following treatment and how they used voluntary cancer support services to fill this support gap.

Several participants ($n=6$) described a lack of hospital support following the end of their treatment. Though they had received medical care and attention throughout their treatment, participants described expectations that there would have been "*more support available*," (P2) after treatment. Participants expected more support in returning to "*normal living*" (P19) after treatment had finished.

“I received fantastic medical support when I was sick but this whole social side of actually just getting you back to normal living and being active for my age and the fitness level that would be deemed healthy for you, you know those supports just seemed to be totally inadequate.” (P19)

There could be long gaps between follow-up medical appointments once treatment had finished. This could make it challenging for some participants, who were left unsure of how to manage their health in between appointments.

“I always found the support wasn’t there for me after I was finished treatment. It was like, ‘off you go now, see you in a year,’ or whatever it was for your next appointment. It’s kind of scary when you finish and you are like, ‘What do I do now?’ There was never follow-up. There was never that kind of self-care looking after yourself. That was never part of your treatment.” (P29)

For some cancer survivors ($n=6$), community-based voluntary cancer support services provided them with support through their diagnosis and treatment prior to their involvement with social prescribing. These third-sector voluntary cancer support services offered counselling services, yoga and mindfulness classes, reflexology and peer support groups specifically targeted towards individuals living with and beyond cancer. These services benefitted cancer survivors by reducing stress related to cancer and offering them somewhere to meet other cancer survivors for peer support. For example, one participant (P14) described how the yoga classes offered in the cancer support service were, *“as much a counselling session, it all dealt on relaxation.”* Another participant described how a stress management class facilitated in the cancer support service offered a safe space to discuss her anxieties:

“The service helped manage my anxiety specifically around the cancer diagnosis. In the stress management classes there was a forum for discussing your anxieties in a very safe group. And the counsellor was trained specifically in dealing with anxieties and problems, and stresses that arise from a cancer diagnosis. So I felt I was in very good hands and that was invaluable to me at the time.” (P5)

Some participants ($n=2$) reported that they had never been offered information about cancer support services but would have probably engaged with these services if they had been made aware of them.

“I would have probably used the cancer support services if I knew about them as a bit of a backup support. The family were great but it’s hard for them because they wouldn’t have known what you were going through.” (P25)

While cancer support services offered support to a number of participants in the early stages of treatment and diagnosis, participants described how over time, as treatment progresses and favourable outcomes are achieved, the need for cancer-specific social support lessens, and that they would prefer to attend activities away from the cancer support services.

“Because I had that backup from [cancer support service] you know what I mean, that had cancer or was dealing with someone who had cancer. So I really didn’t need that you know what I mean.” (P16)

Several participants ($n=5$) were aware of cancer-specific support services but chose not to avail of them. There were a number of reasons reported for this, including that the support offered from family and friends was sufficient, that they didn’t think they needed the support at the time, or that availing of these services reminded them that they had a cancer diagnosis, which they struggled to accept.

“I definitely didn’t avail of any supports. It was something I figured was best to combat on my own, which probably wasn’t the best thing. I definitely think I got through it quite well but there were probably counselling services and whatnot that I should have availed of that I didn’t. Out of stubbornness maybe, I don’t know.” (P43)

Another participant described how she had found the cancer support service beneficial for “*solo activities*,” such as counselling or acupuncture, but preferred to attend group activities in non-cancer-specific settings in the community.

“I actually went to counselling. And I had acupuncture and a few different things. But I never wanted to sit in a support. And then I went into the group choir but that wasn’t based around cancer. ” (P39)

Cancer survivors spoke about their identity as “*cancer patients*,” (P5) and how this was linked to the cancer support services they were availing of. One participant described how she did not want to attend her local cancer support service as she found it difficult to accept her diagnosis.

“The mere fact of going in through the door said to me, ‘oh yeah, you have cancer, you know that don’t you?’ Now nobody said that, it was in my head, talking to myself. I didn’t like the idea of that.” (P9)

Other participants reported that they didn’t feel the needed to attend cancer support services as he had support from his family members at home, each of whom had received a previous cancer diagnosis.

“I kind of grew up around a lot of cancer. My, brother and my sister and my mum all had it so we’re able to support each other. We’ve literally all been there. So I didn’t really feel I needed the cancer service.” (P31)

Whether cancer survivors had engaged with cancer support services or not, they described having an interest in social prescribing as means of meeting other needs. Though they found the support offered by cancer-specific services beneficial, they also highlighted there was a benefit in engaging with non-cancer-specific, “*mainstream*,” (P14) services.

“It is lovely to go someplace where you meet other people that are going to treatments that are losing their hair and everybody gives each other advice but you don’t need that every day. You need something mainstream. I couldn’t say one is better than the other but they complement each other. Because there’s more a social aspect where it’s not just cancer people that you get to know so that’s important too.” (P14)

5.3.3 Barriers to Activity Engagement Prior to Social Prescribing

Participants revealed some of the previous challenges they had faced in attending chosen activities.

Participants found it difficult to identify activities that were both affordable and fit into their schedules. One participant described finding it difficult to identify an activity that was both affordable and scheduled at a time of day when she was not fatigued:

“Anything that I found locally was kind of expensive, like 10, 15 quid a go for a class. I was wondering how can I attend activities when I have financial constraints? And most classes are in the evening but I don’t have energy in the evening times.” (P19)

Participants admitted that there were activities they had wanted to do for a long time, often for years and years, but had never participated in due to being busy or struggling to afford the classes.

“I had started to in the past number of years go to a night class which I had postponed for years and years. When you are working, you are busier and sometimes financially you can’t afford to do these things.”
(P16)

Participants who had recently finished treatment or were still in active treatment reported that the side-effects of their treatment had been a major barrier to activity engagement for them.

“I’d be getting my treatment on the Monday, and on Tuesday the choir would be on, and I would never be in the frame and I wouldn’t feel good.” (P36)

“I became very debilitated. When I was diagnosed first I had an operation and all that so I was very stationary whereas I was used to being very active and out and about and whatever. Whereas I felt I was just sleeping, getting up, sleeping, getting up, was I ever going to be normal again? Even though I wasn’t better and maybe I might never be better, it was difficult even to go for a walk because I was unsteady on my feet.” (P14)

“If you have radiotherapy your whole week is taking up with that, your five days. So at that stage you don’t have time for anything else?”
(P16)

One participant acknowledged that it could be difficult to attend activities during treatment if there were side effects of their cancer treatment such as hair loss, as it could impact on their self-image and identity.

“I’d say it’s probably mostly for women but when you have a bit of hair on your head you feel like you can attend activities, even if it’s not too much but it looks like you just cut it very tight. You feel more able to start becoming yourself again in that sense.” (P16)

5.4 Perspectives of the Social Prescribing Process

Participants spoke about their experiences and perceptions of the social prescribing process, from their initial meeting with the link worker through attending activities and receiving ongoing support throughout the process and beyond.

5.4.1 The Role of the Link Worker

Participants reported positive outcomes from meeting with the link worker and receiving ongoing support. Some participants admitted that they did not know what to expect at the initial meeting with the link worker or what the process of social prescribing entailed. One participant described how they expected to be given a list of activities to attend and report back on to the link worker, instead of something she chose herself:

“When I was at the meeting, the first meeting, I thought I had to get involved in everything. And give you a report on everything. And tell you. And I would’ve ended up exhausted... But then through the meeting I realised there’s not one prescription for all. It’s an individual prescription, if you like.” (P40)

The initial meeting was reported to have helped in clarifying the social prescribing process and the purpose of the service. Participants found it useful to receive resources they could take away and review in their own time:

“I really enjoyed it. You gave me a lot of really good resources and a lot of options. I didn’t really know going into it, the wide variety of things that were available in the area... I had a look at all of the leaflets that you had given me and different online resources that were emailed to me and I just had a think about what I’d really like to do and what was closest to me.” (P20)

Participants spoke about the benefits of meeting with the link worker and speaking about the symptoms and side effects of their cancer diagnosis and treatment. The link worker was described as offering reassurance around common cancer-related symptoms such as fatigue and participants reported feeling better for receiving this kind of validation. For example, one participant spoke about feeling relieved to hear that fatigue was a common symptom of cancer, even several years after diagnosis and treatment.

“That was like a weight lifted off my shoulders. Because then I said, ‘Well this is normal.’ So I can’t pull the house apart in one day, but I’m

satisfied now to be able to pull a couple of rooms apart. Because it's normal. So I was happy, I was delighted with that. That is one of the main things that stuck out at the meeting." (P40)

Participants spoke about feeling socially isolated and misunderstood due to their cancer diagnosis. Because the social prescribing service was advertised as being cancer-specific, participants reported feeling they could talk freely about their cancer diagnosis and treatment and that the link worker would understand. The cancer-specific knowledge of the link worker was viewed by participants as valuable, and a reassurance.

"I was coming here and knew it was for cancer, so I knew I could talk about it without any barriers. I knew I wouldn't put fear into you because you are dealing with it, you are therapists and I was dealing with you and I could talk about it no problem. Believe it or not I felt a big lump off my shoulders going out after the meeting to be able to talk about it." (P21)

The pleasant demeanour of the link worker was highlighted as a positive influence during the first meeting and made the experience more enjoyable for participants.

"Oh, absolutely yeah, it was supportive and beyond. It was a perfectly pleasurable experience. You guys were accommodating, very helpful, very polite, very nice, affable." (P43)

5.4.2 Ongoing Support

Participants spoke about the ongoing support they received from the link worker following their first meeting and the study follow-up. Generally participants reported that they found the ongoing support was helpful, for example, by ringing to check in on their progress and sending on more information about activities as appropriate.

"She'd just ask me how was everything going and would I be interested in anything else. She'd forward me details and things like that. And she did, she'd email me whatever she found. You know she was doing all the legwork. Yeah it was very good." (P34)

"I received emails and different things from the link worker, just different new courses or new activities that she came across, so I definitely knew that support was always there and if I had an issue or

if I needed help working on something that I could just give you a call or let you know what I was doing, things like that.” (P20)

“She's very helpful. She text me about some of these things taking place. She made sure I knew what was going on and asked did I want to go and told me what time they start at. She phoned me once or twice but normally it would be text and she would say there's such a thing happening now this week.” (P4)

As part of social prescribing, the link worker typically offers to meet the individual at their chosen activity the first time they choose to attend. This option was offered to all participants in the study, although only two individuals availed of the option. They found this helped to reduce their anxieties.

“But she has a lovely manner and she met me over there when I went over because I was a bit insecure the first day going over. Because I didn't know what to expect.” (P43)

The second participant who agreed to meet the link worker found it beneficial to meet her the first day, however, he did not find the dance class he'd attended suited him. He arranged to meet with the link worker for coffee a few times afterward, which he found beneficial when he couldn't attend the dance.

“The one time I was there I talked to her because she said ‘will you come and I'll go down with you’ and when she said I'll come down with you, I said ‘okay, I'll go over.’ But that was the one time I was at the dance and I had a meal over there, got coffee there as well.” (P4)

Participants reported that a positive impact of the service was that the link worker offered ongoing support in finding more activities was a positive aspect of the service. For some participants who were unable to attend activities by the ten-week follow-up interview (n=7), knowing that the link worker would continue to support them in identifying and access community resources was seen as a positive.

“But she said it's something she might look into for me, to get back to adult education, you know it's something I'd like to do.” (P23)

5.4.3 Barriers to Activity Attendance following Social Prescribing

Participants described some of the barriers they faced to engaging with the activities the link worker had referred them to, including limited spaces, and location challenges.

Some activities had limited spaces available in each class or group which made it challenging for participants to engage with them. One participant had been trying to attend a yoga class near her home but the class was consistently full. She began doing yoga at home using online videos as a guide, but felt it didn't have the same impact as a group activity would have.

"I did enjoy the yoga at home and feel like that benefited me a little bit but it wasn't like a class setting so I wasn't meeting anybody, which was part of what I was looking forward to as well, meeting new people." (P20)

Health challenges arose for a number of participants throughout the study or created barriers to attending certain activities. For one participant, limited mobility combined with poor weather conditions and dark evenings in the winter restricted him from attending the activities he would have liked.

"There was quite a lot on offer but as I said it just came at a bad time of the year. The weather did affect me, and the weather affects my well-being. I couldn't avail of them. The nights were bad, the weather was bad. And as I say my walking is not great and I don't like walking into the breeze going up to the community centre. I have to walk into town to get a bus and then when I get off the bus, I still have to walk. So I say feck it I won't go up." (P4)

For another participant, the lack of available resources nearby within her own community required her to take a taxi to her chosen activity of a mindfulness class. This was costly and awkward and meant the participant ceased attending after their first session.

"Well it was just a little bit awkward for me to get at. And I haven't got any transport really since June and so I have to rely on taxis and I was a while waiting down there to get a taxi back." (P33)

For some participants there were financial challenges in attending their chosen activities. One participant had chosen to attend one-to-one reflexology sessions every two weeks as she had previously found reflexology to be beneficial for her mood and her stress levels. After meeting the link worker, she returned to her previous reflexologist, but while she experienced benefits from the activity, she reported that she was restricted in attending due to the cost.

“I think the more times I go, I can see my sleep getting better every time. So I am going to keep that up but I probably won't be able to go every two weeks because it's fizzing expensive, it's 60 quid a go. That's €120 a month, that's expensive. So I'm going to try and go once a month.” (P19)

5.5 Impact of Social Prescribing

Participants spoke about their perspectives of the impact that involvement in the social prescribing service had made on various aspects of their lives, including the activities they had attended as a result and their experiences in doing so; and their view of the impact social prescribing had had on their health.

5.5.1 Attending Activities

Participants were referred to and attended a range of activities by the link worker following the first meeting. Some participants (n=7) were referred to and attended more than one activity, based on their preferences. Relaxation-based activities attended included tai chi (n=3), yoga (n=2), mindfulness (n=2), and qigong (n=1) classes based within community centres, and one participant attended one-on-one reflexology sessions. Physical activities included dance classes (n=4), walking (n=3) and one participant also attended a personal trainer for one-on-one sessions. Arts, crafts and music activities included art classes (n=2), guitar classes (n=1) and a choir group (n=1). Those who attended the cancer support services (n=3) attended pilates, yoga and mindfulness classes based within the service, and one participant availed of counselling provided by the service.

Seven individuals participating in the study attended more than one activity recommended by the social prescribing link worker. They described how attending one activity encouraged them to attend more once they'd had a positive experience and discovered the other activities on offer within that setting.

“Sometimes you hear about a place but you don't realise how much it has to offer, not until you start going and using the services. I didn't know what to expect even going. I just said if I like it, I like it, and I'll go again. But I started one thing and then I put my name down for other things.” (P35, attended mindfulness in cancer support centre, followed by reflexology and yoga)

“By attending one thing then I thought I can do something else you know, it’d be nice to come up here and take up something else up here.” (P13, attended yoga in a community centre and then attended tai chi, meditation and dance)

Participants highlighted the importance of feeling understood by others when engaging in activity. Some participants (n=3) who had not availed of cancer support services prior to social prescribing spoke about the benefits of meeting other people who had been through similar experiences and could offer peer support.

“It was just interesting to hear other people’s feelings or identify with what some people said and know you’re not on your own on that level.” (P24)

“When you’re talking to someone that’s after being through what you’ve been through, they understand ... You feel the people that you’re meeting in the likes of the cancer support services know where you’re coming from.” (P35)

Two participants who attended community-based activities also met individuals with experience of cancer and found this to have a positive impact on their experience of the activity.

“I met a fella who had the same bowel cancer like me. And it was great, he gave me a lift. It gave me a lift to meet people. And I feel I could talk to him on a one to one, that’s the best way to describe it.” (P37, attended tai chi in a community centre)

“I found doing that [reflexology] was really good because the lady, it turns out she had breast cancer eighteen years ago. So she could relate to how I was feeling and understood, which lots of people don’t understand. And she knew how I was feeling.” (P29)

The same participant above (P29) described how she had wanted to reduce her five-day-a-week attendance in the gym as she didn’t enjoy it, but didn’t know what other type of physical activity to do. After meeting the link worker, she opted to begin attending reflexology to reduce stress and also to go for daily walks. She reported that her mood improved as a result:

“I probably only realised it after being here that like you can’t go on like this, because I think I was nearly, I’d either have a nervous breakdown or I was going to get depressed or something was going

to happen. I found walking actually more beneficial than going to the gym because I was getting that bit of head space you know listen to podcasts and just off you go and have your own thoughts and not be anxious about going to the gym.” (P29)

5.5.2 Benefits of Social Prescribing to Health

Participants spoke about the impact their involvement in the social prescribing service had had on their health and wellbeing, both physical and mental.

Some participants reported feeling they had increased energy levels as a result of attending scheduled activities in the community.

“I have more energy. And when I’m finished these classes I can go home and I can do a lot more work in the house you know what I mean. You’re more energetic.” (P13, attended yoga, tai chi, meditation and dance classes)

Another participant reported that attending an art studio weekly helped her to build up her energy levels and reduced her fatigue over time.

“So I feel like just getting into the habit of going on a weekly basis and easing myself into it that way, it's helped the fatigue even itself out so I'm at a place now where it's not a big deal. But definitely at the start I think the fatigue was still an issue but by going every week I think it helped it kind of go away I guess.” (P20)

Participants described the impact they perceived social prescribing having on various aspects of their mental health, including reduced levels of anxiety, improved sleep, improved social health, increased motivation and improvements to their routine. Participants described experiencing higher levels of relaxation and feeling less worried about their cancer following involvement in social prescribing.

“I don’t feel as many negative thoughts as I would have had before I went, when I’d be sitting thinking of this, thinking of that. I feel I’m more relaxed.” (P35, attended mindfulness and relaxation classes in a cancer support service)

“I think my mental health is definitely improved since, I don’t feel as anxious and as stressed as I possibly did, no, I definitely don’t.” (P29)

Some participants (n=3) who had reported trouble sleeping found that relaxation-based activities such as mindfulness and reflexology positively impacted their sleep quality.

“All that activity has helped me sleep, and the relaxation and mindfulness and that has helped me sleep.” (P14)

“I couldn't tell you exactly what reflexology does or doesn't do but I know I go there for an hour and I have an amazing night's sleep afterwards. If anything that's worth it like. Because sometimes my sleep is shocking.” (P29)

One participant (P43) described how he had suffered sleep disturbances and poor sleep quality for years prior to engaging in social prescribing. He described how he had tried a number of solutions, including medical prescriptions and exercise, to attempt to improve his sleep. After meeting with the link worker, he researched and uncovered music that had been designed to support sleep. He described how this discovery improved his sleep and positively impacted his health and well-being across a range of domains:

“Just listening to music that is made functionally to help you sleep. Never tried that, always just wrote it off. But then I tried it and it worked a charm and it's like the only thing that has ever truly worked for me. And ever since then every single night, 6 to 8 hours sleep as opposed to the 2 to 4 I was getting. So it's impacted everything from energy to mood, to focus, concentration, motivation, everything. Confidence and then the other stuff like depression and anxiety, the anxiety feels like it's completely gone.” (P43)

Social prescribing was identified as having benefits for social interaction by participants. Participants reported how attending activities through social prescribing offered a chance to meet new people and engage in a new social circle.

“I'm definitely meeting new people and strangers who I've never met before and I really like that, I just think meeting new people is so fun. Usually I'm quite introverted and I don't mind being on my own but it's nice at the same time to be doing activities with somebody too.” (P20)

Participants in the study spoke about the increased confidence they felt following engagement in activities. One participant began attending an art studio following her

meeting with the link worker and described how it gave her increased confidence and something she was engaging in that she could talk to her peers about.

“I think it did boost my confidence a little bit because ... before I think some people knew I was sick and they knew obviously I wasn't working, but then some people didn't. So often when they'd say like, 'oh and what are you doing now?', it was like, 'well, nothing'. So I don't even know how to explain it but basically I just like doing something.”

Another participant described how engaging in activities increased her confidence and made her feel that she was returning to her life prior to the cancer diagnosis.

“I feel I'm going back to myself kind of, the outgoing person I was, by going to these things.” (P35, attended relaxation classes within a cancer support service)

Social prescribing was reported by participants as having a positive impact on their motivation to engage in activity. Prior to engaging in the service, some cancer survivors reported having difficulties with motivation.

“I struggled with motivation before this so I like never did it on my own accord before, when I could have, but I didn't. I wanted to volunteer for a long time, been telling people I was going to for a long time, but never materialised. But it gave me motivation when I found out you could help me with that. Extra motivation, networking, contacts as well was a big thing. I don't know anyone else who does it.” (P43)

For the same participant, there was a range of positive benefits of engaging in social prescribing, including increased mood, increased confidence, increased motivation and the feeling that he was building a sense of direction towards future employment:

“Well my mood is better. I'm more optimistic I think, more motivational, confident in talking to people about it, just in passing or in conversation, that I'm trying this, I'm trying to get in contact with this person or whatever, I'm trying to organise this sort of voluntary work. I think the biggest thing would be motivation. Mood boost, sort of development of a direction, however cringe worthy that might sound but it's like that's the kind of stuff I want to do in the future in terms of work so.” (P43, volunteered with asylum seekers)

Social prescribing was identified as having a positive motivational impact and encouraged participants to get engaged in meaningful activities.

“Pushed me and gave me the motivation to do something, definitely.”
(P38)

“It gets you out because you’d be, ‘oh my god how am I going to get out of bed this morning?’, because you would have aches and pains. But then when you get out and get going, it’s great. You are not going to benefit from staying in the bed. And you are not going to be benefit from staying in the house you know whereas you have to get washed and changed and dressed and get out to go participate.”
(P14)

Routine was something participants spoke about being positively impacted by social prescribing. For example, one participant described how she wanted to use social prescribing to build her routine and her energy levels through engaging in activities on a regular basis.

“I want to be able to get to a Monday to Friday where I can get up at the same time each morning that I can get showered and ready. That I can travel to somewhere, even if it’s for an hour of exercise or an hour of a class and come home. And if I can build that up to be able to do that 3 days out of 5 by the end of the year, that would be a huge success for me. Because I just know I’m not at that stage yet in terms of kind of the stamina side of things.” (P19)

Participants described how engaging in community-based activities supported them in building a routine and structuring their week. One participant described how they used different scheduled activities to build their routine and plan the rest of their week.

“It’s kind of a reference point and then you can look at the calendar like, ‘Okay I have this and then this.’ And then things can sort of hang on from there. I have some routine and so I know what’s going to happen.” (P44)

Having activities to attend in their community encouraged participants to engage in self-care activities they might otherwise forego, possibly due to fatigue or low motivation. Participants outlined how social prescribing supported them to find meaningful activities that gave them a drive to leave the house. One participant

described how attending yoga classes in her local cancer support centre gave her a purpose to get up, get washed and get dressed for the day.

“Literally getting up, dressing, washing, dressing myself, doing myself and heading out you know. Whereas if I wasn’t going to them things, if I was having a tiring day, I’d probably just be a couch potato or lie in the bed looking at the telly.” (P41)

Participants reported a change in their attitude towards activity, which in turn made a positive impact on their motivation to engage. Participants they began to think of the activities they enjoyed engaging in as therapeutic and important to their health, which motivated them to engage more.

“Before I met with you, attending the art studio was just something I was going to do. I didn’t see that it was really going to benefit me health wise. So definitely my conversation with you opened my eyes about that. And just helped me see how it might benefit me in other areas. And even the walk over there. I am kind of getting my physical activity in as well.” (P20)

“I was saying like I have this on, you know, Jesus they actually think its all part of my treatment because you know I hate to miss particularly some of them you know. But yeah it definitely made a big difference to me.” (P14)

“People say you are a fool for doing this and I say no it’s my prescribed therapy.” (P22, engaged in community clean-up volunteering)

5.6 Summary

Twenty-seven individuals living with and beyond cancer participated in semi-structured one-to-one interviews following engagement in social prescribing. Participants spoke about the reasons for their interest in social prescribing, which includes learning to manage cancer related health challenges and a perceived lack of support from the hospital in managing these challenges post-treatment.

Participants reported that cancer support services can be beneficial in offering support throughout treatment and diagnosis, however some participants were unaware of the services, declined to use them or described how over time, their needs change and they want to move on from the cancer support services to new activities.

Cancer survivors' perceptions of social prescribing were gathered, including the key role of the link worker in putting individuals at ease, offering reassurance and offering ongoing support. The cancer-specific knowledge of the link worker appeared to emerge as something of value to participants in particular. They spoke about the feelings of relief and reassurance they had in speaking about their cancer diagnosis to someone they perceived as having knowledge around their diagnosis.

Finally, participants spoke about the impact they perceived social prescribing to have on their health and well-being, which included increased energy, better sleep quality, reduced fatigue, increased socialisation, increased confidence, increased motivation, improved routine and a change in their attitude towards activity as a means of managing their health. The next chapter will discuss these findings in line with previous literature and the results of the quantitative strand presented in the previous chapter.

6. Discussion

6.1 Introduction

The aim of this study was to evaluate whether social prescribing had an impact on the following domains: quality of life, anxiety and depression, fatigue and activity participation levels, of individuals living with and beyond cancer, in addition to gathering the perspectives and experiences of those who engaged in social prescribing. A mixed-methods approach including both qualitative and quantitative methods was employed to achieve these aims. A discussion of the results, synthesising both qualitative and quantitative strands of the study will be presented in this chapter.

6.2 Outcomes of Social Prescribing for Cancer Survivors

This is the first academic study to explore the impact of social prescribing on the health and well-being of cancer survivors and to gather their experiences and perceptions of engaging in the social prescribing process. There are several positive outcomes in this study. Social prescribing had statistically significant impacts on the functional quality of life, depression, activity participation levels and distress related to fatigue of individuals living with and beyond cancer.

6.2.1 Quality of Life of Cancer Survivors

Quality of life is a construct determined by both objective factors and an individual's assessment of their own general well-being, including elements such as their goals, expectations, standards, concerns, and experiences, in relation to their own culture and value systems (Galic, Glavic & Cesarik, 2014; Padmaja, Vanlalhruii, Rana, Tiamongla & Kopparty, 2017).

The European Organisation for Research and Treatment of Cancer Quality-of-life Questionnaire Core 30 (EORTC QLQ-C30) was utilised to investigate whether change was experienced in the quality of life of cancer survivors engaging in social prescribing.

No statistically significant results were detected in the global quality of life of cancer survivors, nor was there a statistically significant reduction in the presence of symptoms detected. However, there were general trends of improvement in both of these domains and a statistically significant improvement in functional quality of life.

Within the qualitative interviews, participants spoke about several benefits to their health that they attributed to their participation in and interaction with the social prescribing service.

Social prescribing has previously been reported to have a positive impact on the quality of life and well-being of individuals living with and beyond cancer (Macmillan Social Prescribing Service, 2018). Though further research is warranted, particularly a study containing a control group to increase the ability to attribute findings to social prescribing, the findings of this study suggest a positive trend in the impact social prescribing services can have on the quality of life of cancer survivors.

Previous social prescribing studies have reported improved quality of life and health and well-being outcomes in mental health populations (Dayson & Bennett, 2016a; Dayson & Bennett, 2016b). Furthermore, Macmillan Social Prescribing Service (2018) reported statistically and clinically significant improvements in the concerns of cancer survivors over their health and well-being. This finding is supported by the qualitative data in this study, in which cancer survivors reported feelings of increased mood, increased confidence, increased motivation and feelings of returning to “their old self”.

6.2.2 Sleep

Although the European Organisation for Research and Treatment of Cancer Quality-of-life Questionnaire Core 30 (EORTC QLQ-C30) assesses participants’ sleep quality as part of its symptom domain, it was not an aim of this study to evaluate sleep disturbance and the impact of social prescribing on cancer survivors’ sleep quality. However, several participants spoke about the positive changes they experienced to their sleeping patterns following involvement in the study.

One participant discussed sleeping an average of two to four hours a night prior to study. By the end of the study, he was sleeping an average of six to eight hours. This participant could not confidently attribute the improvement to sleep to his participation in the study as he had discovered a mobile phone application which played sounds that promoted sleep during the study. He did acknowledge, however, that he had been struggling with poor sleep for years and that meeting with the link worker may have prompted him to pay renewed attention to his sleep. This is not uncommon. Increased attention to one’s health is an outcome that has been reported in previous studies examining social prescribing, including the Macmillan Social Prescribing Service (2018) for individuals living with and beyond cancer (Dayson & Bennett, 2016a; Carnes et al., 2017). In future studies, exploring social prescribing with cancer survivors, it may be

worthwhile exploring the impact of social prescribing on sleep in greater detail to determine whether social prescribing has statistically significant impacts on sleep.

6.2.3 Anxiety

Cancer survivors engaging in this study reported challenges in managing cancer-related anxiety. This is consistent with findings in previous studies. A systematic review (Foster et al, 2009) examined the impact of cancer treatment on survivors and included individuals who had been diagnosed greater than five years previous. Anxiety and depression were identified as negatively impacting survivors' quality of life. The struggle to manage psychosocial symptoms can affect survivors' abilities to develop effective coping strategies (McGinty et al., 2012; Philip et al., 2013). Therefore, addressing the psychosocial impact of cancer may improve wellbeing and confidence in transitioning to cancer survivorship which in turn improves quality of life (Hodges & Winstanley, 2012; Molina et al., 2014; DOH, 2017). Few interventions have addressed psychosocial issues such as anxiety or fear of recurrence (Economou & Reb, 2017) and based on the qualitative and quantitative findings of this study, social prescribing may offer the potential to support cancer survivors in dealing with these psychosocial issues.

The Hospital Anxiety and Depression Scale (HADS) was used to measure the change of cancer survivors' anxiety and depression levels following participation in social prescribing. The HADS-Anxiety subscale presented an improvement in the median between baseline and follow-up, however this change was not statistically significant. Cancer survivors reported in the qualitative interviews, however, that they felt their anxieties had reduced as a result of participating in social prescribing. This is in line with previous social prescribing studies, which have demonstrated statistically significant reductions in anxiety among general and mental health populations (Dayson & Bennett, 2016a; Whitelaw et al., 2017). With consideration of the short follow-up period (10 weeks), it is possible that across a longer time period, statistically significant changes may occur.

Furthermore, qualitative data highlighted that participants expressed reduced concern and anxiety towards common symptoms that they had been experiencing prior to the study. Cancer survivors reported that receiving reassurance about their symptoms reduced their cancer-related anxieties and helped them to feel at ease. A number of positive impacts of social prescribing had been identified by participants as influencing their mental health, including reduced feelings of anxiety, increased mood, increased confidence, increased motivation and a better sense of routine.

6.2.4 Depression

Depression and depressive symptoms have been found to occur frequently in cancer patients (Irwin, 2013). Around one third of UK-based individuals diagnosed with breast, prostate or colorectal cancer or non-Hodgkin lymphoma within five years previous reported experiences of anxiety or depression (Department of Health, 2012). More than one in eight of those individuals reported moderate to extreme levels of anxiety or depression. Additionally, the presence of symptoms related to anxiety and depression have been linked to an increased risk of unmet supportive care needs in individuals with melanoma (Molassiotis et al., 2014).

Six participants within this study reported pre-existing mental health challenges, and depression and depressive symptoms have been found to occur frequently in cancer patients (Irwin, 2013). Social prescribing was found to have a statistically significant reduction ($p=0.025$) on levels of depression experienced by cancer survivors in this study. This is a positive finding and is in line with previous research exploring the impact of social prescribing within populations with long-term health conditions (Dayson & Bennett, 2016a; Dayson & Bennett, 2016b).

6.2.5 Fatigue

Individuals living with and beyond cancer who engaged with the social prescribing service were experiencing symptoms including fatigue, cognitive challenges, low confidence, and sleep disturbances as a result of their cancer. Participants described the impact these symptoms had on their daily activity participation, including their ability to socialise and to engage in work, leisure and family activities, as well as the impact on their overall quality of life. This supports findings that have been reported in previous studies, where cancer-related symptoms have been shown to negatively impact quality of life and activity participation (Silver & Gilchrist, 2011; Aaronson et al., 2014; Shneerson et al., 2015).

Cancer-related fatigue was the most prevalent issue discussed by participants. This is in line with previous literature, where one third of individuals were still experiencing clinically significant levels of fatigue up to six years post-treatment, which was impacting on their daily activities (Jones et al., 2016). Breast cancer survivors six months post-treatment identified fatigue as the largest factor preventing their re-engagement in activities (Fleischer & Howell, 2017).

The Multi-dimensional Assessment of Fatigue (MAF) was used to measure the change in cancer survivor's levels of fatigue following involvement in social prescribing.

Through the changes to fatigue severity, interference of fatigue in activities of daily living and the global fatigue index domains of the MAF were not statistically significant, there were general improvements across each these categories. It is possible that across a longer time-span or among a larger sample, statistically significant changes may be detected (Pallant, 2016).

There was a statistically significant change in the distress caused by fatigue. The median score at baseline had reduced by post-intervention follow-up which suggests that cancer survivors experienced less distress related to fatigue following social prescribing. Cancer survivors spoke about their increased energy and reduced fatigue following involvement in the social prescribing service. This is an interesting finding as it suggests that social prescribing may provide greater support to the psychosocial elements of cancer survivorship over the physical domains. By addressing the emotional impact of cancer-related fatigue, cancer survivors may feel better able to cope with the impact of their fatigue. A previous social prescribing study evaluating the long-term impact of social prescribing on a population of individuals with long-term conditions found that the coping strategies and changes they had made earlier in their engagement with the intervention persisted up to two years post involvement in the social prescribing service (Wildman et al., 2019a).

6.2.6 Activity Participation

Participation in everyday activities is regarded as an important goal for cancer survivors to return to (Palmadottir, 2010). Cancer survivors have identified that returning to their daily routine can help maintain control and stability, develop a sense of self-worth and enhance self-development. Participation in activities that are meaningful, within an environment that is positive and supportive, has been shown to facilitate increased quality of life and well-being (Pizzi, 2010). Active participation in community activities, uptake of social support, and engagement in meaningful activities have all been shown to positively impact community members' health and quality of life (Scaffa & Reitz, 2013).

The Frenchay Activities Index (FAI) was used to determine whether social prescribing had an impact on the activity participation of individuals living with and beyond cancer. Statistically significant improvements were identified in both the "leisure and work," and total activity participation domains. This suggests that social prescribing may have had a positive impact on the activity participation levels of cancer survivors in this study, particularly in the realms of leisure and work. The purpose of social prescribing services is to promote engagement in community-based activities and services.

Reviewing the activities participants attended throughout the study (Appendix 14), it is logical that participants would have rated their participation in activities such as leisure higher in the FAI, though it is interesting to note that this was found across the entire sample of 27 interviewees, as 7 participants did not attend any “formal activities” during the study. This is in line with numerous quantitative and qualitative studies that have examined the impact of social prescribing (Bertotti et al., 2017; Chatterjee et al. 2017, Moffatt et al. 2017).

The qualitative findings of this study also support this result. Cancer survivors described how participation in community activities emerged as a motivating factor to engage in self-care activities, such as showering and dressing. Having scheduled activities to attend in their community enabled cancer survivors to regain a sense of routine and to build their week around those activities. For seven individuals, attending one activity was identified as a motivating factor to engage in self-care activities such as showering and dressing.

Cancer survivors highlighted the benefits of engaging in group activities. Social support is considered a vital component of survivors’ mental health as it can improve the confidence and coping abilities of cancer survivors (Sapp, Trentham-Diaz, Newcomb, Hampton & Moinpour et al., 2003). Socially isolated breast cancer survivors have reported more problems with physical functioning, role limitations and provision of emotional support (Michael, Berkman, Colditz, Holmes & Kawachi, 2002).

6.3 Experiences of Social Prescribing

One of the aims of this study was to explore participants’ perspectives of engaging in a social prescribing service. Within the qualitative interviews, they spoke about their experiences throughout the process of engaging in the service, including their views on the role of the link worker and the ongoing support they received. Social prescribing was seen not only as a once-off meeting, but a continuing support throughout their time in the study and beyond.

6.3.1 Role of the Link Worker

Cancer survivors in this study identified the link worker as a key factor in their experience of social prescribing. This was a positive and somewhat expected finding as the role of the link worker has been highlighted repeatedly in the literature as a key mechanism to promote change through social prescribing (Bertotti et al., 2018; Friedli et al., 2012; Wildman et al., 2019a). A strong and supportive relationship between the

client and link worker has even been described as vital to the success of social prescribing (Moffatt, Steer, Penn, & Lawson, 2017).

6.3.1.1 Personality

The friendly, easy-going personality of the link worker was highlighted by participants in this study as having a positive influence on their mood and helping them to feel at ease. The link worker was described by participants as helpful, supportive, pleasant, accommodating, and offering reassurance. The link worker offered emotional support and reassurance to cancer survivors, which has been found to be important in supporting services users who lack self-esteem and experience anxiety (Wildman et al., 2019b). The type of support offered by the link worker to cancer survivors in this study meets with Brandling and House's (2007; pg. 15) description of the 'ideal' link worker as "someone with high developed interpersonal communication and networking skills, with a motivating and inspiring manner to encourage clients to make brave decisions or take up new opportunities."

A realist evaluation of a social prescribing scheme identified that active-listening and empathetic skills served to build trust between link workers and clients (Bertotti et al., 2017). As this is the first study to explore the impact of a social prescribing service established specifically for cancer survivors, there is limited evidence of link workers offering reassurance around common symptoms. However, in the United States, the concept of a cancer navigator is receiving growing attention. This role involves offering advice and reassurance around the management of ongoing cancer symptoms, educating individuals on their conditions, addressing financial barriers, and supporting individuals in identifying relevant supports and activities that may benefit them within their community (Fischer, Sauaia & Hutner, 2007; McBrien et al., 2018; Shlay et al., 2011).

6.3.1.2 Training

Cancer navigator roles are often fulfilled by trained healthcare professionals, such as nurses or social workers (Shlay et al., 2011). Social prescribing link workers, on the other hand, may have backgrounds and training in community health, or they may be lay people and volunteers (Bertotti et al., 2017; Brandling & House, 2007). In this study, the social prescribing link worker was a community health worker with training in community health and had some familiarity with the common symptoms and side-effects related to cancer and cancer treatment. This may have contributed to the link worker's ability to offer appropriate emotional support and reassurance around

common cancer symptoms to participants. Participants in this study spoke about the cancer-specific knowledge of the link worker and suggested that it made them feel more at ease in speaking about their cancer journey so far, which promoted trust and strong rapport between participant and link worker.

The value of initial and ongoing training in health, welfare rights advice and support work for link workers to better support individuals with chronic health conditions and complex needs has been previously highlighted in the literature (Bertotti et al., 2017; Wildman et al., 2019a). Further research is warranted to determine what additional training needs social prescribing link workers may require to adequately support individuals living with and beyond cancer and whether the role of reassurance and education around common cancer symptoms falls to the link worker or to primary care services.

6.3.2 The Value of Social Prescribing?

All participants who had not yet attended an activity or support service at time of follow-up ($n=7$) discussed their intentions to continue working with the link worker and intentions to engage in activities in the future. Whether they had engaged in a preferred activity or not by the time of data collection, all 27 participants had received an average of 5.3 interactions with the social prescribing link worker (appendix 13). As such, it was determined through discussion with both the link worker and the research supervisor, that these participants had still received support from the link worker, including the dissemination of information and supportive conversations and discussions regarding their cancer that were highlighted in the qualitative interviews as being valuable aspects of their experience. They were therefore included within all of the quantitative analyses conducted in this study.

This is an important finding as it suggests there may be value in social prescribing interventions merely through interaction with a link worker providing support and information regarding the potential to engage in activity. This could be an important finding for future studies considering the use of a control group while exploring the impact of social prescribing for cancer survivors. It would be interesting to determine whether it is the role of the link worker and the support provided by the social prescribing service or the engagement in community activities that may have a positive impact on the health and well-being of cancer survivors.

6.3.3 Ongoing Support

There is mixed evidence regarding the benefits of long-term social prescribing intervention. In previous studies, individuals have been encouraged to exit the service after a maximum of six individual on-to-one sessions with the link worker to avoid dependency on the social prescribing service (South et al., 2008; Woodall et al., 2018). However, a recent study examined the impact of social prescribing involvement of up to two years on the health and well-being of individuals with long term conditions and multi-morbidity (Wildman et al., 2019b).

Due to health challenges, family circumstances and social, cultural and economic factors, many of these individuals required ongoing support social prescribing support from the link worker to access voluntary and community services, supports and activities. As shown in appendix 13, individuals had between 3 and 9 interactions with the link worker, including the initial meeting, with an average of 5.3 interactions. This suggests that for individuals living with and beyond cancer, longer-term social prescribing intervention may be necessary to overcome the health challenges associated with the condition. Further research is warranted to identify the positive and negative implications of long-term social prescribing support for individuals living with and beyond cancer.

6.4 The Practicalities of a Social Prescribing Service for Cancer Survivors

In chapter 3 of this thesis, a description of the processes of recruitment were outlined. The findings and learning from these processes are discussed below.

6.4.1 Referral and Engagement from Healthcare Professionals

The majority of social prescribing models have found the primary care team to be the main source of referral (Keenaghan, Sweeney & McGowan, 2012; Polley, Fleming, Anfilogoff & Carpenter, 2017). As such, it was envisaged that local GP practices and primary care teams may be utilised as sites for further recruitment for this study. Unfortunately, it was found that there was limited engagement from both. Efforts made to engage with these sites, potential reasons for low engagement, and potential solutions for future studies are outlined below.

6.4.1.1 Attempts to increase buy-in from GPs and primary care services

Twenty-six GP practices were contacted repeatedly with information regarding the study utilising written communication, telephone communication and physical

attendance by the researcher at each practice. Ultimately, only 2 GP practices engaged in communication with the researcher, agreeing to distribute information to participants they felt were suitable for the study. 2 of 43 participants who engaged with the study were identified as coming from the GP Practice Recruitment Sites, though it should be noted that only one of these participants was given information about the study directly by their GP. The second participant was advised to contact the research team regarding the study by a close friend, who had seen the study advertised on a notice board within her GP practice.

Similarly, attempts were made to make contact with healthcare professionals working in primary care centres based within the areas designated for inclusion. The researcher was invited to speak with occupational therapists working within Dublin south city on two occasions to highlight the study and attempt to increase understanding and engagement. One participant in the study sample was referred to the study by their primary care occupational therapist.

6.4.1.2 Reasons for limited recruitment and engagement from primary care services

It is unknown why there was such limited engagement from GP services within this study, however, previous social prescribing studies have encountered similar problems.

Studies evaluating social prescribing services for mental health populations and individuals with long-term health conditions in the UK have found that engagement from primary care practitioners and GPs remains a challenge to practice (Bertotti et al., 2017; Brandling & House, 2009; Mercer et al., 2019; Wildman et al., 2019a). It has been acknowledged that social prescribing is unfamiliar to many GPs and requires strong, clear explanation to engage them in understanding the benefit of social prescribing and to encourage them to refer individuals to social prescribing services as appropriate (Bickerdike et al., 2017; Faulkner, 2004; Friedly, Themessl-Huber & Butchart, 2012). While attempts were made to communicate with GPs in this study and to increase understanding, due to the busy schedules of GP practices, it was difficult to even make first contact with them.

The importance of healthcare professionals' engagement with social prescribing has previously been highlighted as crucial to the successful implementation of social prescribing services (Wildman et al., 2019a; White, Kinsella & South, 2010; Whitelaw et al., 2017). It may be beneficial for future studies to attempt to draw local GP practices in as stakeholders, or to perhaps interview them regarding their understanding of social prescribing and their opinion of its usefulness and applicability to their patients, particularly those with a cancer diagnosis.

6.5 Acceptability of Social Prescribing for Cancer Survivors

An aim of this research study was to explore the acceptability of social prescribing for cancer survivors. It should be noted that this study did not set out to definitively identify whether social prescribing is or is not an acceptable intervention for cancer survivors, but indeed whether it might be in future, with further study and refinement.

The Medical Research Council framework suggests that acceptability is best assessed in the feasibility phase of intervention development (Medical Research Council, 2008). Within this study, an existing social prescribing service was utilised to provide support to individuals living with and beyond cancer, utilising a link worker that had community health training and some knowledge of the common symptoms and side effects of cancer. To more appropriately assess the acceptability of social prescribing for cancer survivors, it would be beneficial to include stakeholders in the development phase through to a pilot and feasibility phase of intervention development. This would promote the ability for a social prescribing service to best meet the needs of individuals living with and beyond cancer.

According to the theoretical framework put forth by Sekhon, Cartwright & Francis in 2017, acceptability is, “a multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experiential cognitive and emotional responses to the intervention,” (p. 8). These constructs are outlined below.

6.5.1 Affective Attitude

Affective attitude refers to how an individual feels about the intervention prior to participating in it (Sekhon, Cartwright & Francis, 2017). Interviews completed with participants prior to engagement in the social prescribing service would have been a beneficial way to gain further information around cancer survivor’s affective attitudes to the intervention and may be a consideration for future studies evaluating the acceptability of social prescribing. Exploring the perceptions of those who declined to engage in the social prescribing intervention may also provide valuable insight into the affective attitudes of cancer survivors prior to participating in social prescribing and the acceptability of the intervention for this cohort.

6.5.2 Burden

Burden refers to the perceived amount of effort that is required to participate in the intervention. The nature of social prescribing is that participants are supported and encouraged to engage in desired activities and services and therefore constitutes a reasonable degree of effort. Participants in this study identified barriers to engagement prior to social prescribing including the identification of activities that are affordable and align with their schedule. This was identified as a positive role of the link worker in this study – the provision of detailed information regarding resources and activities in one's local area. This appears to have reduced the burden of cancer survivors needing to identify these activities themselves; although it should be noted that not all activities identified were deemed suitable by participants.

For those less mobile or living far from their desired activity, the cost and effort of acquiring a taxi to access the activity was sometimes deemed too high; two participants reported disengaging from their activity due to this problem. These pose important considerations for the acceptability of social prescribing for cancer survivors engaging in social prescribing.

6.5.3 Intervention Coherence

This refers to the extent to which the participant understands the intervention and how it works. It is important to note that a large number of participants declined to participate in the study.

In this study, 520 people declined to participate in the social prescribing intervention, however the level of information provided to these participants was varied. It is unknown why these participants declined, however one possible reason is that they were not given enough information on the study, or did not understand what would be involved. This is an important consideration for the acceptability of social prescribing for individuals living with and beyond cancer. If the intervention is not well understood, participants may be disinclined to engage from the outset.

Some participants who did engage with the service spoke about their expectations entering the study however, and described the concern that they were going to be prescribed or assigned specific activities to attend. They identified that clarity was given in the initial meeting with the link worker, which suggests it may be important to ensure cancer survivors are educated on the purpose of social prescribing to increase the acceptability of the intervention for this population.

6.5.4 Opportunity Costs

This refers to the extent to which benefits, profits or values must be given up to engage in the intervention. The cost to engage in some activities identified by the link worker was noted by some participants as a barrier to engagement. One participant, for example, spoke of the benefits of attending a reflexology specialist identified by the link worker, however due to the high cost (€60) of each session, this participant did not feel they could continue to engage with the reflexologist long-term. Engagement with the link worker and in the social prescribing process itself does not cost any money however as it is a fully funded and subsidised service. This may increase the acceptability of social prescribing itself for participants, however, the cost of activities identified should be considered when working with individuals living with and beyond cancer.

6.5.5 Perceived Effectiveness

This refers to the extent to which the intervention is perceived as likely to achieve its purpose. Cancer survivors spoke positively about the benefits they perceived social prescribing to have had on their health, as outlined previously. Though seven participants were not able to attend activities, they spoke positively of the ongoing support of the link worker, and their optimism to attend activities in the future (appendix 14). This suggests participants perceived social prescribing as effective in achieving its purpose as they described feeling positive about attending activities in the future and the ongoing support received.

6.5.6 Self-Efficacy

This refers to the participant's confidence that they can perform the behaviours required to participate in the intervention. Increased confidence was identified within the qualitative interviews as a positive impact of social prescribing and examples of high self-efficacy can be noted within participants who engaged in desired activities over time, or who attended several activities due to the increase confidence they received in attending one.

Reviewing the participants who engaged in social prescribing but did not attend an activity prior to the second data collection period ($n=7$), five of them spoke of activities they planned to attend in the near future. It is unclear whether these participants felt they had the confidence to engage in these activities, however they indicated to both the researcher and link worker that they wanted and intended to attend desired activities when possible.

Barriers to participation arose for some participants, as outlined above, including reduced mobility and the cost of travel to chosen activities. In these cases, participants appeared to have low confidence in being able to participate in desired activities.

6.5.7 Is Social Prescribing Acceptable for Cancer Survivors?

Post-intervention assessments of acceptability may focus on participants' experience of the intervention from initiation through to completion, or on anticipated acceptability based on participants' views of what it would be like to continue with the intervention on an on-going basis. Following participation in this study, participants spoke about the benefits they perceived social prescribing to have on their activity participation, anxiety, mood, energy levels and confidence.

While taking the above criteria into account and based on the qualitative findings presented in this study, it would appear that participants within this study perceived social prescribing to be an acceptable intervention for cancer survivors. However, there is additional evidence to suggest that barriers such as cost of engagement in activities and geographical limitations may reduce the acceptability of social prescribing services for cancer survivors. Further research is necessary to determine the acceptability of social prescribing for cancer survivors as a wider population. In particular, exploring the reasons cancer survivors may decline to engage in a social prescribing service would be important to identify to what extent it is acceptable to the wider population of cancer survivors.

6.6 Implications for The Future

This study is the first of its kind to explore the impact of social prescribing for individuals living with and beyond cancer in Ireland. It supports the findings of an evaluation undertaken by Macmillan Social Prescribing Service in 2018 exploring the impact of social prescribing on individuals living with and beyond cancer, in addition to a number of findings reported in studies exploring social prescribing with other populations (Chatterjee et al., 2017; Dayson et al., 2017; Pescheny et al., 2018). Implications for future research, policy and practice based on these findings are provided below.

6.6.1 Implications for further research

This study has highlighted areas requiring further research. The following recommendations are made:

- To conduct a study utilising a control group. This research has indicated that social prescribing may be a factor contributing to improved functional quality of life, symptoms management, aspects of mental health including depression, confidence, routine management and motivation; and ability to cope with and manage cancer-related symptoms including fatigue, sleep disturbance and cancer-related anxiety. The attribution of these results to social prescribing, however, are limited due to the lack of a control. In order to validate this connection and determine if other significant results exist, it is recommended that a randomised controlled trial with a larger sample size is conducted.
- The follow-up period for this study was ten following the initial meeting with the link worker. Though significant findings were identified by this time point, many participants were engaging in ongoing support from the social prescribing link worker at this time and 7 had not yet engaged in an activity or service but had plans to in the future. It would be beneficial for future research to include additional data collection points, potentially at 6 or 12 months follow-up. This would provide further insight into the optimal duration of social prescribing input for individuals living with and beyond cancer, as well as determine if findings are sustained over a longer period of time.
- Further research is warranted to identify the training needs of social prescribing link workers when interacting with and supporting individuals living with and beyond cancer. The link worker involved in this study had a community health background and training which enabled them to offer reassurance around common cancer symptoms experienced by participants. Other models of social prescribing utilise volunteers or lay people within the link worker role, however, and it is unclear whether these individuals would be as effective in their role without proper training.
- To conduct further research exploring the relationship between healthcare professionals and social prescribing programmes based within the community. There was limited buy-in from healthcare professionals for referral of participants into the social prescribing study, and this has been identified in previous literature as a challenge for social prescribing services.
- Further research exploring the acceptability of social prescribing for cancer survivors is warranted. The findings of this study suggest that social prescribing may be an acceptable intervention for cancer survivors however due to the small sample size and the inability to complete a pilot or feasibility study involving the input of cancer survivors, these findings are limited. Future studies would benefit from the inclusion of cancer survivors in the development and

review of the social prescribing model, perhaps by gathering their perspectives and opinions through qualitative focus groups, and to consider these in the optimisation of the social prescribing process for individuals living with and beyond cancer.

6.6.2 Implications for Policy and Practice

Cancer survivors experience continuing symptoms post-treatment such as pain, fatigue, anxiety and cognitive difficulties which can impact upon survivors' ability to participate in activities of importance to them, which in turn affects their quality of life (Silver & Gilchrist, 2011). In this study, some cancer survivors reported difficulty managing these symptoms and a need for better follow-up care and increased support post-treatment. Though cancer support services are available to meet the needs of some individuals, cancer survivors reported a lack of awareness of available cancer support services and in some cases a lack of interest in availing of those services due to available support from family and friends. Social prescribing was perceived by cancer survivors to be a positive implication of filling the gap in post-treatment support. The appeal of social prescribing to these individuals may be in the opportunity to attend activities that are not cancer-focused or facilitated within a cancer-specific service. By addressing the needs of cancer survivors' post-treatment, this ensures cancer services provide an all-round, high quality of care, another key area of development in the National Cancer Strategy (DOH, 2017). In this study, social prescribing, a social support, community-referral intervention, was considered acceptable by cancer survivors, therefore further research regarding its effectiveness and sustainability is warranted.

A barrier to engagement in activity for some participants in this study was the availability (or lack thereof) of voluntary and community sector resources. Some areas offered a greater variety of activities or options that were more financially viable when compared to others, which resulted in some cancer survivors being forced to travel unviable distances to attend their chosen activity or support service. Equitable allocation of resources across all links in the social prescribing chain has been identified as vital for the long-term sustainability of social prescribing (Bertotti et al., 2017; Brandling & House, 2007; Keenaghan et al., 2012; Wildman et al., 2018). Future policy in Ireland should strive to support the voluntary and community sector in providing supports, services and activities to communities throughout the country.

6.7 Study Strengths and Limitations

The strengths and limitations of this study are outlined below.

6.7.1 Study Strengths

The strengths of this study's design and results make it a valuable addition to the current body of literature. These strengths include use of a mixed-methods design, the use of standardised assessment, the role of the researcher and the findings of the study.

Mixed-methods designs utilise both quantitative and qualitative methods, which can help to reduce the disadvantages of using either method in isolation (Matthews & Kostelis, 2011). By using a mixed methods approach, the strengths of each approach are emphasised and the weaknesses can be compensated for (Creswell, 2014). The qualitative data collected in this study provided context and background to the results obtained through the quantitative data collection.

The quantitative findings were obtained by means of four standardised assessments which were chosen due to their high levels of validity and reliability, in addition to their suitability in meeting the objectives of the study. Standardised assessments are regarded as effective in measuring subjective constructs and improve the reliability and external validity of the study (Schofield & Forrester-Knauss, 2015).

Consistent efforts were made by the researcher to reduce the impact of limitations on this study. A strength of this study was the presence of the researcher during quantitative data collection, to enable participants to ask questions and attempt to standardise the environment. In addition to this, the researcher kept a research diary, which regular inputs allowed for reflection and highlighted areas of development, both for the research process and the researcher.

The final strength of this study are the findings. This study contributes to the current body of literature for social prescribing programmes, but is also the first academic study of its kind to explore the impact of social prescribing on individuals living with and beyond cancer. The findings of this study suggest there may be scope for social prescribing to support individuals living with and beyond cancer to improve quality of life and increase activity participation levels. Recommendations for further research in the area have been suggested.

6.7.2 Limitations

This study fulfilled the aim and objectives of the research, however, it is important to consider the challenges and limitations of the study when interpreting these results.

6.7.2.1 Control

The greatest limitation of this study is the lack of a control. Though the quantitative and qualitative results of this study can be compared and corroborated to support the findings of both strands, without a control, the results cannot be confidently attributed to the social prescribing intervention alone. Social prescribing can, however, be considered as a factor that contributed to the results, and this is supported by the qualitative data collected in this study, which provided contextual background to the quantitative measures used.

6.7.2.2 Attrition

There was a high attrition rate within this study, which creates the potential for internal bias. While forty three participants agreed to participate and completed pre-intervention measures, only twenty seven participants were available to complete the follow-up measures and post-intervention interviews. This is due to a variety of reasons, primarily health challenges related to cancer and inability to contact participants at follow-up. This creates the potential for internal bias within the data.

6.7.2.3 Recruitment

Recruitment was slow and difficulties were encountered in the recruitment process. Medical teams were consistently reminded regarding the provision of the PIL at outpatient clinics by the researcher who also attended these clinics. However, survivors suitable for inclusion were not always provided with the PIL. In addition, it is unknown what level of information was given to individuals suitable for inclusion, if any, beyond the participant information leaflet. Future studies should consider how best to increase the rate of recruitment. This may include attending multidisciplinary meetings or medical team meetings to remind staff of the study. Recruitment also took place in a cancer support service located nearby, however this commenced later in the recruitment stage. It may have been more beneficial to have liaised with this service at an earlier stage regarding recruitment in order to increase sample size. Cancer survivors also declined to participate in the study and further research into the reasons for this would be beneficial.

6.7.2.4 Sample Size

The sample size of this study did not meet the criteria for parametric quantitative analysis, which can more sensitively detect statistically significant changes. However, for a qualitative study, the sample provided rich, in-depth data from twenty-seven participants. The findings of this study should therefore be interpreted with caution.

6.7.2.5 Pilot Interview

Due to limitations with recruitment and access to suitable individuals, the interview guide for this study was not piloted. Though the guide was reviewed with various individuals, including the research supervisor, an advanced nurse practitioner and the social prescribing link worker, it would have been advantageous to the study to complete a pilot interview to increase construct validity and reliability.

6.7.2.6 Data Collection Timepoint

An unforeseen challenge of this study was identifying the appropriate time to bring participants in for follow-up completion of measures and engagement in qualitative interview. It was originally envisaged that participants would meet with the link worker and begin engaging in activity within 1-2 weeks, however, this was not the case for a significant number of participants; indeed, some participants had not attended any activity by the second point of data collection. Due to resource limitations, including time, it was determined that it would still be valuable to include these participants in the final study and gain their perspectives of the social prescribing process and the support they received, as well as to identify what barriers they had faced in attending activities.

This poses a challenge for future studies exploring social prescribing for individuals living with cancer to consider. Is engagement with the social prescribing link worker, regardless of attendance at a chosen activity or asset, considered successful social prescribing intervention? The results of this study would suggest that it is, however further research on this phenomenon is warranted to clarify the value of social prescribing regardless of attendance at an activity.

Similarly, if a participant does not attend a formal group activity, but reports a sense of greater occupational balance and engages in more personal activity such as walking, or time with family, and they attribute this change to their interaction with the social prescribing link worker – how is that recorded? Future studies should consider means by which to capture this information.

6.7.2.7 Intervention Fidelity

Though efforts were made to track participant's frequency of engagement in chosen activities and to identify the content and intensity of activities attended (Appendix 14), it was difficult to obtain sufficient data for the purposes of comparison. Furthermore, due to the individualised nature of the social prescribing service, participants attended a wide variety of activities based on their own need and function. As such, it was considered appropriate to focus more on the support provided by the link worker and the impact of social prescribing as an intervention itself than on that of the activities attended. However, it is possible that the results obtained in this study were influenced by the activities participants opted to attend and the frequency with which they attended them. This remains an ongoing challenge for social prescribing studies generally and is likely to pose a challenge for any future attempts to isolate the impact of social prescribing itself as an intervention. Future research studies should take into consideration the difficulties with defining whether successful social prescribing interventions account for the activities participants attend, and if so how to account for the impact of these activities on study outcomes.

6.7.3 Conclusion

This chapter has concluded this research by discussing the research findings in depth, outlining a summary of the research process, providing recommendations for practice and for future research and finally, highlighting the research's strengths and weaknesses.

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During the past week:

	Not at All	A Little	Quite a Bit	Very Much
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you29. How would you rate your overall health during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

30. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

8.2 Appendix 2: Frenchay Activities Index (FAI)

Frenchay Activities Index (FAI)

In the last 3 months how often have you undertaken:

1. Preparing main meals	<input type="checkbox"/> Never (0) <input type="checkbox"/> Less than 1x/week (1) <input type="checkbox"/> 1-2 times a week (2) <input type="checkbox"/> Most days (3)
2. Washing up after meals	<input type="checkbox"/> Never (0) <input type="checkbox"/> Less than 1x/week (1) <input type="checkbox"/> 1-2 times a week (2) <input type="checkbox"/> Most days (3)
3. Washing clothes	<input type="checkbox"/> Never (0) <input type="checkbox"/> 1-2 times in 3 months (1) <input type="checkbox"/> 3-12 times in 3 months (2) <input type="checkbox"/> At least weekly (3)
4. Light housework (dusting, polishing, ironing etc.)	<input type="checkbox"/> Never (0) <input type="checkbox"/> 1-2 times in 3 months (1) <input type="checkbox"/> 3-12 times in 3 months (2) <input type="checkbox"/> At least weekly (3)
5. Heavy housework (changing beds, cleaning floors, hoovering etc.)	<input type="checkbox"/> Never (0) <input type="checkbox"/> 1-2 times in 3 months (1) <input type="checkbox"/> 3-12 times in 3 months (2) <input type="checkbox"/> At least weekly (3)
6. Local shopping	<input type="checkbox"/> Never (0) <input type="checkbox"/> 1-2 times in 3 months (1) <input type="checkbox"/> 3-12 times in 3 months (2) <input type="checkbox"/> At least weekly (3)
7. Social Occasions (incl. at home e.g. visits from friends/family)	<input type="checkbox"/> Never (0) <input type="checkbox"/> 1-2 times in 3 months (1) <input type="checkbox"/> 3-12 times in 3 months (2) <input type="checkbox"/> At least weekly (3)
8. Walking outside for >15 minutes	<input type="checkbox"/> Never (0) <input type="checkbox"/> 1-2 times in 3 months (1) <input type="checkbox"/> 3-12 times in 3 months (2) <input type="checkbox"/> At least weekly (3)
9. Actively pursuing a hobby (e.g. gardening, knitting, painting, window shopping etc.)	<input type="checkbox"/> Never (0) <input type="checkbox"/> 1-2 times in 3 months (1) <input type="checkbox"/> 3-12 times in 3 months (2) <input type="checkbox"/> At least weekly (3)
10. Driving car/going on bus	<input type="checkbox"/> Never (0) <input type="checkbox"/> 1-2 times in 3 months (1) <input type="checkbox"/> 3-12 times in 3 months (2) <input type="checkbox"/> At least weekly (3)

In the last 6 months how often have you undertaken:

11. Travel outing/car ride (e.g. "day out", travel for pleasure)	<input type="checkbox"/> Never (0) <input type="checkbox"/> 1-2 times in 6 months (1) <input type="checkbox"/> 3-12 times in 6 months (2) <input type="checkbox"/> At least weekly (3)
12. Gardening outside	<input type="checkbox"/> None (0) <input type="checkbox"/> Light (occasional weeding or sweeping paths) (1) <input type="checkbox"/> Moderate (regular weeding, raking, pruning) (2) <input type="checkbox"/> Heavy (all necessary work incl. heavy digging) (3)
13. Household maintenance	<input type="checkbox"/> None (0) <input type="checkbox"/> Light (repairing small items, replacing light bulbs) <input type="checkbox"/> Moderate (spring cleaning, picture hanging, routine car maintenance) <input type="checkbox"/> Heavy (painting/decorating)
14. Reading books	<input type="checkbox"/> None (0) <input type="checkbox"/> 1 book in 6 months (1) <input type="checkbox"/> Less than 1 book in 2 weeks (2) <input type="checkbox"/> More than 1 book every 2 weeks (3)
15. Gainful work	<input type="checkbox"/> None (0) <input type="checkbox"/> Up to 10 hours/week (1) <input type="checkbox"/> 10-30 hours/week (2) <input type="checkbox"/> 30+ hours/week (3)

8.3 Appendix 3: Hospital Anxiety and Depression Scale (HADS)

Mood Questionnaire

	I feel tense or 'wound up' (A)		I feel as if I am slowed down (D)
3	Most of the time	3	Nearly all the time
2	A lot of the time	2	Very often
1	From time to time	1	Sometimes
0	Not at all	0	Not at all
	I still enjoy the things I used to enjoy (D)		I get a sort of frightened feeling like 'butterflies' in the stomach (A)
0	Definitely as much	0	Not at all
1	Not quite so much	1	Occasionally
2	Only a little	2	Quite Often
3	Hardly at all	3	Very Often
	I get a sort of frightened feeling as if something awful is about to happen (A)		I have lost interest in my appearance (D)
3	Very definitely and quite badly	3	Definitely
2	Yes but not too badly	2	I don't take as much care as I should
1	A little, but it doesn't worry me	1	I may not take quite as much care
0	Not at all	0	I take just as much care as ever
	I can laugh and see the funny side of things (D)		I feel restless as if I have to be on the move (A)
0	As much as I always could	3	Very much indeed
1	Not quite so much now	2	Quite a lot
2	Definitely not so much now	1	Not very much
3	Not at all	0	Not at all
	Worrying thoughts go through my mind (A)		I look forward with enjoyment to things (D)
3	A great deal of the time	0	As much as I ever did
2	A lot of the time	1	Rather less than I used to
1	From time to time but not too often	2	Definitely less than I used to
0	Only occasionally	3	Hardly at all
	I feel cheerful (D)		I get sudden feelings of panic (A)
3	Not at all	3	Very often indeed
2	Not often	2	Quite often
1	Sometimes	1	Not very often
0	Most of the time	0	Not at all
	I can sit at ease and feel relaxed (A)		I can enjoy a good book or radio or TV program (D)
0	Definitely	0	Often
1	Usually	1	Sometimes
2	Not often	2	Not often
3	Not at all	3	Very seldom

8.4 Appendix 4: Multidimensional Assessment of Fatigue

MULTIDIMENSIONAL ASSESSMENT OF FATIGUE (MAF) SCALE

Instructions: These questions are about fatigue and the effect of fatigue on your activities.

For each of the following questions, circle the number that most closely indicates how you have been feeling during the past week.

For example, suppose you really like to sleep late in the mornings. You would probably circle the number closer to the "a great deal" end of the line. This is where I put it:

Example: To what degree do you usually like to sleep late in the mornings?

1 2 3 4 5 6 7 8 9 10
Not at all A great deal

Now please complete the following items based on the past week.

1. To what degree have you experienced fatigue?

1 2 3 4 5 6 7 8 9 10
Not at all A great deal

If no fatigue, stop here.

2. How severe is the fatigue which you have been experiencing?

1 2 3 4 5 6 7 8 9 10
Mild Severe

3. To what degree has fatigue caused you distress?

1 2 3 4 5 6 7 8 9 10
No distress A great deal of distress

CONTINUED ON NEXT PAGE →

8.5 Appendix 5: Participant Information Leaflet

PARTICIPANT INFORMATION LEAFLET

An exploration of the impact of a social prescribing service for individuals living with and beyond cancer

Principal Investigator: Dr. Deirdre Connolly, Discipline of Occupational Therapy, Trinity Centre for Health Sciences, St James' Hospital, James' Street, Dublin 8

Co-Investigators: Professor John Kennedy, Consultant Oncologist, St James' Hospital; Dr. Cliona Grant, Consultant Oncologist, St James' Hospital; Dr. David Robinson, Consultant Geriatrician, St James' Hospital; Ms. Roisin Ryder, Community Development Worker, Fatima Groups United; Ms. Chloe O'Hara, Discipline of Occupational Therapy, Trinity College, Dublin

You are being invited to participate in a research project to explore social prescribing as a method for helping individuals with cancer to link with activities in their community. However before you decide whether to give permission to participate in the study you should understand what the study will involve. Please read this leaflet carefully and discuss it with others before you decide if you want to take part.

PART 1 – THE STUDY

Why is this study being done?

Previous research has identified that participating in community-based activities help people with chronic health conditions to improve their health and well-being. However, some people sometimes have difficulty finding suitable activities in their communities or lack self-confidence to attend their local community-based activities. Social prescribing is a community-based service that links people to activities in their local community to help them to improve their physical and/or mental health. We are therefore carrying out this study to explore if social prescribing is helpful for people with cancer help them to participate in community-based activities during or after their cancer treatment.

There are many individuals who attend different types of activities in their communities and that do not require the assistance of a social prescriber to link them with these activities. For those individuals who are already engaging in activities in their community and therefore do not need a social prescribing service, we want to find out what kind of activities help people to manage their cancer during and/or after treatment.

Why am I being asked to take part?

This study is for people with cancer attending St. James' Hospital oncology services. You have therefore been asked to take part in this study as you have been diagnosed with cancer and are currently attending St. James' Hospital oncology services.

Do I have to take part? What happens if I say no? Can I withdraw?

You are under no obligation to take part in this study. If you decide not to take part it will not affect your current or any future treatment in St. James' Hospital in any way. If you decide to take part in the study, you can change your mind and withdraw your participation at any time by contacting the principle investigator, Dr. Deirdre Connolly. This will not affect your current or future treatment in St. James' Hospital in any way.

How will the study be carried out?

If you decide to participate in the study you will be invited to come to the Discipline of Occupational Therapy in the Trinity Centre for Health Sciences (in the grounds of St. James' Hospital) where you will meet a member of the research team. Taking part in this study involves agreeing to participate in a social prescribing service as a method for linking people with cancer with community-based activities and/or services. If however, you do not wish to participate in the social prescribing study, you will be invited to participate in an interview to discuss what activities you currently do during your cancer treatment.

What happens if I agree to take part?

If you want to participate in social prescribing you will be asked to complete four questionnaires before and after you participate in the social prescribing service and ten weeks following your final involvement with the service. The questionnaires are:

- The Hospital Anxiety and Depression Scale. This scale measures levels of depression and anxiety and is valid for community-dwelling adults with chronic diseases.
- Quality of life scale: EORTC QLQ-C30. This is a cancer specific quality of life measure.
- Frenchay Activities Index (FAI). The FAI measures the frequency in which individuals engage in activities of daily living and community and leisure activities.
- The Multidimensional assessment of Fatigue. This measures the level of fatigue you are experiencing.

You will also be required to participate in an interview with the researcher about your experiences of the social prescribing service. This will take place ten weeks after you finish attending the service. The questions that will be asked during the interview will focus on your experience of attending the service. These questions will include:

- How did you hear about the service?
- Did the service help you to identify activities in your local area in which you wanted to participate?
- Did you attend the activities?
 - If no, why not?
 - If yes, what did you attend? Did you enjoy the activities?
- Did attending the service make any difference to your physical and/or mental health and well-being?
- Have you started doing other activities as a result of attending the service?

- Have you any recommendations for changing and/or improving the social prescribing service?

It is anticipated that the interview will take approximately 30-40 minutes. The interview will be audiotaped and fully transcribed. You may review the interview transcript and can remove any section/s you do not wish to be included in the research findings.

Are there any benefits to me or others if I take part in the study?

If you decide to take part in the study you will get help from the social prescribing link worker to identify activities you want to do. The social prescribing link worker will then find out for you where and how you can access these activities in or near your local community. The findings from this study will hopefully help to inform the development of future social prescribing services for individuals living with and beyond cancer.

Are there any risks to me or others if I take part in the study?

We do not anticipate any risks to you from participating in this study. However should you become distressed at any point during the study period the following supports services are available:

- AWARE: 1800 80 48 48
- Samaritans in Ireland: Freephone 116 123

Will I be told the outcome of the study? Will I be told the results of any tests or investigations performed as part of this study that relate to me?

You will be invited to a seminar when the study has finished to tell you about the findings of this study. We also hope to present the findings at cancer-related medical conferences and submit an article about the study to a cancer-related medical journal.

PART 2 – DATA PROTECTION

What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

Your medical records will be consulted to make sure you are eligible to participate in the study. Personal identifiable data that will be collected about you is your name, age, date of birth and the type of cancer you have.

What will happen my personal data?

Measures will be taken to protect your identity when processing the data. Any identifying information will be removed from the stored data. Instead of your name, a research number will be used. This number will be put on your questionnaires. A document (called the “key”) will link your name to the number. This document will be kept separate from the

questionnaires to protect your identity. This document will be destroyed at the end of the study. All other data collected will be stored securely and confidentially for five years and then destroyed.

Who will access and use my personal data as part of this study?

The PI, Dr. Deirdre Connolly and the research assistant on this study, Ms. Chloe O’Hara, are the only two people who will have access your personal data.

Will my personal data be kept confidential? How will my data be kept safe?

All data collected for this study will be stored securely on an encrypted, password protected computer that is accessible only by the PI, Dr. Deirdre Connolly and the research assistant on this study, Ms. Chloe O’Hara. No personal data will appear in any reports, presentations or journal publications arising from this study.

Until the data has been fully analysed by the researchers you have the right to the following:

- request access to your data and a copy of it
- to have any inaccurate information about you corrected or deleted
- to have personal data deleted
- to limit who has access to your data for processing

What is the lawful basis to use my personal data?

Your data will be processed for the legitimate interest of health research (Article 6;1(f), General Data Protection Regulation, 2016) and scientific research purposes (Article 9;2(j), General Data Protection Regulation, 2016).

Is this project covered by insurance?

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

PART 3 – COSTS, FUNDING & APPROVAL

Will it cost me anything if I agree to take part?

There will be travel costs incurred to drive or take public transport to meet the researcher who is based in the Trinity Centre for Health Sciences, St. James’ Hospital. However, every effort will be made to minimise this cost such as meeting you when you attend a medical appointment in St. James’ Hospital if you prefer this to a separate meeting with the researchers.

Who is funding this study? Will the results study be used for commercial purposes?

This study is being funded by the Dean of Health Sciences Research Initiative fund and the Irish Cancer Society. No funding is used to pay the researchers to recruit participants for this study. The findings will not be used for commercial purposes.

Has this study been approved by a research ethics committee?

This study received ethical approval from the St James' and Tallaght University Hospitals' research ethics committee (<https://www.tuh.ie/Departments/Research-and-Ethics>) on 26.6.2018. None of the research team have any links to this ethics committee.

PART 4 – FUTURE RESEARCH

Will my personal data be used in future studies?

Your personal data will not be used in any future studies without obtaining your explicit consent.

PART 5 – FURTHER INFORMATION

Where can I get further information?

You can get further information or answers to any questions about the study, your participation in the study, and your rights, from the principle investigator Dr Deirdre Connolly, Discipline of Occupational Therapy, Trinity College, Dublin. She can be contacted by telephone at (01) 8963216 or by email at deirdre.connolly@tcd.ie.

The data controller for this study is Dr. Deirdre Connolly

The data processors for this study are Dr. Deirdre Connolly and Ms. Chloe O'Hara, research assistant

What happens if I wish to make a complaint?

If you wish to make a complaint about any aspects of this study, you can contact the principle investigator Dr Deirdre Connolly, Discipline of Occupational Therapy, Trinity College, Dublin. She can be contacted by telephone at (01) 8963216 or by email at deirdre.connolly@tcd.ie

Will I be contacted again?

You will not be contacted again beyond the study completion date of 31st August 2019.

8.6 Appendix 6: Consent Form

CONSENT FORM

An exploration of the impact of a social prescribing service for individuals living with and beyond cancer

To be completed by the **PARTICIPANT**:

I have read and understood the information leaflet.	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I have had the opportunity to discuss the study, ask questions about the study and I have received satisfactory answers to all my questions.	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I have received enough information about this study.	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I understand that I am free to withdraw from the study at any time without giving a reason and this will not affect my future medical care.	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I agree to allow the researchers use my information (personal data) as part of this study as outlined in the information leaflet.	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I agree to allow the researchers access my medical records as part of this study	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I agree to be contacted by researchers as part of this study	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I agree to take part in the study	YES <input type="checkbox"/>	NO <input type="checkbox"/>

Participant's Name (Block Capitals):	
Participant's Signature:	
Date:	

To be completed by the **RESEARCHER**:

I have fully explained the purpose and nature (including benefits and risks) of this study to the participant in a way that he/she could understand. I have invited him/her to ask questions on any aspect of the study.	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I confirm that I have given a copy of the information leaflet and consent form to the participant.	YES <input type="checkbox"/>	NO <input type="checkbox"/>

Researcher's Name (Block Capitals):	
Researcher's Title & Qualifications:	
Researcher's Signature:	
Date:	

8.7 Appendix 7: Interview Guide

NB BEFORE YOU START Participant #, Date, Time.

Points to Cover: Interview will be recorded. Can stop at any time and if they wish to omit any section of interview they are entitled to inform researcher of same. Encourage openness and honesty; study is to evaluate the impact of social prescribing and their opinion, both good and bad, is invaluable.

- **Do you have any questions before we start?**

- **Getting involved in and accessing the service – how and why? Attitudes and expectations prior to engaging**
 - How did you hear about the service?
 - Why did you decide to get involved with the service?
 - What did you hope to get out of the service?
 - Did you have a set goal in mind when starting out? Can you elaborate?
 - Did you attend other activities before? Can you tell me about them? Where? When? With who? Do you still attend? If no, was there a reason you stopped?

- **Could you tell me about your experience of participating in the social prescribing service?**
 - Tell me about the activities that the service identified for you.
 - What did you attend? Where? When? With who? How often?
 - Did you enjoy the activity?
 - Did you learn anything new from attending the activity?
 - If you were not able to attend activities, could you tell me more about why?
 - Barriers – time? Other commitments? Lack of interest?

- **Could you tell me about the impact the service has had on your health and wellbeing?**
 - Physical e.g. energy, strength, fitness, pain

- Mental e.g. mood, outlook
 - Social e.g. interaction, isolation
 - Activity participation – doing more now than before?
-
- **Could you tell me about the impact the service has had on your activity participation levels?**
 - Have you started attending other activities as a result of the SP service?
 - Did you achieve what you wanted to get out of the service i.e. did you reach your goal?
-
- **Have you any recommendations on how social prescribing could be improved for individuals living with and beyond cancer?**
 - Outreach methods/advertisement
 - Support offered by link worker
 - Frequency of support

8.8 Appendix 8: Ethical Approval Letter

SJH/TUH Research Ethics Committee Secretariat
email: researchethics@tuh.ie



Tallaght
University
Hospital

Ospidéal
Ollscoile
Thamhlachta

An Academic Partner of Trinity College Dublin

Prof. Deirdre Connolly
Occupational Therapy Department
School of Medicine
Trinity Centre for Health Sciences,
St. James's Hospital
James's Street
Dublin 8

26th June 2018

RE: An exploration of the impact of a social prescribing service for individuals living with and beyond cancer

REF: Reference 2018/06 Chairman's Action (7)
(please quote reference on all correspondence)

Dear Prof Connolly

The REC is in receipt of your recent request to SJH/TUH Research Ethics Committee in which you queried ethical approval for the above named study.

The Chairman, Prof. Richard Dean, on behalf of the Research Ethics Committee, has reviewed your correspondence and granted ethical approval for this study.

Yours sincerely,

A handwritten signature in black ink, appearing to be 'D. Connolly'.

Secretary
SJH/TUH Research Ethics Committee

The SJH/TUH Joint Research and Ethics Committee operates in compliance with and is constituted in accordance with the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.

 Ospidéal na hOllscoile, Thamhlacht
Thamhlacht, Baile Átha Cliath, D24 NR0A, Éire
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Tallaght University Hospital is a registered
business name of 'The Adelaide and Meath
Hospital, Dublin Incorporating The National
Children's Hospital'.

	receiving treatment for cancer?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
7.	Treatments undergone/undergoing	Radiotherapy <input type="checkbox"/>	Chemotherapy <input type="checkbox"/>
		Surgery <input type="checkbox"/>	Hormone therapy <input type="checkbox"/>
		Other (please specify)	

8.	Marital Status	Single <input type="checkbox"/>	Married <input type="checkbox"/>
		Separated/divorced <input type="checkbox"/>	Widowed <input type="checkbox"/>
		Coupled <input type="checkbox"/>	
9.	Living Situation	Living alone <input type="checkbox"/>	Living with family <input type="checkbox"/>
		Living with non-family <input type="checkbox"/>	
10.	Highest Level of Education	Primary <input type="checkbox"/>	
		Secondary as far as junior/inter cert <input type="checkbox"/>	
		Secondary to Leaving cert <input type="checkbox"/>	
		College/University <input type="checkbox"/>	
11.	Employment Status	Currently working full-time <input type="checkbox"/>	
		Currently working part-time <input type="checkbox"/>	

		<p>Not working due to cancer <input type="checkbox"/></p> <p>Not working (Retired) <input type="checkbox"/></p> <p>Not working (Other) <input type="checkbox"/></p>
12.	<p>Do you currently attend any community activities?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>If yes, please specify:</p> <p>What? _____</p> <p>Where? _____</p> <p>How _____ often?</p> <p>When did you start? _____</p>

8.10 Appendix 10: Excerpt from Reflective Journal

This extract was originally hand-written in the researcher's reflective journal. It has been typed for the purpose of this document.

Met with two participants this week. The first meeting felt slightly chaotic, but may have been a result of my own nerves. I had not met this participant before, only spoken to him on the phone.

I first reviewed the PIL with him again and asked him to sign the consent form. He seemed quite active and restless and asked me to read through the pages with/for him – this turned out to be as a result of low literacy, as per the participant. This resulted in me asking him every question in the measures rather than him completing it himself. This eventually led to some agitation from him and, as per the participant, made the interview feel somewhat like an interrogation. I apologised and asked him how I could make him feel more comfortable. I made him a cup of tea and explained that some of the questions across the measures repeated themselves, but that each measure was included in the study for a different purpose. This was a good learning experience as I had to stop and look at my measures and justify the inclusion of each verbally, to a participant. It also gave me a better idea of the length of time it could take to do the measures and that realistically, unlike those attending social prescribing in the [local] community centre, it would not be feasible to refer everyone to their desired activities in the first session.

This was also emphasised by the fact the participant said he did not want to attend the centre as he used to live in that area and didn't want to meet anyone he knew there. He asked if I could find somewhere else to attend. This showed me the requirement to be flexible when meeting participants and that the process of social prescribing, like that of OT, may not be fluid. It also suggests that running a service based on the idea that one session is enough to properly support people to attend activities would unlikely be enough. Going forward, it will be interesting to see how often the link worker may need to meet clients - ? twice or three times perhaps (or at least have some form of communication with them, be that by phone, etc.) before they can attend the activities they like.

The second was a more relaxed meeting. I felt more comfortable with what I was doing and what might work well for the participant to feel at ease. It appears important that the participants feel listened to and are given time to share their story and how chit

chat can give me a more comprehensive view of the people I'm working with. So with this participant, [link worker] encouraged chit chat and endeavoured to ask questions and probe him when interesting topics came up, e.g. around his initial diagnoses, his treatment and his anxiety. This gave us a better idea of what might help him and to try and set shared goals prioritising activities that he would both like to attend and also that might help him, e.g. men's shed could be good as he's interested in tinkering and building things and it would also provide him with a social outlet.

8.11 Appendix 11: Audit Trail Extract

Please note names and identifying details of participants and contributors to the study have been redacted for purposes of confidentiality.

Wednesday 13/02/2019

Meetings: Was due to meet [supervisor] at 10am but she needed to reschedule. Now due to meet for feedback on Monday 18th of Feb at 2pm.

Clinic: Met [Consultant's secretary] to inquire re: potential participants. One participant identified as eligible – gave leaflet to [secretary], advised she will attach leaflet to NOTES section of chart as [secretary] noticed that the doctors missed the leaflet just inside the chart the previous week. New referrals will first meet the Registrar but returning patients will meet [Consultant]. [Secretary] also offered to take a leaflet and remind [Consultant] of the study.

Clinic: Contacted [CNS] regarding the palliative care clinic today. She said with the nurses strikes there was nobody particularly suitable. I told her I would call in next Tuesday 19th of Feb to catch up and review.

GPs: Received missed call & voicemail from [GP] of the [GP practice address]. He said he would be interested to help us recruit for the study and asked me to ring him back. Rang back and was informed he isn't in work until tomorrow – will ring back then.

Intakes: Rang [potential participant] to answer questions about the study and book her into an intake for Friday 22nd Feb at 10am. Rang [P9] to arrange for her to come in and complete her baseline assessments prior to starting an activity – due in for Thursday 14th of Feb at 1:30pm.

Journal: Completed reflective journal entry

Thursday 14/02/2019

Clinic: Attended Kennedy/O'Donnell clinic. Approached by three potential participants; two ladies and one man. They told me they would think about it and get in contact if they were interested or had further questions.

GPs: Rang [GP]. He would be happy to help us with recruitment and said they have several individuals with cancer. He gave me his address and I agreed to send him out more leaflets. I told him I would follow up with him in a week or two to see how they were getting on.

Intakes: Met [P9] and completed baseline assessments.

Clinic: Followed up with [Consultant]. Only suitable participant did not appear in clinic that day.

Friday 15/02/2019

Intake: [potential participant] rang to ask if she could come in early – I asked her to come in for 11am. At 10:30am she texted me to say the doctor's words were just sinking in with her – she needs reconstruction after her eye surgery and feels unsettled by the thought so she would prefer to contact me after the treatment. I told her that was fine and that I was here for support at any time if she needed it.

Monday 18/02/19

Clinic: Attended clinic. Nobody suitable, as per CNS. Checked in with day ward nurses, advised nobody within catchment area. Left more leaflets.

Meetings: Met [supervisor] for Literature Review feedback & review of study progress.

Tuesday 19/02/2019

Clinic: Attended [consultant] clinic, approached by 2 people with queries regarding the study and distributed further information. Advised they would be in contact if they were interested; wanted to think further about it.

Wednesday 20/02/2019

Meeting/Promotion: Went out to [D24] Primary Care Centre to speak with 9 OTs, some of whom work in the areas relevant to our study. Distributed 5 leaflets to the 5 OTs who work in that area and promised to follow up with an email to [OT Manager] with more information.

Participant: [potential participant] cancelled meeting at 2pm when I rang her an hour before to check as she had visitors. Will try again next week.

Participant: [P19] cancelled intake meeting Fri 22nd at 10am when I rang to confirm. Tentatively rebooked for Wednesday 27th but she would like me to ring her the day before to confirm and pick a time.

Meeting with [Link Worker]: Met to figure out what areas we would expand the study to. Ultimately decided most suitable to add would be D1, D2, D4, D20, D22 and D24. First three are centrally located and feature regularly on charts on St. James' as per nursing staff, latter three are large areas likely to yield higher numbers and they have links in the F2 to other centres there which may make service mapping easier. Caught up regarding several participants, including P4, P9, P10, P11, P12 and P13

Follow Ups: Rang P7 to book him in for follow up

Journal: Completed reflective journal entry

8.12 Appendix 12: Participants Lost to Follow-Up

Participant Number	Reason for Withdrawal	Number of SP Interactions	Activity Attended	Activity Prior to SP?
1	Health (stroke onset)	1	None, health declined	None
3	RIP	4	None	None
6	RIP	4	None	Irish Classes, Knitting
8	Health (cancer progression)	5	None, health declined	None
12	Uncontactable	3	None as of last contact	None
15	Health (cancer progression)	8	None	None
17	Health (mental health decline)	15	Drama, Cooking, Art, Career Guidance, Counselling	Dance Group
18	Uncontactable	7	Career Guidance	None
21	Uncontactable	6	Unknown, referred to cancer support services	None

26	Health (cancer progression)	5	None, health declined	None
27	Uncontactable	5	None as of last contact	Community allotment (gardening)
28	Bereavement	2	None, bereavement occurred	None
30	Family commitments (small children)	4	None, withdrew from study	None
32	Health (cancer progression)	5	None, health declined	None
41	Health (cancer progression)	4	Hospital physio OPD pilates	None
42	Unable to contact	5	Referred to hospital physio OPD	None

8.13 Appendix 13: Social Prescribing Interactions

P#*	Activity Pre SP?	# of SP interactions
2	None	8
4	None	9
5	Tutoring	7
7	None	4
9	Piano Lessons	9
10	Part-time education courses	4
11	Cancer Support Service (Yoga)	6
13	None	4
14	None	4
16	Art	5
19	None	6
20	None	5
22	None (previously community clean up)	5
23	None	6
24	None	5
25	Knitting Class	3
29	Cross Fit	5
31	Community allotment (gardening), book club,	5

cycling		
33	None	5
34	None	4
35	None	4
36	None	4
37	None	6
38	Dance class	5
39	Cancer support (counselling)	4
40	None	5
43	None	6

8.14 Appendix 14: Description and Frequency of Activity Attended

P#	Activity Attended	Frequency of Engagement
2	<u>Guitar Lessons:</u> taught by one instructor in a group setting (~6 people, same group week by week) in a local community college classroom, held once a week	6
4	<u>Dance:</u> taught by one instructor in a group setting (up to 20 people, varied week by week) weekly and intended for light exercise purposes. Begin seated for warm-up, includes a tea-break. Post tea-break, progress to standing exercises/dancing. Held in same community centre as SP service. Participant limited by weather and decreased mobility to attend group regularly.	2
5	<u>Qi Gong:</u> taught by one instructor in a group setting (up to ~10 people) in local community centre. Group remains same for 8 weeks. Stopped attending after bad experience with instructor ~week 5.	5
7	<u>Hot Yoga:</u> 2 classes held weekly in local gym, lasts approx. one hour, group setting facilitated by one instructor. Participant sometimes attended more than 1x per week	10
9	<u>Ukelele:</u> one to one lessons with skilled instructor, held once a week in own home.	2
10	<u>Cooking Group For Men:</u> Group class held weekly in same community centre as SP. For men only. Facilitated by one instructor.	5
11	Did not attend formal activity, limited by active chemotherapy	0

	<p>and surgery input.</p> <p>Began walking after meeting with link worker. Planning to begin swimming and art classes in autumn.</p>	
13	<p><u>Tai Chi:</u> Group class held weekly in same community centre as SP service. Facilitated by one instructor. Lasts approx. 1 hour. Focuses on gentle movements.</p> <p><u>Yoga:</u> Group class held weekly in same community centre as SP service. Facilitated by one instructor. Lasts approx. 1 hour. Focuses on gentle movements.</p> <p><u>Relaxation/Meditation:</u> Group class held weekly in same community centre as SP service. Facilitated by one instructor. Lasts approx. 1 hour. Uses various methods including progressive muscular relaxation, visualisation and mindfulness.</p> <p><u>Dance:</u> taught by one instructor in a group setting (up to 20 people, varied week by week) weekly and intended for light exercise purposes. Begin seated for warm-up, includes a tea-break. Post tea-break, progress to standing exercises/dancing. Held in same community centre as SP service.</p>	<p>Tai Chi: 4</p> <p>Yoga: 4</p> <p>Relaxation: 4</p> <p>Dance: 2</p>
14	<p><u>Culture Club:</u> Individuals sign up to a texting service that alerts them to upcoming theatre shows in the Abbey Theatre. The Culture Club facilitates low-cost purchasing of the tickets for members and arranges for members to meet as a group at the show, facilitating increased social interaction. Organised and funded by same community centre as SP.</p> <p><u>Tai Chi:</u> Group class held weekly in community centre and facilitated by one instructor. Lasts approx. 1 hour. Focuses on gentle movements.</p> <p><u>Yoga:</u> Group class held weekly in same community centre as SP. Facilitated by one instructor. Lasts approx. 1 hour. Focuses on gentle movements.</p>	<p>Culture Club: 1</p> <p>Tai Chi: 4</p> <p>Yoga: 3</p> <p>Mindfulness: 4</p>

	<u>Mindfulness:</u> 4-week course held in same community centre as SP, facilitated by one instructor, group setting.	
16	Did not attend formal activity. Attributed this to low motivation. Was already attending art class weekly.	0
19	<u>Mixed Media Art:</u> Group class held weekly in same community centre as SP. Facilitated by one instructor. Lasts approx. 1 hour. <u>Cancer Support Pilates:</u> Pilates class held twice weekly in cancer support service for cancer survivors. Lasts approx. 45 minutes, with 15 minutes at end for socialisation.	Art: 6 Pilates: 4
20	Did not engage in formal activity as began engaging in yoga at home online as yoga class was consistently full when she attempted to attend. Was already attending an art studio weekly but began walking over to studio in attempt to increase physical fitness after meeting with link worker. Had acquired a job during the study period and was planning to move to the Midlands in September 2019. Was hopeful to identify yoga and art classes there.	0
22	<u>Community Clean-Up Volunteering:</u> Though not a formally organised activity, participant was once part of informally scheduled community clean up in local estate. Had identified this as a goal to begin engaging in again. Participant began spending one evening a week weeding, sweeping and tidying estate and was joined by other neighbours in doing so, therefore creating a weekly community clean-up volunteer group.	~4-5 evenings overall
23	Did not attend formal activity. Was working part-time and did not find anything of interest to engage in further, though was continuing to work with the link worker to identify opportunities for adult education.	0
24	<u>Career Guidance:</u> One to one session with adult guidance	Career

	<p>counsellor in local community college. Follow-up phonecall provided.</p> <p><u>Volunteering:</u> Began volunteering at the Food Co-Op assisting in the shop weekly.</p>	<p>Guidance: 2</p> <p>Volunteering: 2</p>
25	<p>Did not attend any activity due to fatigue and anxiety regarding further investigations related to cancer. Was hopeful to begin mindfulness in September 2019.</p>	0
29	<p><u>Reflexology:</u> One to one reflexology sessions. Due to price (€60 per session), participant attended twice per month. Unknown prior to attendance but facilitator had history of breast cancer which was of benefit to participant.</p> <p><u>Walking:</u> Participant began daily walks on her own, approx. 1 hour in duration, and listened to podcasts during same.</p>	<p>Reflexology: 4</p> <p>Walking daily</p>
31	<p>Did not attend formal activity. Was already member of gay men's book club and began engaging in community allotment (gardening) just prior to meeting with link worker. Was hopeful to join an orchestra in September 2019.</p>	0
33	<p><u>Tai Chi:</u> Group class held weekly in community centre and facilitated by one instructor. Lasts approx. 1 hour. Focuses on gentle movements.</p> <p><u>Relaxation/Meditation:</u> Group class held weekly in same community centre as SP service. Facilitated by one instructor. Lasts approx. 1 hour. Uses various methods including progressive muscular relaxation, visualisation and mindfulness.</p> <p>Felt tai chi too sore on knee. Community centre was far away, required taxi to attend (barrier).</p> <p>Hoping to attend Reflexology in Cancer Support Service in September 2019.</p>	<p>Tai Chi: 1</p> <p>Relaxation: 1</p>
34	<p><u>Sewing Workshop:</u> 3 hour sewing workshop held in local</p>	1

	shop.	
35	<p><u>Cancer Support Mindfulness:</u> Drop-in class held twice weekly in cancer support service for cancer survivors. Approx. 1 hour.</p> <p><u>Cancer Support Reflexology:</u> Drop-in class held twice weekly in cancer support service for cancer survivors. Approx. 1 hour.</p> <p><u>Cancer Support Yoga:</u> Drop-in class held twice weekly in cancer support service for cancer survivors. Approx. 1 hour.</p>	<p>Mindfulness: 7</p> <p>Reflexology: 2</p> <p>Yoga: 5</p>
36	<p><u>Men's Health Day:</u> Health promotion event held in same community centre as SP service. Focused on men's health. Provided health check-ups, weigh-ins and socialisation.</p> <p><u>Choir:</u> Local choir group, held weekly. Approx. 2 hours practice per week. Sing at mass every Sunday. Participant was previous member but rejoined after meeting with link worker.</p> <p>Planning to take up swimming lessons in September 2019.</p>	<p>Men's Health: 1</p> <p>Choir: 5</p>
37	<p><u>Cancer Support Counselling:</u> Free one to one counselling sessions provided within cancer support service to cancer survivors. Course of 6 sessions provided initially, with possibility to extend to 8, 10 or 12 if required.</p> <p><u>Men's Health Day:</u> Health promotion event held in same community centre as SP service. Focused on men's health. Provided health check-ups, weigh-ins and socialisation.</p> <p><u>Tai Chi:</u> Group class held weekly in community centre and facilitated by one instructor. Lasts approx. 1 hour. Focuses on gentle movements.</p>	<p>Counselling: 3</p> <p>Men's Health: 1</p> <p>Tai Chi: 3</p>
38	<p><u>Career Guidance:</u> One to one session with adult guidance counsellor in local community college. Follow-up phonecall provided.</p>	<p>Career Guidance: 2</p> <p>Support Group:</p>

	<u>Cancer Support Group:</u> Support group held within cancer support service for individuals with secondary cancer diagnoses.	1
39	Did not attend formal activity. Had bereavement mid study, worked Mon-Weds and children off during summer which took up her time. Planned to attend Living Well With Cancer Conference in September.	0
40	<u>Knitting Group:</u> Knitting group in local wool shop, held weekly. Not facilitated by any trainer but intended for group occupation in knitting. <u>Bloom:</u> Gardening festival held yearly. <u>Hiking:</u> Took up hiking with family members. Went on walk to Howth, plans to complete Bray to Graystones week post data collection. <u>Walking:</u> Took up walking with husband and grandchildren 2-3 times weekly.	Knitting: 5 Bloom: 1 Hiking: 1 Walking: 2-3 times weekly
43	<u>Volunteering:</u> Volunteering with asylum seekers. Arranged through volunteer.ie. Started only one week prior to data collection due to phone being broken and unable to contact.	Volunteering: 1

A STUDY ON SOCIAL PRESCRIBING FOR PEOPLE LIVING WITH CANCER



Do you live in...

D1	D2	D6	D7	D8
D10	D12	D20	D22	D24?

Are you interested in receiving information & support to access community-based activities such as:

- | | | |
|-----------------|------------------|-------------|
| Mindfulness | Exercise | Education |
| Healthy Cooking | Computer Classes | Gardening |
| Dance | Art/Drawing | Men's Sheds |



You are invited to participate in a research study conducted by Trinity College to explore the impact of social prescribing on individuals living with/beyond cancer in Ireland

FOR MORE INFORMATION & ENQUIRIES PLEASE CONTACT CHLOE O'HARA AT 089 941 1740 OR EMAIL HER AT OHARAC3@TCD.IE

Social Prescribing Call Chloe 0899411740	Social Prescribing Call Chloe 0899411740	Social Prescribing Call Chloe 0899411740	Social Prescribing Call Chloe 0899411740	Social Prescribing Call Chloe 0899411740	Social Prescribing Call Chloe 0899411740	Social Prescribing Call Chloe 0899411740	Social Prescribing Call Chloe 0899411740
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