Learning what really matters to older adults living with and beyond cancer through co-design

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March 2024

A thesis submitted in partial fulfilment of the requirements of Edinburgh Napier University, for the award of Doctor of Philosophy

Acknowledgements

I would like to thank my supervisors Dr Catherine Mahoney and Dr Karen Campbell, with special thanks to Prof Richard Kyle. Without Richard’s patience and encouragement, I definitely wouldn’t be at this point or submitting this thesis. I would also like to thank everyone who took part in the study or contributed in any small way, your contribution was so valuable and without it the study would not have been possible. I enjoyed getting to know everyone who took part and contributed, and this has definitely been one of the best parts of doing a PhD. Thanks also to Alix, Annie, Graham and Jenny all of whom acted as second facilitators or reviewers, and who joined me in a moan at the pub on many occasions. Finally, I would like to say thanks to my husband, as well as my family and friends, who have been very supportive, especially in these last few months where I’ve definitely been very boring and maybe a little grumpy.

Abstract

In the UK 66% of all cancers are diagnosed in those aged 65 and over. Increased physical activity, healthy diet and reduced sedentary time can alleviate the impact of cancer and associated treatments. Behaviour change interventions are becoming increasingly common. First a systematic review was conducted to explore the effectiveness and acceptability of these interventions. Issues were identified in the current literature base, leading to the aim: To use co-design to develop intervention recommendations with and for older adults living with and beyond cancer to improve the behaviours diet, physical activity, and sedentary time.

This thesis reports a 12-month co-design process, involving eleven older adults living with and beyond cancer (mean age=72), and nine professionals/volunteers. The process consisted of three parts: Part A - Preparing, Part B - Co-designing and Part C - Evaluating. Part B drew on Experienced Based Co-Design, a structured method of co-design. The key stages of EBCD were incorporated in the process, with the addition of some adaptations to achieve the planned aims and objectives. Data generated was analysed using a 2-step thematic analysis approach.

Participants expressed a greater interest in social interactions than the target behaviours throughout the process. Three key recommendations were developed: (1) Social is key – any future intervention for this population should have a significant social element; (2) Considering the individual – different individuals have different needs and different expectations from interventions; and (3) Enabling access – considering practical barriers to participation in programmes and interventions. The tensions, challenges, and benefits of using co-design for intervention development are also explored.

Co-design should continue to be used to ensure interventions and services are acceptable for older people living with and beyond cancer. However, efforts should be made to ensure these processes move beyond consultation and truly put the individuals at the centre.

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Chapter 1. Introduction

This thesis provides evidence to inform the development of future interventions and services to support older adults living with and beyond cancer, with an initial focus on the promotion of physical activity, healthy diet and reduced sedentary time. It does this by reporting findings from a co-design process with older adults living with and beyond cancer. Throughout, I propose the needs of individuals in intervention and service design must be put at the forefront from the outset.

1.1 Chapter overview

This chapter lays the foundation for this work by providing a broad overview of the rationale behind the study drawing primarily on current literature, as well as my personal perspective. This chapter also describes the thesis structure. Firstly, I consider some key terms in the thesis. I then propose the rationale for the work, also exploring my perspective and describing how my background and previous experience has led to an interest in collaborative approaches, working with the target population, rather than to or for them (“doing with, not to”). After, I explain the selected setting for the research, i.e., in the community. I then discuss the current literature regarding our understanding of health and the necessity to focus on older adults living with and beyond cancer due to the increase in this population. I explore the behavioural focus of the research, specifically considering the beneficial effects of physical activity, diet and sedentary time for older adults living with and beyond cancer. All of which culminates in the acknowledgement of a need for interventions to promote these behaviours in this population. Finally, I briefly describe the flow of the thesis, wherein I acknowledge some chapters do not follow the format of a ‘traditional’ thesis and justify this based on the iterative flow of the methods used.

1.2 Phrases and terms

Throughout the thesis I have selected and used some specific terms and phrases. I want to consider these terms and phrases at the outset before proceeding with the body of the thesis. These phrases have been considered here as they can be open to different interpretations. These phrases include older adult living with and beyond cancer, older adult, and participants.

The term **older adult** has been selected to reflect that all participants were over the age of 65. Sixty-five is the age at which most Westernised countries defines individuals as older adults, including the UK and specifically Scotland (Kowal & Dowd, 2001; NHS England; Scottish Public Health Network, 2013).

Next to consider is the term **older adult living with and beyond cancer**. This phrase effectively reflects the target population but also moves away from the term survivor. This is in line with current policy use and understanding of the negative connotations associated with the term survivor, for example having a good outcome only due to personal characteristics or the assumption that "survivors" must take on an advocacy role (Berry et al., 2019; Department of Health et al., 2013; Surbone et al., 2013). Individuals included in the study could be at any stage in the cancer journey, if they were not receiving any treatment (e.g., surgery, chemotherapy, radiotherapy) but could be taking long term medication and felt able to participate. In essence those not currently being seen in acute review settings, which was important as the study was community based.

The term **participants** has been used to refer to those involved in the study, other than the researcher. In hindsight it may have been more suitable to use another term, for example co-designer. However, as the term participants is commonplace in research this is what was used.

1.3 Rationale for the study

The following sections describe the initial rationale for the research, firstly from my perspective and then from the available evidence base, including the literature and current policy/guidance. In short, the influence of my previous experience and work is described, before the need for interventions targeting physical activity, diet and sedentary time in older adults living with and beyond cancer is emphasised via current evidence, guidelines, and rates of participation. Furthermore, the timeliness of this work will be considered in light of the increasing rates of cancer incidence and prevalence in older adults.

1.4 Understanding my perspective

Having a background in Health Psychology has shaped my perspective on research. Mostly working on quantitative projects in the past, the decision to work on this predominantly qualitative project was influenced by my previous work. In the past I have focussed on intervention delivery and evaluation. However, I always wondered whether the participants enjoyed and wanted to attend what was on offer, considering the acceptability of the intervention rather than solely the effectiveness. I felt in research we, as researchers, often "did things to people" rather than understanding their perspective and needs. We often decided what was best for them and what the best way to achieve this was. This led me to the conclusion that there is the potential to develop effective interventions when working with those who will ultimately use and/or deliver them, ensuring the intervention suits their needs rather than those of the researchers.

Along with this I had a personal interest in the benefits of health behaviours for older adults living with and beyond cancer. It also seemed from my initial reading that this population was often excluded (be that deliberately or not) from much of the research focussing on behaviour change. I, therefore, felt it important to give these individuals a voice and decided to focus on this population for my research. Throughout the PhD process I built on and explored these beliefs, ultimately resulting in the study described in this thesis. This process has greatly influenced my thinking and more recent work. Since I have co-designed recommendations for the implementation of a future lung cancer screening programme, development and implementation of a social prescribing scheme, service improvement of a respiratory pathway and information materials to promote access to primary care (Brown, Sullivan, et al., 2022; Brown, Williams, et al., 2022).

1.5 Understanding the selected setting of the research

This research was conducted in Scotland, specifically Edinburgh, the Lothians (Mid & East) and Fife (Figure 1). This geographical area was selected from the outset due to the expected similarities of services and experiences but also potential differences. This setting was also selected as it was likely there would be scope to recruit the necessary participants for the research, while also ensuring travel around the area was manageable for a PhD study, i.e., primarily a sole researcher. (Table 1 for further detail on geographical areas).

Given that I was interested in working with individuals in some capacity, I felt it was necessary to consider the setting of the work. Working within the participants' local communities instantly felt like the right path to take for this research, as this meant I could go to the target population in an environment that was comfortable and familiar to them. It was therefore, decided the work would be community-based, working with local community groups and third sector organisations, as opposed to health care or other statutory settings. Moreover, as I had selected older adults living with and beyond cancer, as opposed to those undergoing treatment in acute settings, the community seemed the most suited setting for any research working with this group.

Table 1: Overview of research areas

Area	Population size	Urban	Town	Rural
Edinburgh	527,620	96.2%	2.8%	1%
Fife	374,130	67.1%	15.4%	17.5%
Midlothian	93,150	77.2%	8.8%	14.1%
East Lothian	107,900	44.9%	29.3%	25.8%

(Data obtained from (National Records for Scotland, 2021a, 2021b, 2021c, 2021d; Scottish Government, 2018))

[redacted]

Figure 1: Map of study location

1.5.1 Understanding the community

Community became a key component throughout this work, with set actions taken to engage and build relationships within the community. However, before this can be explored it is important to understand my perspective of community and how those involved in this research constitute a community. This is especially important as the map in Figure 1 makes the geographical area seem more disparate than was actually the case.

The standard dictionary definition of community is:

> “the people living in one particular area or people who are considered as a unit because of their common interests, social group, or nationality” (Cambridge Dictionary, 2022)

Although area is considered in this definition of community, more importantly, aligned to the context of this research, community may also be those with common interests, a social group or more widely a nationality. This concept of community is further reflected in academic literature with definitions such as:

> *“a group of people with diverse characteristics who are linked by social ties, share common perspectives and engage in joint action”* (MacQueen et al., 2001)

> *“a group of people with a sense of belonging, with a common perception of collective needs and priorities”* (Suliman, 1983).

This idea of community was reflected through this work. From the outset I understood those who had experienced a cancer diagnosis and those who support this population as a community due to their shared experience, interaction and common goals or needs. Although the geographic area may seem disparate (Chapter 1, Section 1.5) those with a diagnosis of cancer will have attended the same hospital and will have interacted with the same or similar services, as there are two dominant cancer charities in this area. Similarities and common experiences of both older adults living with cancer and the professionals/volunteers who provide these services constitute a community. It is, therefore, this community I sought to explore and work with throughout the PhD.

In developing the co-design process and building relationships with individuals and groups, I also became aware that the participants included would become part of a small community solely associated with the research. This community consisted of individuals with all the points above in common but also participation in the project as a significant means of cohesion. I was, therefore, aware that I would essentially be creating or contributing to a smaller community embedded within the larger community and landscape of cancer care. This gives weight to the notion that communities can sit within communities.

It also important to consider the potential pitfalls of this idea of community, the primary pitfall being that this interpretation was based on my perception of this particular community, which may be different to the perception of those I perceive as being part of this community. This has been explored elsewhere in the literature, concluding that often there is a fundamental difference between the perception of communities between non-members and members of the supposed community (Jewkes & Murcott, 1996). In addition, I was also aware that although I perceived the groups of participants included as members of a community, it was possible that those who participated in the process had not met or interacted with one another before. Although I am aware some had met before and were part of the same community groups, through which participants were recruited. Therefore, although deemed as being part of a community, a specific approach was required to ensure the participants were comfortable and confident working together, as individuals, members of the broader community and as smaller groups who already had connections. This was considered throughout, and measures were taken to ensure everyone was comfortable, as described in Chapter 5. These measures were successful and the community built is explored in Chapter 6.

1.6 Understanding the current literature and policy landscape

The following section will explore the current literature and policy landscape concerning health behaviours, specifically physical activity, diet, and sedentary time in older adults living with and beyond cancer. To frame this discussion, I will first explore definitions of health, as I felt it necessary to understand what health is before tackling health behaviours. After which, I will discuss the significance of the target population (i.e., older adults living with and beyond cancer) and then the behavioural focus, detailing policy and guidelines, benefits and risks, and participation levels of the target population. All of which supports the need to further explore the development and implementation of behaviour change interventions for older adults living with and beyond cancer.

1.6.1 What is health?

To understand the varied impact of cancer and the potential for protective health behaviours it is necessary to determine a perspective on health. For many years individuals from various fields have attempted to define health and/or develop models to explain, explore and measure health (Blaxter, 2010; Warwick-Booth et al., 2012; World Health Organization, 2022). However, it is still argued that "we can assume nothing about the nature of health – it is contested, varied and changing," (Duncan, 2007). When beginning this research, I identified with the World Health Organization (WHO) definition of health, as being:

> “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 2022).

It is, however, useful to consider the possible differences between the World Health Organization definition and potential lay perspectives. Lay perspectives of health are said to be central to the social model of health, which encompasses social, cultural, political and environmental factors (Warwick-Booth et al., 2012). For example research has found lay perspectives of health often focus on the ability to function, linking with the notion of an ability to adapt and maintain social roles (Blaxter, 2010). Moreover, research indicates lay perspectives particularly focus on happiness (Chapman et al., 2000), while other work has associated physical activity and dietary behaviours with health in older adults specifically (Alizadeh & Salehi, 2015). Further differences among older adults have also been noted with health associated with absence of pain, wellbeing, individual satisfaction and positive events (Alizadeh & Salehi, 2015), as have differences by class (Blaxter, 2010) and gender (Emslie & Hunt, 2008). Thus, as a researcher I felt it necessary to have in mind the commonly accepted definition of health (i.e., the WHO definition) but also be open to the implications and understanding of health from the perspective of those I anticipated working with (Chapter 5, Section 5.12.1 for further details on participants’ perspectives of health).

1.6.2 Older adults and cancer

Globally it is estimated that there are 14.1 million new cancer cases annually, 8.2 million deaths each year due to cancer and 32.6 million people living with cancer

(WHO GLOBOCAN, 2015). Incidence rates worldwide increase greatly in those aged 65 and over (WHO GLOBOCAN, 2018). An increase in prevalence of those living with cancer has also been predicted at a rate of around 38% when comparing estimated figures from 2020 with 2014, with a majority falling under the older adult category (Marosi & Koller, 2016).

In the UK there are 375,400 new cancer cases each year (Cancer Research UK, 2022), with an estimated 3 million people living with cancer (those who have been diagnosed at any time (Macmillan Cancer Support, 2021)). Figures from Cancer Research UK (2022) demonstrate that 36% of all cancers diagnosed in the UK are diagnosed in adults aged 70 and over, while approximately 66% are diagnosed in adults aged 65 and over (Cancer Research UK, 2022). It is estimated that 1.1 million individuals are aged 65 and over are living with and beyond cancer in England in comparison with only 500,000 in age group 45-64 (Department of Health et al., 2013). One in eight adults aged 65 and over were living with a cancer diagnosis in 2010, with this expected to rise to one in five in 2030 (Macmillan Cancer Support, 2012), highlighting the extensive prevalence of cancer in older adults. While in Scotland, the geographical focus of this research, there was 32,234 new cancer cases in 2017 with 65% of these being diagnoses in those age 65 and over (Public Health Scotland, 2020).

Increasing incidence of cancer diagnoses and subsequent prevalence of those living with cancer, particularly those aged 65 and over, emphasises the need to ensure optimum health is maintained during and after treatment; where health is not just merely the absence of disease but physical, social and mental well-being, as described in Section 1.6.1 (World Health Organization, 2022). Thus, focus on prevention, control, and reduction of the effects of cancer and treatments of cancer in this population is paramount. A means to achieve this is through the promotion of health behaviours.

1.6.3 Behavioural focus

Although it is generally agreed many behaviours have the potential to impact the health and well-being of all individuals, including older adults living with and beyond cancer, the behaviours physical activity, diet and sedentary time are the primary focus of the current research.

These behaviours have been selected due to the known links between them and their likely preventative impact on future cancer recurrence and diagnosis of other chronic illness. These behaviours are associated with similar risks (e.g., cancer, diabetes, cardiovascular disease (Chomistek et al., 2013; Divisi et al., 2006; Kyu et al., 2016)) and have been associated with health by older adults (Alizadeh & Salehi, 2015). These behaviours have also been previously linked due to the health benefits expected, with a healthful diet and physically active lifestyle, as well as reduced sedentary time being recommended to prevent recurrence, secondary primary cancers and other chronic diseases, and are associated with improved well-being, physical function and quality of life (Rock et al., 2012).

Therefore, the behaviours **physical activity**, **diet** and **sedentary time** were the initial target behaviours of this work, with a view to increasing participation in each of these behaviours in the selected population. To understand the current literature around the benefits of these behaviours for older adults living with and beyond cancer, it is first necessary to explore the recommendations and guidance regarding these behaviours.

1.6.4 Current guidelines and policy

Due to the benefits and/or risks associated with the behaviour's physical activity, diet and sedentary time guidance and recommendation for behaviour participation has been developed. This guidance sets out the minimum criteria necessary to reap the benefits and avoid the potential risks associated with participation in the behaviours or lack thereof. Such recommendations and guidance are a focus of the World Cancer Research Fund (WCRF) Expert Report (World Cancer Research Fund, 2018). Recommendations and guidance for each of the behaviours targeted in this work will be discussed below.

1.6.4.1 Physical activity and diet

Previously guidelines and recommendations for individuals living with and beyond cancer regarding physical activity and diet have stated individuals should:

- Achieve and maintain a healthy weight.

- If overweight or obese, limit consumption of high-calorie foods and beverages and increase physical activity to promote weight loss.
- Engage in regular physical activity.
- Avoid inactivity and return to normal daily activities as soon as possible following diagnosis.
- Aim to exercise at least 150 minutes per week.
- Include strength training exercises at least 2 days per week.
- Achieve a dietary pattern that is high in vegetables, fruits, and whole grains.
- Follow the American Cancer Society Guidelines on Nutrition and Physical Activity for Cancer Prevention. (Rock et al., 2012)

The guidance from 2012 is considered here, as that was the most up to date guidance when setting out with this research. Since then, the guidance has been refined somewhat but still generally follow the same premise. For example, current guidelines in the UK for diet consumption and physical activity participation for individuals living with cancer state they should generally follow the same guidance as the general population but seek advice if necessary (i.e., if limitations due to recent treatment and/or dietary restrictions due to cancer type/treatment side effects (Macmillan Cancer Support, 2020)). Generally therefore, those living with and beyond cancer are encouraged to do at least 150 minutes of physical activity per week (Macmillan Cancer Support, 2020; UK Chief Medical Officer, 2019). In addition to the 150 minutes per week guidance it is also recommended individuals spend some time doing activities targeting strength and balance (Macmillan Cancer Support, 2020; UK Chief Medical Officer, 2019).

A healthy balanced diet is also recommended, consuming the recommended amount of varied food groups to obtain the benefits associated with a healthy diet (Macmillan Cancer Support, 2020). Guidance may be required from a professional or more general guidance may be drawn on for example the Eat Well guide, which stipulates nutritional recommendations for the general population of the UK (NHS, 2019). In essence it is recommended individuals have a varied diet, focussing on the proportions of the plate, with a high in-take of fruit and vegetables (NHS, 2019). This reiterates the previous evidence from 2012 focussing on recommendations for those living with cancer (Rock et al., 2012). However, there is still room for improvement regarding dietary guidelines for those living with cancer, as reflected in qualitative work highlighting uncertainty around dietary advice, particularly with regards to potential impact on recurrence (Beeken et al., 2016). Regardless of this uncertainty individuals were found to be interested in dietary guidance and said to welcome such support (Beeken et al., 2016). For the purposes of this work the generic guidance of maintaining a healthful, balanced diet with at least five portions of fruit and vegetables per day, as recommended by the NHS and Macmillan was drawn upon (Macmillan Cancer Support, 2020; NHS, 2019), with additional considerations for specific dietary changes where available (e.g. Chapter 2).

1.6.4.2 Sedentary time

Sedentary time is an emerging concept and recommendations regarding breaking up and/or replacing sedentary time with more active options is limited. Yet, this is currently being woven into policy and guidelines, including that of the World Health Organization, with reducing sedentary time as a protective health behaviour (Bull et al., 2020). It is also recommended that individuals minimise their time spent sedentary (UK Chief Medical Officer, 2019). At present it is stated there is not enough evidence to determine how much sedentary time without a break is too much but it is recommended in the UK that long periods of sitting time are broken up by just 1 or 2 minutes of activity (UK Chief Medical Officer, 2019). All recommendations explored regarding physical activity, diet and sedentary time are also reflected in those of the World Health Organization (Bull et al., 2020).

1.6.5 Benefits associated with physical activity, diet and reduced sedentary time

The benefits of physical activity for health, well-being and quality of life have been emphasised greatly in recent years, including in adults living with and beyond cancer and less frequently but still considerably, older adults living with and beyond cancer. For example, participating in exercise and regular physical activity can significantly reduce rates of cancer recurrence, co-morbidities and improve mental/physical/social functioning in adults living with and beyond cancer, as well as having significant positive impact on quality of life (Cheville et al., 2012; Sabiston & Brunet, 2011; Wang et al., 2022). Moreover, research has indicated physical activity can improve fatigue, and sleep quality in individuals living with and beyond cancer (Brown et al., 2011;

Rogers et al., 2017) and reduce the adverse side effects associated with cancer treatment, as well as reduce all-cause mortality in those who have had a previous cancer diagnosis (Friedenreich et al., 2020; Gunnell et al., 2017; Lahart et al., 2015). Thus, it is clear participating in physical activity can have a variety of beneficial effects for those living with and beyond cancer.

Less research has been conducted on the benefits for older adults living with and beyond cancer, as opposed to solely adults living with cancer. However, as most of the population diagnosed and living with cancer is older (i.e. aged 65+ (Macmillan Cancer Support, 2021)), it is reasonable to suggest the benefits will be similar for this population. Research has pointed to a beneficial effect of physical activity on health-related quality of life, fatigue, and reduced symptoms of depression and anxiety in those living with and beyond cancer (Forbes et al., 2020; Luctkar-Flude et al., 2007; Reynolds et al., 2014).

Sedentary behaviour on the other hand is a newer concept, which potentially indicates why, unlike physical activity and diet, it was not considered when exploring definitions of health (Alizadeh & Salehi, 2015; Chapman et al., 2000) (Section 1.6.1). Sedentary behaviour or a sedentary lifestyle is distinct from low levels of physical activity and is defined as spending prolonged periods of time sitting/lying, equating to little, if any energy expenditure (Gardiner, Eakin, Healy, & Owen, 2011). For the purpose of this research physical activity and sedentary time have been treated as separate concepts, as I maintain that an individual can both meet the current recommended rates of physical activity (150 minutes per week; (Bull et al., 2020; Macmillan Cancer Support, 2020) to be deemed physically active but also spend the majority of the day sedentary. For example, an individual may sit for 12 hours of the day and walk for 150 minutes. This individual would, therefore, be classed as both sedentary and physically active, as explored by Thivel (2018). Moreover, recent research has found prolonged sitting time is associated with CVD regardless of time spent active (Chomistek et al., 2013). Therefore, it is necessary to consider sedentary time both as part of the activity continuum but also as a separate influencing behaviour that can potentially be altered to achieve improved wellbeing, i.e., by breaking up sitting time.

Despite the relative recent emergence of sedentary behaviour as a concept, it too has been linked to various health outcomes. For example, greater sedentary time is associated with reduced physical function in older age (Seguin et al., 2012). Further risks associated with a sedentary lifestyle include: all-cause mortality risk (de Rezende, Rey-López, Matsudo, & do Carmo Luiz, 2014), as well as increased risk of disease and disability (e.g. type 2 diabetes; Rillamas-Sun et al., 2013). This research underpins the need to reduce sedentary time, particularly in older adults and those with chronic illnesses to reduce the likelihood of co-morbidities.

Emerging evidence indicates increased sedentary time may exacerbate many of the negative side effects of cancer including increased fatigue severity (Phillips et al., 2016). Increased sedentary time is also associated with poor quality of life, all-cause and disease specific mortality, as well as some co-morbidities in those living with cancer (Lynch, 2010; Lynch et al., 2013; van Roekel et al., 2016). All of which indicates the need for a new focus on reducing sedentary time in those living with and beyond cancer. Although evidence is limited in older adults specifically, the evidence available replicates that of the general cancer population in that sedentary time is associated with an increase in all-cause mortality (Gilchrist et al., 2020). Identifying means to break up sedentary time and/or replace it with moderate to vigorous physical activity, in line with current recommendations and guidance (Section 1.6.4.2) could reduce these risks.

Research also points to a positive impact of a healthful diet in those living with and beyond cancer. A healthful diet adhering to the recommendations and guidance available (Section 1.6.4.1) can reduce the risk of overall mortality in those living with and beyond breast cancer (George, Bernstein, et al., 2014; Thomson, 2012). A recent review has also cited a healthful diet as having an inverse relationship with all-cause mortality across cancer types, emphasising the importance of diet for those living with cancer (Schwedhelm et al., 2016). Furthermore, this review also emphasised the negative impact of the Western diet on all-cause mortality in those living with and beyond cancer (Schwedhelm et al., 2016). Evidence also suggests a healthful diet is associated with all-cause mortality but also reduced risk of breast cancer recurrence, particularly in those who are post-menopausal (i.e., older adults (Vrieling et al., 2013)).

While saturated fat intake has been shown to negatively affect breast cancer survival (Brennan et al., 2017). Moreover, increased fruit and vegetable intake, consuming at least five portions per day has been shown to have protective effects for those living with cancer and in some instances has been associated with reduced mortality (Hurtado-Barroso et al., 2020). Dietary programmes targeting improvement have also been shown to have a positive impact on quality of life in individuals living with prostate cancer (Menichetti et al., 2016) and health related quality of life in older adults living with and beyond cancer (Forbes et al., 2020). Although there is limited evidence directly considering older adults in this field, it is clear from the evidence available that a healthful diet, that meets current recommended intake guidance, has a variety of beneficial effects for those living with and beyond cancer, including older adults.

1.6.6 Behaviour participation

Regardless of the risks and benefits associated with each of the target behaviours, rates of participation in these behaviours and adherence to current/past guidelines in adults and older adults living with and beyond cancer are generally low, emphasising a need for concern and improvement. For example, research has found only a minority of individuals living with and beyond cancer were meeting any of the current behavioural recommendations including dietary and physical activity (Blanchard et al., 2008). Participation and adherence to the recommended guidelines for each of the target behaviours in individuals living with cancer, and specifically older adults living with and beyond cancer, will now to be discussed.

Research has shown older adults living with and beyond cancer are participating in significantly less physical activity (light, moderate and vigorous) than their younger counterparts (Thraen-Borowski et al., 2017). Moreover, it has been found older adults living with and beyond cancer were more likely to be less active than those who had not experienced cancer (Grimmett et al., 2009). Yet, Bellizzi, Rowland, Jeffery, & McNeel (2005) found adults living with and beyond cancer were 9% more likely to adhere to physical activity guidelines than controls. The work of Bellizzi et al., (2005) could, however, be highlighting the low rates of participation in healthy adults, rather than high rates in adults living with and beyond cancer. All of which is corroborated by the evidence that few cancer survivors are sufficiently active to obtain health benefits (Sabiston & Brunet, 2011).

Research has shown older adults living with and beyond cancer spent an average of 95 minutes more per day sedentary, with 11 fewer breaks in sedentary time than younger adults (Thraen-Borowski et al., 2017). While other research has found those living beyond cancer spend approximately 11 hours per day sitting (George, Alfano, et al., 2014), at least three hours more than the general population (Strain et al., 2018). Further evidenced through work in which adults living beyond cancer were found to be more sedentary than individuals of a similar age who have not experienced cancer (Kim et al., 2013).

Similar issues can be seen with regards to diet with evidence indicating those living with and beyond cancer perceive their diet as good but, in comparison to current guidance, it is actually relatively poor (Xue et al., 2020). Further research has found those living with and beyond cancer are less likely to eat fruit and vegetable and are specifically not meeting the common recommendation to eat five pieces of fruit and vegetables per day (Blanchard et al., 2008). This may be due to lack of knowledge around the impact of diet with individuals' aware that diet can have an influence in the development of cancer but less knowledge of the impact of diet on recurrence of cancer (Beeken et al., 2016).

1.6.7 Changing behaviours

Reflecting on the literature discussed it is clear there are specific benefits and risks associated with the behaviours, physical activity, diet, and sedentary time. Such risks and benefits emphasise the need to consider individuals' participation in these behaviours. However, it is also clear older adults living with and beyond cancer are often unlikely to adhere to the guidance laid out as evidenced in Section 1.6.6 and therefore, interventions to improve participation in these behaviours are required.

Evidence has called for a multi-behaviour change intervention as the most likely to have an impact on overall mortality and risk of recurrence (Dieli-Conwright et al., 2016), indicating the need to target multiple behaviours in one intervention. However, this call was focussed on breast cancer patients only, and must therefore be considered more widely. This is also emphasised through the interlinking nature of the behaviours identified as explored in Section 1.6.3 There has also been calls to understand what older adults would like to see from an intervention targeting physical activity and diet, as the majority of studies are based on the needs of younger adults living with and beyond cancer (Forbes et al., 2020). Therefore, according to the literature a sufficient means to change and improve these behaviours and consequently adherence to the guidance is necessary. A possible means for this is a behaviour change intervention, yet it is necessary to understand what this should look like from the perspective of those who may use it in the future. Previous research has suggested it may be beneficial to incorporate the views of older adults into the design of community-based interventions (Farrance et al., 2016). It is likely this can be carried over to older adults living with and beyond cancer, with the intention of creating an acceptable and effective intervention.

Behaviour change interventions are commonly developed in line with the MRC framework (Medical Research Council, 2006), at the time of this study being conducted the framework was as follows (Figure 2):

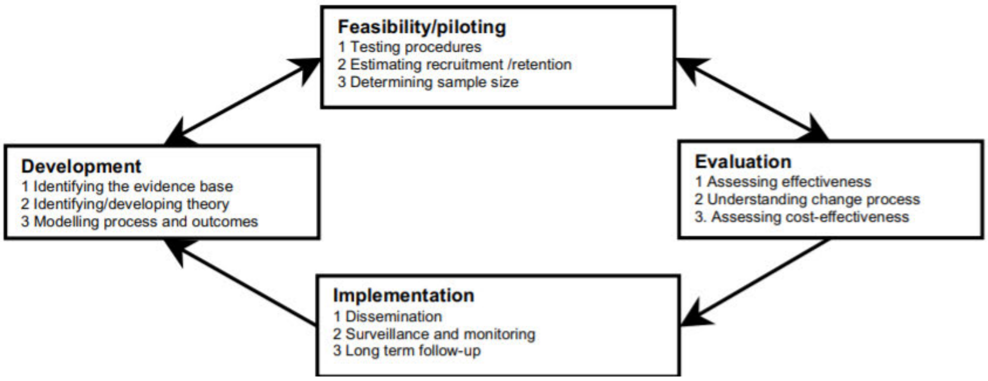


Figure 2: Medical Research Council Framework for complex interventions 2008

Thus, the current research focussed on the development phase of the framework with an initial aim being:

> To develop a suitable behaviour change intervention to improve the behaviours of physical activity and diet, as well as reduce sedentary time in older adults living with and beyond cancer.

However, recently this framework has been revised and now includes “engaging stakeholders” as a core component (Skivington et al., 2021a). This new focus on stakeholder engagement emphasises the timeliness of this research and the necessity of collaborative design and development, as the research was conducted before this revision was implemented.

Another consideration of behaviour change interventions is the theoretical basis. The MRC framework calls for interventions to have a theoretical basis. A number of behaviour change theories are available to consider including the Transtheoretical model of change (Prochaska & DiClemente, 1983), COM-B Model (Michie et al., 2011), social cognitive theory (Bandura, 2002), theory of planned behaviour (Ajzen, 2011), self-determination theory (Deci & Ryan, 2012), and relevant to this research Health belief model (Rosenstock, 1974) and self-regulation model (Leventhal et al., 2016) among others. However, no set theory was selected from the outset instead an adaptive approach (Layder, 1998) to theory was implemented suited to the pragmatic and collaborative nature of the research. The adaptive theory approach was developed by Layder (1998) in order to enable an iterative process of theory use/development, incorporating both what is already known and what will be learned from data collection.

1.7 Thesis structure

The remainder of the thesis is split into a further seven chapters, each of which is described below. Unlike the ‘traditional’ thesis the decision was made to describe the process as it happened, in keeping with the iterative nature. I detail each of the key parts and stages, including methods and results in succession to emphasise the way in which the research built up the story around potential intervention development. I also include reflection boxes throughout to relay my thinking regarding decisions and findings. Figure 3 for an overview of the thesis structure in comparison with a more traditional format (Vitae, 2022). This also enables understanding of the work required to facilitate a co-design process and develop the relationships necessary to make it successful.

Chapter 2: Systematic review

This chapter reports systematic review findings which identify current evidence informing interventions targeting physical activity, diet and sedentary time in older adults living with and beyond cancer. Findings from this review highlight the gaps in available evidence with a view to informing the key aims of this research.

Chapter 3: Methodology

This chapter explores the philosophical and methodological underpinnings of the selected methods. After which the broad methods of the work are described.

Chapter 4: Part A-Preparing

Chapter 4 explores the methods of the preparatory phase. Each of the materials and tools used are discussed. The findings from this Part are then relayed before discussion of how these influenced the second Part of the research, Part B-co-designing.

Chapter 5: Part B-Co-designing (Stages 1-3)

This chapter explores the methods and key findings of Part B, divided into three stages, Stage 1: Interviews, Stage 2: Focus Groups and Stage 3: Workshop. Each stage is considered in turn, exploring the methods, findings, and then how these findings informed each of the proceeding stages of Part B.

Chapter 6: Part C-Evaluating

This chapter explores Part C, the evaluation component. Quantitative and qualitative data from evaluative surveys are analysed, as well as my own perspective on the process.

Chapter 7: Reflections and recommendations

Chapter 7 explores the reflective analysis and findings regarding the three main recommendations to consider in future interventions. My reflections regarding theories of behaviour change are also discussed in this chapter.

Chapter 8: Discussion

This chapter explores the results and process in the context of past literature. Strengths and limitations of the study are also described.

Chapter 9: Conclusions and future recommendations

This chapter considers recommendations regarding future research, practice, and theory. Overall conclusions and contributions are also stated.

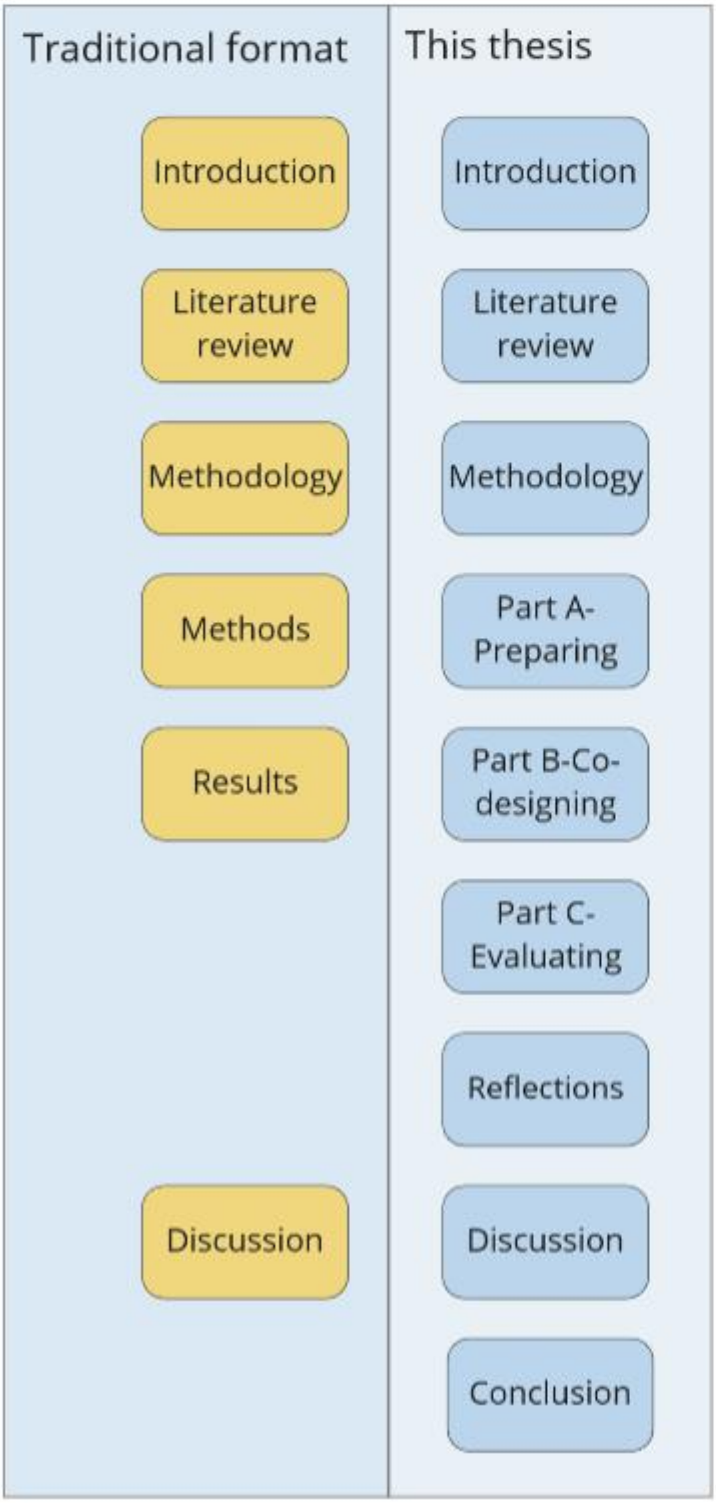


Figure 3: Thesis structure in comparison to traditional thesis

1.8 Chapter summary

This chapter has explored my perspective detailing the insights and experience that led to this research. This chapter has also highlighted the rising number of older adults living with and beyond cancer across the globe, as well as the potential benefits of participating in physical activity, reducing sedentary time, and eating a healthy diet for older adults living with and beyond cancer. Yet, it is clear from the evidence that older adults living with and beyond cancer are rarely meeting the prescribed guidelines for these behaviours, and therefore, will not be reaping the benefits. Thus, there is a necessity for behaviour change interventions tackling physical activity, diet and sedentary time in older adults living with and beyond cancer. The next chapter will describe the systematic review conducted to explore previously implemented interventions.

Chapter 2. Systematic review

2.1 Chapter overview

This chapter reports the systematic review conducted and the specific study aims based on current gaps, as highlighted through consideration of the current literature. Following on from the literature discussed in Chapter 1 that identified a need for interventions to promote and improve the behaviours physical activity, diet and sedentary in older adults living with and beyond cancer, the systematic review aims to determine the acceptability and effectiveness of previously implemented interventions. This chapter moves through methods, results, and discussion of the systematic review before concluding that current evidence regarding the acceptability of interventions is weak and where evidence is available, for example attrition, retention and completion rates, acceptability is poor. Firstly, the aims of the systematic review are described in relation to the evidence from Chapter 1. Secondly the methods are described, exploring the inclusion/exclusion criteria, searches conducted, extraction methods, quality appraisal and finally analysis. Thirdly, results are described in a way that answers each question posed individually, before culminating in a broad overview of meaning in the discussion. And finally, the thesis aims are described based on the gaps identified in this chapter and the previous one.

The decision was made not to update the review at the time of writing up the thesis, as the research that followed the review was conducted in part due to the results of the review. Therefore, to tell the story as it was, I have decided to report the original review. However, more recent literature will be brought into the discussion to consider the process and findings in light of progressions in the field.

2.2 Purpose of the review

After establishing the need for a behaviour change intervention targeting physical activity, diet and sedentary time in older adults living with and beyond cancer, it was necessary to understand what interventions had been used previously and whether these were acceptable to the target population and effective in changing their behaviour. Therefore, the following systematic review was conducted drawing on the principles of a Cochrane review, as best practice (Higgins et al., 2022).

2.2.1 Aim

To review existing evidence regarding the effectiveness and acceptability of behaviour change interventions designed to increase physical activity levels, reduce sedentary time, and improve diet in older adults with cancer.

Reflection box 1-A need for “doing with and not to”

At this point in the PhD journey I was unsure of the methods and overall aims of the work. My past experience of primarily quantitative work definitely influenced the structure of the review. However, the findings from the review conducted were useful in emphasising the necessity for qualitative work in this area. The findings also supported my argument that it was necessary to work with individuals to develop appropriate and acceptable interventions. Essentially supporting the premise of “doing with and, not to”.

2.3 Methods

The protocol for this review was submitted to PROSPERRO (CRD42017068700). The protocol was submitted to PROSPERO in line with best practice and the pursuit of transparency in the research process (Stewart et al., 2012).

2.3.1 Search strategy

The databases PsycInfo, Medline, CINAHL, EMBASE and The Cochrane Library were searched using a combination of key words and subject headings for studies published between January 2007 and June 2017 (Appendix 1 for example search strategy). A cut-off date of 10 years was implemented on the recommendation of an expert librarian. The search strategy consisted of five major themes: cancer, the older adult, physical activity, diet, and sedentary time. An expert subject librarian was consulted to ensure an effective search strategy was implemented. Included articles were restricted to primary research of a qualitative and quantitative design. Reference lists of included articles were hand searched for further studies meeting the eligibility criteria.

2.3.2 Inclusion criteria

2.3.2.1 Population

The included population was older adults with cancer, aged ≥65 years old, as defined in Scotland (Scottish Public Health Network, 2013). Articles indicating a population aged ≥65 were included. In instances where no age range was reported an average age ≥70 was used, as it was expected this would effectively capture the target population.

2.3.2.2 Interventions

All interventions designed to improve physical activity, diet and sedentary time were included, where measures of change were presented. Studies could address one or all the target behaviours. Studies detailing interventions where other behaviours were addressed as well as the target behaviours were included only where results regarding the target behaviours were presented separately. No limitations were applied to the intervention design and delivery.

2.3.3 Outcomes of interest

2.3.3.1 Effectiveness

Primary outcomes for intervention effectiveness were measures of changes in behaviour, specifically for the target behaviours: physical activity, diet, and sedentary time. Examples include accelerometery, physical activity questionnaires, food diaries and dietary intake questionnaires.

2.3.3.2 Feasibility/Acceptability

In addition to effectiveness measures of acceptability and feasibility were included, adherence, attrition rates, recruitment rates and participant/stakeholder feedback.

2.3.4 Secondary outcomes of interest

Additional effects of the interventions beyond behaviour change were also considered, such as: social wellbeing, physical wellbeing and mental wellbeing were considered as secondary outcomes, specifically Quality of Life, anxiety/depression, and physical capacity/function etc. These outcomes were considered in addition to the primary outcomes of effectiveness and acceptability of the intervention, as they have previously been linked to the target behaviours and can be seen to have a positive impact on individual’s lives.

2.3.5 Study design

All studies detailing peer-reviewed, primary research relevant to the aims of the review were considered for inclusion.

2.3.6 Exclusion criteria

Articles were excluded where the lower age range was less than 65. However, as age range was often omitted in reporting, an average age of ≥70 was used in these instances, as this average was expected to capture the target population. Articles which included populations other than those with cancer, as well as articles that did not include a measure of behaviour change assessing the target behaviours were also excluded, as were secondary research, grey literature and theses, conference/meeting abstracts were excluded.

2.3.7 Article selection process and data extraction

Search results were retrieved and exported directly to the reference manager Endnote X7. Duplicates were then removed. A four-stage selection process involving two independent reviewers was implemented as follows:

> **Stage 1:** All retrieved articles were scanned by title by the first reviewer and those meeting the eligibility criteria at this stage were retained. The second reviewer scanned 10% of included titles, an agreement rate of 95% was necessary to move to the next stage. If this was not achieved a further 10% was reviewed and so on, until the rate was achieved.
>
> **Stage 2:** Articles retained at Stage 1 were reviewed independently by abstract by both the first and second reviewer. Those meeting the eligibility criteria were retained for review in Stage 3.
>
> **Stage 3:** The full texts of articles retained after Stage 2 were reviewed independently by both the first and second reviewer. Those meeting the eligibility criteria were retained and included in the review.
>
> **Stage 4:** Reference lists of included articles and any relevant reviews identified were hand searched by the first reviewer for further studies meeting the eligibility criteria. Articles obtained in this manner were discussed with the second reviewer to ensure eligibility was agreed before inclusion in the review.

At all stages, any differences were discussed, and a third reviewer settled any unresolved disagreements. Preferred reporting items for systematic reviews and meta-analyses (PRISMA) guidelines (Moher et al., 2009) were followed throughout this process.

Data extraction was conducted using an adapted version of the Cochrane data collection form for interventions-non RCT and RCT (Cochrane Effective Practice and Organisation of Care (EPOC), 2017). Extracted variables can be found in Appendix 2. Examples of extracted variables include participant demographics, target behaviour, acceptability or effectiveness and measures used.

2.3.8 Quality assessment

Two independent reviewers conducted the quality assessment using the Effective Public Health Practice Project (EPHPP) tool, a standardised tool for assessment of public health interventions (Thomas et al., 2004). This tool was chosen as it has been reported to have content and construct validity, and it is the most appropriate tool for use with public health interventions (Armijo-Olivo et al., 2012). This tool assesses studies against selection bias, study design, confounders, blinding, data collection methods, attrition, intervention integrity and data analyses, which it provides “strong”, “moderate” or “weak” quality rating. Both reviewers assessed the quality of articles included at the final stage. Any differences were resolved by discussion and where necessary a third reviewer not involved in the extraction or quality assessment process resolved any disagreements. As the aim of the study was to inform intervention development, quality assessment was conducted to assess the strengths and limitations of evidence rather than to exclude.

2.3.9 Data analysis

Study results from included articles were analysed using narrative synthesis. In essence, narrative synthesis refers to the process of synthesis that brings the study findings together to form a conclusion. A narrative as opposed to a statistical summary was provided to describe if, how, for whom and why the interventions were effective. This involved looking for patterns from the data extracted from the studies to examine the relationships between study results and comparing and contrasting these relationships across the studies, as recommended by (Popay et al., 2006). Effectiveness and acceptability/feasibility were addressed individually to ensure results fully addressed both components, with data extracted and analysed as above.

2.4 Results

2.4.1 Selection of studies

A total of 4,148 articles were identified for potential inclusion after the removal of duplicates (Figure 4). After Stages 1 and 2 of the article selection process were completed a total of 82 articles were retained for full text review (Stage 3). At Stages 1, 2 and 3 agreement rates were 94%, 92% and 74% respectively. Disagreements at each stage were discussed untill 100% agreement was achieved. No further articles were included at Stage 4 (hand searching of reference lists). A total of 15 articles were retained after completion of the article selection process for inclusion in the review. All articles included explored primarily quantitative studies, with one also conisdering brief qualitative components.

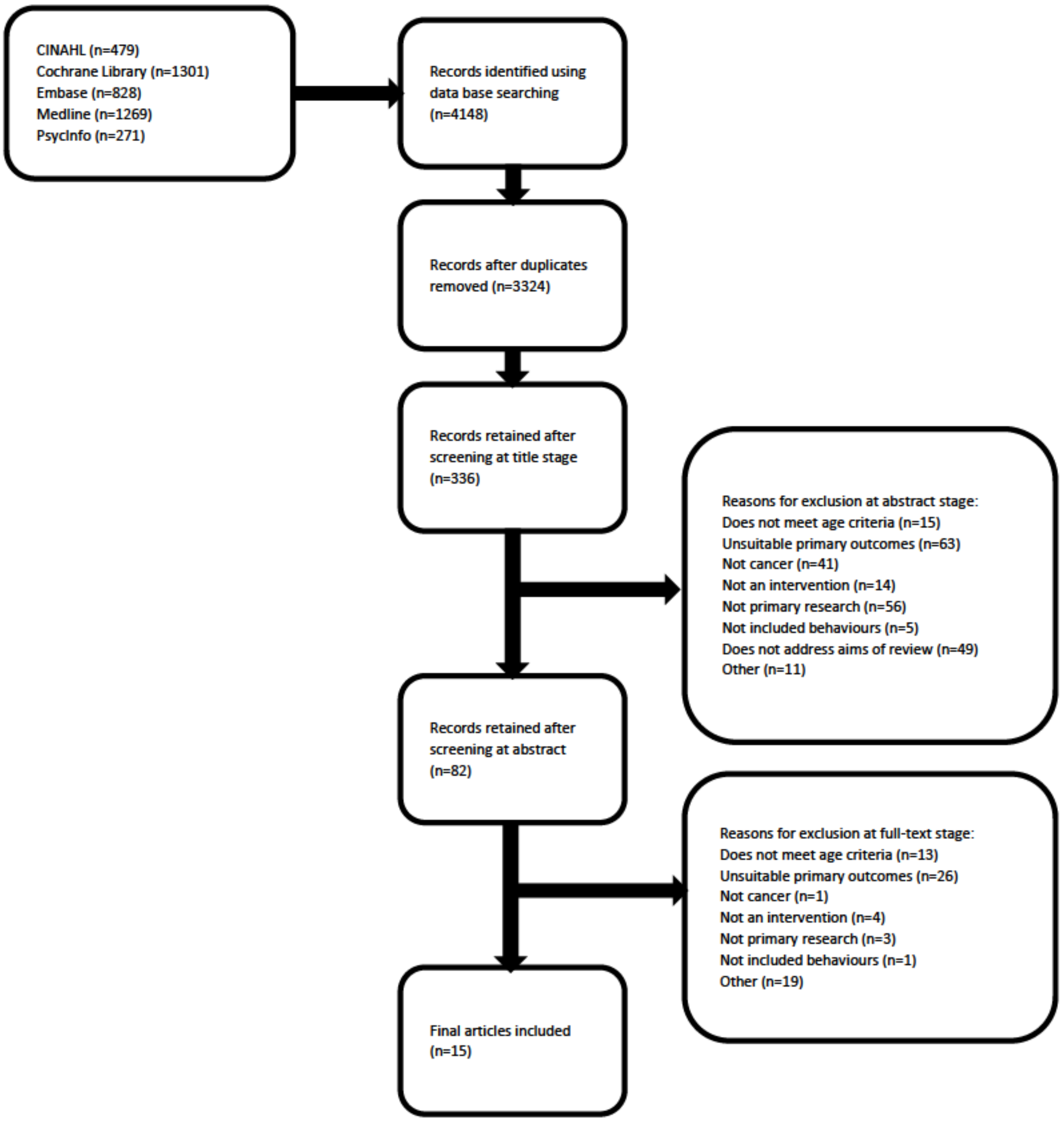


Figure 4: PRISMA flow diagram

2.4.2 Study characteristics

2.4.2.1 Study design

The majority (n=9, 60%) of included articles described randomised controlled trials (RCT; (Bourdel-Marchasson et al., 2016; Buffart et al., 2015; Clutter Snyder et al., 2007; Demark-Wahnefried et al., 2012; Dronkers et al., 2010; Morey et al., 2009; Sajid et al., 2016; Suh et al., 2013; Winger et al., 2014). Of the remaining six articles, four described cohort studies (Maeda et al., 2016; Nyrop et al., 2014; Reynolds et al., 2014; Yamamoto et al., 2017), one described a randomised trial with no control (Santa Mina et al., 2013) and one described results from a sample drawn from a larger RCT (Loprinzi et al., 2012). All included articles referred to effectiveness (Bourdel-Maechasson et al, 2016; Buffart et al, 2015; Clutter Snyder et al, 2007; Demark-Wahnefried et al, 2012; Dronkers et al, 2010; Loprinzi et al, 2012; Maeda et al, 2016; Santa-Mina et al, 2013;

Morey et al, 2009; Nyrop et al, 2014; Reynolds et al, 2015; Sajid et al, 2016; Suh et al, 2013; Winger et al, 2014; Yamamoto et al, 2016) and five referred to acceptability or facets related to acceptability (Dronkers et al, 2010; Loprinzi et al, 2012; Nyrop et al, 2014; Reynolds et al, 2015; Winger et al, 2014). Inferences were made regarding the acceptability of all included articles using attendance, recruitment, and attrition rates. The included 15 articles reported the results of 13 independent studies. For a full overview of study characteristics see Appendix 3.

2.4.2.2 Target behaviour

Eight of the included articles targeted physical activity (Buffart et al, 2015; Dronkers et al, 2010; Loprinzi et al, 2012; Maeda et al, 2016; Santa-Mina et al, 2013; Nyrop et al, 2014; Reynolds et al, 2015; Sajid et al, 2016), two targeted diet (Bourdel-Maechasson et al, 2016; Clutter Snyder et al, 2007) and five targeted both diet and physical activity (Demark-Wahnefried et al, 2012; Morey et al, 2009; Suh et al, 2013; Winger et al, 2014; Yamamoto et al, 2016. However, one (Clutter Snyder et al, 2007) of the two articles detailing changes in diet originally derived from a multiple behaviour change intervention, targeting diet and physical activity. Three of the included articles referring to an intervention targeting both diet and physical activity reported results from the same study (Demark-Wahnefried et al, 2012; Morey et al, 2009; Winger et al, 2014). Therefore, only three independent studies addressed a multiple-health behaviour change intervention targeting both diet and physical activity. No included articles targeted sedentary time.

2.4.2.3 Study population

Included articles identified a variety of specific populations within the broader population of older adults with cancer. For example, those currently being treated (Bourdel-Maechasson et al, 2016; Dronkers et al, 2010; Maeda et al, 2016; Santa-Mina et al, 2013; Nyrop et al, 2014; Yamamoto et al, 2016) and those having completed treatment (Buffart et al, 2015; Clutter Snyder et al, 2007; Demark-Wahnefried et al, 2012; Loprinzi et al, 2012; Morey et al, 2009; Reynolds et al, 2015; Sajid et al, 2016; Suh et al, 2013; Winger et al, 2014). For the most part interventions were aimed at a variety of cancer types (Bourdel-Maechasson et al, 2016, Clutter Snyder et al, 2007; Demark-Wahnefried et al, 2012; Morey et al, 2009; Reynolds et al, 2015; Winger et al, 2014). However, some also targeted specific cancer types e.g., breast (Loprinzi et al, 2012; Nyrop et al, 2014), prostate (Buffart et al, 2015; Santa-Mina et al, 2013; Sajid et al, 2016), lung (Maeda et al, 2016) and gastrointestinal (Dronkers et al, 2010; Suh et al, 2013; Yamamoto et al, 2016). Sample sizes of studies were generally small and the majority of participants in all included articles were white, while a variety of male to female ratios were observed.

2.4.2.4 Intervention

A range of interventions were deployed in different settings. Most prominent were home based interventions (Clutter Snyder et al, 2007; Demark-Wahnefried et al, 2012; Santa-Mina et al, 2013; Morey et al, 2009; Nyrop et al, 2014; Sajid et al, 2016; Winger et al, 2014), with a further three being set in a combination of the home and a controlled environment (Buffart et al, 2015, Suh et al, 2013; Yamamoto et al, 2016). The remaining interventions were implemented in a variety of settings; including a treatment setting (Bourdel-Maechasson et al, 2016; Dronkers et al, 2010; Maeda et al, 2016), university (Loprinzi et al, 2012) and community setting (Reynolds et al, 2015). The included interventions targeting physical activity comprised of a variety of activities and tasks, for example aerobic/resistance exercise training (Buffart et al, 2015; Santa-Mina et al, 2013), virtual exercise training (Sajid et al, 2016) and gentle exercise training, e.g., walking (Nyrop et al, 2014). Of the two dietary interventions one consisted of tailored dietary advice and a further six sessions with a dietician throughout the chemotherapy period (Bourdel-Maechasson et al, 2016) and the other derived from a multiple behaviour change intervention but provided six counselling sessions for diet, as well as a personalised workbook (Clutter Snyder et al, 2007). The most dominant combined intervention was the Reach out to Enhance Wellness (RENEW) intervention (Demark-Wahnefried et al, 2012; Morey et al, 2009; Winger et al, 2014), which consisted of tailored information and telephone counselling sessions. The other two interventions targeting both physical activity and diet implemented a culturally specific tailored intervention consisting of QI exercise and counselling, and tailored exercise programme along with nutrition advice respectively (Suh et al, 2013; Yamamoto et al, 2016).

2.4.2.5 Outcome measures

A variety of measures were used in the included articles to assess the outcomes of interest in this review. These included both objective and subjective measures. For example: standardised surveys, as well as non-standardised surveys, accelerometery, objective physiological measures and food diaries/dietary recall.

2.4.3 Intervention effectiveness

All included articles referred to intervention effectiveness in some way. Included articles referred to interventions targeting physical activity and/or diet; none targeted sedentary time. The following explores the results for the effectiveness of the interventions with regards to improving participation in each of the behaviours (i.e., physical activity and/or diet), creating scope to explore the difference between single and multiple health behaviour change interventions.

2.4.3.1 Physical activity

Eight of the included articles detailed changes only in physical activity, derived from a single health behaviour change intervention (SHBC: Buffart et al, 2015; Dronkers et al, 2010; Loprinzi et al, 2012; Maeda et al, 2016; Santa-Mina et al, 2013; Nyrop et al, 2014; Reynolds et al, 2015; Sajid et al, 2016). Of the eight included interventions targeting physical activity, five concluded the intervention had improved physical activity post-intervention (Maeda et al, 2016; Santa-Mina et al, 2013; Nyrop et al, 2014; Reynolds et al, 2015; Sajid et al, 2016), while two did not (Buffart et al, 2015; Dronkers et al, 2010). The final article referring to physical activity by Loprinzi et al (2012) referred to an effective intervention but focussed primarily on theoretical predictors of behaviour.

2.4.3.2 Diet

Two of the included articles focussed only on diet (Bourdel-Maechasson et al, 2016; Clutter Snyder et al, 2007). However, the results from one of these articles derived from a previous multiple behaviour change intervention (MHBC) but only described the dietary results (Clutter Snyder et al, 2007). Results indicated a significant improvement in diet in the intervention group at post-intervention measurement (Clutter Snyder et al, 2007). However, no significant differences between the diets of the intervention and control group at a 12-month follow-up measure using a three-day dietary recall and the diet quality index were found (Clutter Snyder et al, 2007). Bourdel-Maechasson et al (2016) identified a significant improvement in dietary intake compared to the control group. However, the intervention group had a higher dietary intake score at baseline.

2.4.3.3 Multiple or single health behaviour change interventions

Five of the included articles detailed results from multiple health behaviour change interventions (MHBC), derived from three intervention studies (Demark-Wahnefried et al, 2012; Morey et al, 2009; Suh et al, 2013; Winger et al, 2014; Yamamoto et al, 2016). Of these, four detailed the effectiveness of the interventions explicitly (Demark-Wahnefried et al, 2012; Morey et al, 2009; Suh et al, 2013; Yamamoto et al, 2016). One referred to an effective intervention namely the RENEW intervention but focussed on facilitators and associations of behaviour change (Winger et al, 2014). The RENEW intervention identified significant improvements in physical activity and diet, measured using unannounced dietary recall and a standardised physical activity questionnaire in the intervention group from baseline to post-intervention, between intervention and control group at post-intervention measurement (Demark-Wahnefried et al, 2012; Morey et al, 2009; Winger et al, 2014). At 24 months follow up both the intervention group and control had received the intervention, at this time both groups exhibited significant improvements in physical activity and diet (Demark-Wahnefried et al, 2012). Moreover, changes evident in the initial intervention group at post-intervention measurement were maintained to the 24 month follow up (Demark-Wahnefried et al, 2012). The other two MHBC intervention also emphasised the effectiveness of the interventions (Suh et al, 2013; Yamamoto et al, 2016). Suh et al (2013) identified significant improvements in physical activity, nutritional status and weight management, while Yammamoto et al (2016) identified increased calorie and protein intake (improved diet) after completion of the program. However, Yammamoto et al (2016) failed to report any changes evident in physical activity levels but did highlight participants in the intervention group exhibited improved skeletal muscle mass and increased gait speed.

10 of the 15 included articles described a single health behaviour change intervention (Bourdel-Maechasson et al, 2016; Buffart et al, 2015; Clutter Snyder et al, 2007;

Dronkers et al, 2010; Loprinzi et al, 2012; Maeda et al, 2016; Santa-Mina et al, 2013; Nyrop et al, 2014; Reynolds et al, 2015; Sajid et al, 2016), although one derived from a multiple health behaviour change intervention (Clutter Snyder et al, 2007). While the remaining five described a multiple health behaviour change intervention (Demark Wahnefried et al, 2012; Morey et al, 2009; Suh et al, 2013; Winger et al, 2014; Yamamoto et al, 2016), of these only three were independent studies. Two of the single health behaviour change interventions identified no significant changes in physical activity (Buffart et al, 2015; Dronkers et al, 2010). However, these interventions did achieve other significant changes, for example: significant improvement in 400m walk and chair rise time (Buffart et al, 2015) and inspiratory muscle function (Dronkers et al, 2010). The other eight SHBC interventions reported significant changes in their target behaviour (Bourdel-Maechasson et al, 2016, Clutter Snyder et al, 2007, Maeda et al, 2016-39, Nyrop et al, 2014; Reynolds et al, 2015 Sajid et al, 2016) or referred to a previous effective intervention (Loprinzi et al, 2012). Of the multiple behaviour change interventions, the RENEW study concluded the intervention to be effective at post-intervention and follow-up (Demark-Wahnefried et al, 2012; Morey et al, 2009; Winger et al, 2014). However, Yammamoto et al (2016) observed a significant change in diet but not physical activity, while Suh et al (2013) found significant changes in physical activity and nutritional status across and between groups.

2.4.3.4 Secondary outcomes of interest

Improvements post intervention for QoL were identified (Buffart et al, 2015; Morey et al, 2009), as well as improvements in physical function or reductions in physical function decline (Buffart et al, 2015; Morey et al, 2009; Sajid et al, 2016). Further significant improvements associated with the interventions included depression, anxiety, and mental health (Reynolds et al, 2015, Winger et al, 2014 and symptom management (Suh et al, 2013). However, follow up evidence was limited or suggested these results were not maintained beyond 12 months (Buffart et al, 2015).

2.4.3.5 Summing up

Overall, 13 of the 15 included articles found the interventions to be somewhat effective (Bourdel-Maechasson et al, 2016; Clutter Snyder et al, 2007; Demark-

Wahnefried et al, 2012; Loprinzi et al, 2012; Maeda et al, 2016; Santa-Mina et al, 2013; Morey et al, 2009; Nyrop et al, 2014; Reynolds et al, 2015; Sajid et al, 2016; Suh et al, 2013; Winger et al, 2014; Yamamoto et al, 2016), emphasising the potential of behaviour change interventions in this population. Yet, both Dronkers et al (2010) and Buffart et al (2015) found the interventions to be ineffective with regards to physical activity, highlighting the possible ineffectiveness of such interventions. Moreover, it is difficult to establish final results regarding the effectiveness of these interventions as many measurements were used and few articles detailed a follow-up period.

2.4.4 Intervention acceptability

Only one of the included articles explicitly detailed the acceptability of the intervention from the participants' perspective (Dronkers et al, 2010), although this was limited in terms of the question asked and potential responses. Dronkers et al (2010) found participants appreciated the intervention, felt it prepared them for surgery and that they did not experience/report any discomfort. Moreover, the retention and recruitment rates for this study were high, further emphasising the expected acceptability of this intervention. However, it is necessary to consider the setting and context of the results in this study, as the intervention was hospital based and implemented before surgery, which may impact the perceived acceptability. Those receiving an intervention in a hospital setting may have other motives for participation. It is, therefore, difficult to ascertain whether the activities and interventions prescribed in hospital settings were in fact acceptable.

Four other articles briefly referred to feasibility and acceptability (Loprinzi et al, 2012; Nyrop et al, 2014; Reynolds et al, 2015; Winger et al, 2014). For example, Reynolds et al (2015) indicated the intervention was feasible, as a specified recruitment target was reached and retention was high (68%), participants were also interested in continuing the programme after completion of the study. While Nyrop et al (2014) suggested the intervention was feasible due to the success in recruitment, eligibility of participants and engagement of participants. Moreover, the Loprinzi et al (2012) and Winger et al (2014) articles detailed results of relevance to acceptability for example engagement/attendance and theoretical predictors.

Although only five of the included articles referred to feasibility and/or acceptability, insights were identified regarding the acceptability of interventions via recruitment rates, attrition rates and attendance to the intervention. In all recruitment rates were poor (range=3.2%-82.1%), while attrition rates were moderate at best (Table 2). Articles reporting lower rates of attrition were generally hospital based (Bourdel-Maechasson et al, 2016, Dronkers et al, 2010, Maeda et al, 2016 or originating in a hospital setting Yamamoto et al, 2016, once again highlighting the likelihood that motivations are different in this setting. Attendance was only detailed in five of the 13 included studies, ranging from 5.5% to 97% (Buffart et al, 2015, Dronkers et al, 2010, Santa-Mina et al, 2013, Reynolds et al, 2015, Yamamoto et al, 2016), indicating potential issues with acceptability. However, many of the included interventions were home-based, so measurement of attendance rates would not be possible. Table 2 provides further information regarding recruitment, attrition and attendance rates.

Numerous barriers to intervention participation were identified throughout most studies (Table 3). These included: no time (Santa-Mina et al, 2013), lack of transport/too far away (Santa-Mina et al, 2013; Suh et al, 2013), not interested (Demark-Wahnefried et al, 2012, Santa-Mina et al, 2013, Sajid et al, 2016, Suh et al, 2013), not able (self-determined; Santa-Mina et al, 2013) and a dislike of the intervention (Sajid et al, 2016). It is possible using a local newspaper for recruitment is a possible facilitator, as it was described as the best means of recruitment by Reynolds et al (2015). Moreover, Winger et al (2014) identified study attendance as a facilitator to change but no facilitators for participation were identified. Loprinzi et al (2012) also found components of the TTM predicted physical activity participation but once again no reference was made regarding facilitators to participation in the intervention. Owing to the number of barriers identified it is likely the interventions employed were perceived as unacceptable to the participants, however, participants were rarely if ever asked their views on the interventions. Therefore, conclusions are predominantly drawn based on the quantitative data available, i.e., recruitment, attrition, and attendance rates.

2.4.5 Theoretical underpinnings

For the most part the interventions included detailed little information regarding the theories used to inform intervention development (Table 3). The most prominent theories identified were social cognitive theory (SCT) and the trans-theoretical model (TTM; Clutter Snyder et al, 2007; Demark-Wahnefried et al, 2012; Loprinzi et al, 2012; Morey et al, 2009; Winger et al, 2014). Further theories drawn on include culturally specific theories and theories specifically related to older adults (Suh et al, 2013).

Table 2: Acceptability characteristics

Reference	Recruitment	Attendance		Attrition		Attrition at follow up		Total Attrition	
				Intervention	Control	Intervention	Control	Intervention	Control
(Bourdel-Marchasson et al., 2016)	44% includes some exclusion by researchers	Not described		0%	3%	0%	0%	0%	3%
(Buffart et al., 2015)	29%	EX 77%	PA (control) N/A	EX Not described	PA (control)	EX	PA (Control)	EX	PA (Control)
(Clutter Snyder et al., 2007)	33%	Not described		8%		5%		12%	
(Dronkers et al., 2010)	Not described	Intervention 97%	Control N/A	Intervention 4.5%	Control 0%	N/A		Intervention 4.5%	Control 0%
(Loprinzi et al., 2012)	82.1%	N/A		Not described					
(Maeda et al., 2016)	Not described	Not described		Intervention 0%	Control 0%	N/A		Intervention 0%	Control 0%
(Santa Mina et al., 2013)	32%	AET Booster sessions 16.4%	RET Booster sessions 5.5%	AET 25%	RET 41%	AET 21%	RET 40%	AET 41%	RET 65%
RENEW trial (Demark-Wahnefried et al., 2012;	3.2%	Immediate N/A	Wait list	Immediate 16%	Wait list 10%	Immediate 10%	Wait list 15%	Immediate 24%	Wait list 24%

Morey et al., 2009; Winger et al., 2014)											
(Nyrop et al., 2014)	77%	N/A	5%			N/A			5%		
(Reynolds et al., 2014)	Not described	75%	32%			N/A			32%		
(Sajid et al., 2016)	Not described	N/A	Wii Fit 0%	EXCAP 0%	Control 0%	Wii fit 37.5%	EXCAP 17%	Control 40%	Wii Fit 37.5%	EXCAP 17%	Control 40%
(Suh et al., 2013)	23%	Not described	Intervention 9%		Control 11%	N/A			Intervention 9%		Control 11%
(Yamamoto et al., 2017)	Not described	50%	0%			0%			0%		

Table 3: Theoretical underpinnings and barriers/facilitators identified

Reference	Theories used for intervention	Setting	Barriers/Facilitators to participation
Boudel-Maechasson et al, 2016	None mentioned	Cancer treatment setting	None mentioned although 2 participants refused to continue with the intervention but no reasons were given. No loss of participants at follow up so difficult to discern barriers.
Buffart et al, 2015	None mentioned	6 months supervised (unsure of setting) and 6 months home based	Mentions response rate of 29% but no barriers/facilitators
Clutter Snyder et al, 2007	Trans-theoretical model (TTM) and Social Cognitive Theory (SCT)	Home based	No reasons for refusal to participate provided, doesn't seem to be reasons for drop out provided either, so difficult to discern barriers
RENEW TRIAL Demark-Wahnefried et al, 2012; Morey et al, 2009; Winger et al, 2014	TTM and SCT	Home based	67,161 participants were identified; however, only 641 took part. The main reasons for not taking part were ineligibility, non-responders/refusal, death, duplicate cases, not approved by physician, incomplete info or new cancers-not really facilitators or barriers as no info on why they refused. 17, 486 refused, which is particularly high, reasons for refusal reported elsewhere
Dronkers et al, 2010	Based on previous research rather than specific theory	Hospital	Not mentioned
Loprinzi et al, 2012	TTM	University	Not mentioned

Maeda et al, 2016	None mentioned	Outpatient setting	Not mentioned
Santa-Mina et al, 2013	None mentioned	Home based	Reasons for refusal to take part included, no time, lack of transport/too far away, travelling during intervention period, not interested, not able (self-determined), already exercising.
Nyrop et al 2014	None Mentioned	Home based	Participants could not be recruited because of medical conditions, did not meet the criteria regarding AI therapy, were too active or refused. 24 were initially recruited but 4 did not complete any measures yet this was not addressed. 1 participant of the final 20 dropped out but no reasons for this.
Reynolds et al, 2015	None Mentioned	Aerobics room in local community health centre	Newspaper advertisement was the best means of recruitment, which in a way could be deemed as a facilitator. There was no mention of barriers. The population was self-selecting, so there was no discussion of refusal.
Sajid et al, 2016	None mentioned	Home based	Barriers/reasons for attrition included 1 patient lost their Wii-fit, 2 lost interested in the Wii-fit and 1 did not like exercises in EXCAP. A further 2 dropped out of control arm due to finding the measurements (diary) cumbersome. At recruitment stage, 31 participants were recruited and completed consent. However, 12 complete enough of the baseline diary, deeming them ineligible for the intervention, yet no reasons are given as to why they did not complete the diary. It does; however, seem the diary itself was a barrier.
Suh et al, 2013	conceptual model of elderly cancer survivorship, cultural competence	A combination of home based and cancer care centre	Few reasons provided for refusal but those mentioned include, too far from cancer centre, no need for health promotion, no desire to participate.

	and a model of selective optimization compensation		
Yamamoto et al, 2016	None mentioned	Hospital for initial advice but continued in the home	All eligible participants took part but there is no mention of the facilitators for this.

2.4.6 Quality assessment

Quality assessment was conducted using the Effective Public Health Practice Project Tool (EPHPP). The initial agreement rate for the quality assessment between the two independent reviewers was 75%, all differences were discussed until an agreement rate of 100% was achieved. Results of the quality assessment (Table 4) highlights four key limitations with the current evidence. First, the potential of selection bias, with 13 of the included articles rated weak in this area (Bourdel-Maechasson et al, 2016; 33 Buffart et al, 2015; Clutter Snyder et al, 2007; Demark-Wahnefried et al, 2012; Loprinzi et al, 2012, Santa-Mina et al, 2013; Morey et al, 2009; Nyrop et al, 2014; Reynolds et al, 2015; Sajid et al, 2016; Suh et al, 2013; Winger et al, 2014; Yamamoto et al, 2016) and the final two achieved a rating of moderate (Dronkers et al, 2010; Maeda et al, 2016). Second, studies had high drop-out rates, with three of the 15 included articles rated weak indicating a drop-out rate of 40% or more (Buffart et al, 2015; Loprinzi et al, 2012; Santa-Mina et al, 2013). Third, all of the included articles rated poorly in terms of blinding, however, this is likely due to the difficulties associated with blinding participants to behaviour change interventions. Fourth, nine of the 15 included articles were rated as weak overall (Buffart et al, 2015; Loprinzi et al, 2012; Maeda et al, 2016; Santa-Mina et al, 2013; Nyrop et al, 2014; Reynolds et al, 2015; Sajid et al, 2016, Winger et al, 2014; Yamamoto et al, 2016), while the remaining six were rated as moderate (Bourdel-Maechasson et al, 2016; Clutter Snyder et al, 2007; Demark-Wahnefried et al, 2012; Dronkers et al, 2010; Morey et al, 2009, Suh et al, 2013). No included articles were rated as strong overall, indicating issues with the quality of evidence available. However, study strengths included study design and study collection methods, in that most data collection methods were standardised and validated.

Table 4: Quality assessment

Reference	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and dropouts	Overall
Bourdel-Maechasson et al (2016)	Weak	Strong	Strong	Moderate	Strong	Strong	Moderate
Buffart et al (2015)	Weak	Strong	Strong	Moderate	Strong	Weak	Weak
Clutter Snyder et al (2007)	Weak	Strong	Strong	Moderate	Moderate	Strong	Moderate
Demark-Wahnefried et al (2012)	Weak	Strong	Strong	Moderate	Strong	Moderate	Moderate
Dronkers et al (2010)	Moderate	Strong	Moderate	Weak	Strong	Strong	Moderate
Loprinzi et al (2012)	Weak	Weak	Weak	Weak	Strong	Weak	Weak
Maeda et al (2016)	Moderate	Moderate	Weak	Weak	Strong	Strong	Weak
Santa-Mina et al (2013)	Weak	Weak	Strong	Weak	Strong	Weak	Weak
Morey et al (2009)	Weak	Strong	Strong	Moderate	Strong	Strong	Moderate
Nyrop et al (2014)	Weak	Moderate	N/A	Weak	Weak	Strong	Weak
Reynolds et al (2015)	Weak	Moderate	N/A	Weak	Strong	Moderate	Weak
Sajid et al (2016)	Weak	Strong	Strong	Moderate	Weak	Moderate	Weak
Suh et al (2013)	Weak	Strong	Strong	Moderate	Moderate	Strong	Moderate
Winger et al (2014)	Weak	Strong	Weak	Moderate	Weak	Strong	Weak
Yamamoto et al (2016)	Weak	Moderate	N/A	Moderate	Weak	Strong	Weak

2.5 Discussion

A total of 15 articles from 13 studies, were included in this systematic review, 60% of which were Randomised Controlled Trials (RCT). These referred to a variety of interventions targeting diet and physical activity. None of the included articles targeted sedentary time, identifying a gap in the literature regarding the implementation and evaluation of interventions designed to reduce sedentary time in older adults with cancer.

Included interventions were implemented in a variety of populations within the broader population of older adults with cancer, for example varied cancer types, treatment types and treatment stages. Therefore, the conclusions drawn are derived from a relatively heterogeneous sample. The majority were deemed effective to a degree in changing the targeted behaviours, although there was limited follow up. Limited evidence was available regarding the acceptability of the interventions.

The small sample sizes of many of the included articles (i.e., Dronkers et al, 2010; Maeda et al, 2016; Nyrop et al, 2014; Sajid et al, 2016; Yamamoto et al, 2016) must be considered. A variety of outcome measures were also used, however, the majority of these were self-report, subjective measures leading to the likelihood of biased results due to the Hawthorne effect (McCambridge et al., 2014). Quality assessment of the included articles identified the majority as being weak (60%), with particular issues around selection bias and attrition. Therefore, there are limitations in the current evidence base around the effectiveness and acceptability of these interventions.

Little evidence was available regarding the acceptability of health behaviour change interventions for older adults with cancer, targeting physical activity and diet. Few included articles referred to acceptability, while the inferences made from attrition, recruitment and attendance indicated further acceptability issues. The disparities between acceptability and effectiveness seem surprising, as the majority of the interventions were deemed effective in some way, yet few conclusions could be drawn regarding the acceptability. However, the low recruitment and high attrition rates may shed some light on this. It is possible those who agreed to participate and completed the intervention period found the intervention to be acceptable, which explains the bias towards effectiveness. However, as these numbers were often low, it is necessary to consider the acceptability of the intervention with regards to those who did not participate or complete the intervention and the potential influence this could have on effectiveness. Future research must ensure interventions are acceptable to most or all of the target population, including those who are often underserved, to promote effectiveness and sustainability. Measures and effort must be taken to ensure this for example employing participatory techniques for intervention development. Co-design is likely a suited method to overcome these issues and lead to the development of an acceptable intervention.

Limited evidence indicated some barriers were prevalent such as: lack of transport (Santa-Santa-Mina et al, 2013; Suh et al, 2013), no time (Santa-Mina et al, 2013) and dislike of the intervention (Sajid et al, 2016). However, little evidence was available regarding facilitators. Moreover, the preferences of the participants regarding the interventions were not considered in the included articles, except for one (Dronkers et al, 2010). However, the evidence available from the Dronkers et al (2010) study was particularly limited, addressing only a small facet of acceptability.

When considering research regarding the preferences and potential facilitators of health behaviours in this population and the wider older adult population, it is unlikely the included interventions can be viewed favourably. For example, current research suggests older adults prefer sociable and fun activities (Devereux-Fitzgerald et al, 2016; French et al, 2014; Zubala et al, 2017), yet most of the included interventions in this review were home-based and individual. Due to this interest in fun and sociable activities it is likely community-based interventions may be more suited. It is therefore unlikely they encapsulated the social aspect deemed preferable in previous research, perhaps attributing to the poor attrition and recruitment rates. Again, a means to ameliorate this issue could lie in co-designing future interventions in a community setting, building on our understanding of the needs of such an intervention. Developing said intervention in such a way, by building collaboratively in a social setting could ensuring a tailored, acceptable and effective intervention is achieved.

2.5.1 Secondary outcomes of interest

Improvements post intervention for QoL were identified (Buffart et al, 2015; Morey et al, 2009), as well as improvements in physical function or reductions in physical function decline (Buffart et al, 2015; Morey et al, 2009; Sajid et al, 2016). Further significant improvements associated with the interventions included reductions in depression and anxiety symptoms, improvement in mental health (Reynolds et al, 2015; Winger et al, 2014) and improved symptom management Suh et al, 2013). However, follow up evidence was limited or suggested these results were not maintained (Buffart et al., 2015). Research indicates physical activity, diet and reduced sedentary time can have significant effects on mental, social, and physical well-being (Forbes et al., 2020; Luctkar-Flude et al., 2007), hence, the promotion of interventions to improve these behaviours. However, further evidence is required to ascertain the effectiveness of these interventions, as well as the associations of these changes with broader health outcomes. It is particularly important to consider these changes across time, as at present there is limited evidence available for the effectiveness of interventions at long term follow-up, indicating interventions are potentially ineffective after they have ended.

2.5.2 Theoretical considerations

The predominant theories used were the trans-theoretical model (TTM) and social cognitive theory (SCT). However, the majority of interventions were not theory based. Therefore, it is difficult to discern which theory is the most effective, although the interventions with a theoretical basis were described as effective (Clutter Snyder et al, 2007; Demark-Wahnefried et al, 2012; Loprinzi et al, 2012; Morey et al, 2009; Suh et al, 2013; Winger et al, 2014), seven out of nine with no theoretical basis were also effective in achieving some behaviour change (Maeda et al, 2016; Santa-Mina et al, 2013; Morey et al, 2009; Nyrop et al, 2014; Reynolds et al, 2015; Sajid et al, 2016 Winger et al, 2014; Yamamoto et al, 2016). Such results highlight the differences between interventions delivered in a research capacity as opposed to those delivered in a clinical capacity, with those that were theoretically driven being predominantly research focussed. Consequently, emphasising the necessity to reconsider the role of theories, particularly with regard to intervention context. Yet, the Medical Research Council (MRC, 2008) framework for complex interventions calls for interventions to have a theoretical basis. Considering such theory through an adaptive and participatory lens may lead to new insights and understandings regarding what works and for who, such analysis may be usefully embedded in a co-design process for intervention development.

2.5.3 Strengths and limitations of review

The review completed for this thesis set out to internationally assess the effectiveness and acceptability of behaviour change interventions for diet and physical activity in older adults with cancer. The review was conducted in a rigorous and systematic manner. Two independent reviewers, the second being a fellow PhD student conducted the article inclusion process and quality assessment, which ensured the reliability of the results. Standardised guidelines and tools were used throughout, including PRISMA and Cochrane guidelines for article selection and data extraction, as well as the Effective Public Health Practice Project (EPHPP) quality appraisal tool.

Four limitations with this review can be identified. First, the date range (i.e., Jan 2007-Jun 2017) may have led to the exclusion of some relevant articles. For example, one included article derived from a larger study which was published before the inclusion date (Clutter Snyder et al, 2007). However, this date range captured the majority of research conducted in this area and ensured included articles were current, which is particularly important in the fast-paced field of cancer research. Second, issues with reporting the age range of samples in articles retrieved for possible inclusion led to difficulties with comparison against the inclusion/exclusion criteria. Steps were taken to ameliorate this issue within the review process (e.g., an average age was used where no age range was reported). It must be emphasised that this limitation is only apparent due to limitations with the original articles. Third, as per the prospectively registered protocol, the current review was intended to be an integrative review. Although qualitative articles were assessed for inclusion none were retained for inclusion in the review. Once again, although this is a limitation of this review, it also highlights the lack of qualitative evidence available in the current literature, an issue which can only be addressed through further research. Fourth, it is likely publication bias has influenced the evidence available, as all of the articles included referred to a positive effect, be it behaviour change or improvements in psycho-social well-being.

2.5.4 Informing the thesis

This review indicates the need for future research in three areas. First, research is required regarding the development, implementation and evaluation of interventions targeting sedentary time in older adults living with and beyond cancer, as no evidence was available regarding sedentary time. Second, research ascertaining which behaviour change techniques and theories are effective in this population would be beneficial. The current evidence has relied on commonly used theories and techniques for the general population (e.g., TTM, goal setting). However, evidence suggests older adults prefer activities which are fun and have a social element, which could in turn limit the effectiveness of common behaviour change techniques. Third, research is required to address the issues raised regarding the acceptability of the interventions included, as well as the lack of evidence for the acceptability of the included interventions. Using a co-design process for future intervention development has the potential to create an acceptable and effective behaviour change intervention for older adults with cancer.

Reflection box 2-Initial perceptions of co-design

At this time co-design was new to me. It was recommended by my supervisory team. In these discussions and my subsequent reading, it became apparent that co-design could be key in ameliorating the issues raised in the systematic review. I was somewhat apprehensive at first about using these methods, as I was aware it was a complete change to the way I had been working previously. These methods were engaging, inclusive and primarily qualitative, unlike previous projects I had been involved where the key was extracting data to answer questions set out by the researcher, primarily through quantitative means. However, it was also an exciting prospect and led me to new learning about methods and research more generally.

This thesis will consider all three of these areas and will explore the use of co-design to develop recommendations for a future behaviour change intervention for older adults living with and beyond cancer, targeting physical activity, diet, and sedentary time.

Based on the evidence available and described in Chapter 1 and Chapter 2, the aims and objective of this thesis are:

Aim: To use co-design to develop intervention recommendations with and for older adults living with and beyond cancer to improve the behaviours diet, physical activity, and sedentary time.

Objectives:

1. To engage the community of those who may use and or deliver a future behaviour change intervention for older adults living with and beyond cancer
2. To understand the needs, requirements, perceived barriers, and facilitators of major stakeholders including those who use, deliver, and support such services, with regards to behaviour change intervention design for older adults living with and beyond cancer
3. To determine an appropriate theoretical basis for behaviour change interventions designed for older adults living with and beyond cancer
4. To evaluate the experience of using co-design from the perspective of both the participants and researcher.

2.6 Chapter summary

This chapter has described the first review to address the effectiveness and acceptability of behaviour change interventions, targeting physical activity, diet, and sedentary time for older adults with cancer. This review has highlighted the potential of behaviour change interventions for older adults with cancer, targeting physical activity and diet. No evidence was available for sedentary time. The evidence available for the acceptability and effectiveness for physical activity and dietary interventions among older adults with cancer is limited. The review identified a range of issues, including study quality, lack of acceptability, lack of follow-up, selection bias, high rates of attrition and a paucity of theoretically informed interventions. Adopting a co-design process for intervention development could ameliorate the identified issues with acceptability, selection bias and attrition, as well as create an effective behaviour change intervention targeting physical activity, diet, and sedentary behaviour for this population. The next chapter, Chapter 3 will explore the methodological underpinning of the thesis, with a particular focus on participatory research and co-design. These approaches are considered as co-design has been highlighted as being suitable to achieve the aims and objectives of the thesis, providing a means to successfully explore the gaps identified in this chapter and Chapter 1.

Chapter 3. Methodology

3.1 Chapter overview

In this chapter I explore the methodological underpinnings of co-design, with a detailed explanation of the selection of co-design, as opposed to co-production or co-creation. Later the specific approach of Experience Based Co-Design (EBCD) is considered and evidence for the selection of this approach as most suited to the aims and objectives of this work is detailed. Finally, I describe the overarching design of this research and expected adaptions to the standard EBCD process, alongside the necessary adaptive approach to theory and ethical considerations of the research.

3.2 Selecting co-design

Co-design has been selected due to the issues identified with current interventions available and the potential of this method in creating an intervention that ameliorates these issues. Below provides a detailed rationale for the selection of co-design.

3.2.1 The three Co-s

Ultimately, I chose co-design as the best fit for the purposes of the study. However, to understand this decision it is first necessary to understand my perspective of the differences between the 3 Co-s: co-design, co-creation, and co-production. Co-production, co-design and co-creation all derive from the founding work of Elinor Ostrom and Edgar Cahn, predominantly in economics, with co-design also having roots in Scandinavia (Matias, 2011; New economic foundation, 2008; Robert, Williams, et al., 2021). The main premise of the three Co-s lies within the co-. These methods were intended to be radical at the time and are still expected to be radical now (Burkett, 2022).

There is debate and uncertainty regarding the meaning of each of the three Co-s, with some working to overcome this in more recent years (Vargas et al., 2022). It is likely this debate has arisen as the three are often used interchangeably in research and practice, leading to semantic drift. However, from my perspective and for the purposes of this research at the time it was being conducted, it was important to differentiate between these. To do so I explored key definitions before settling on those below, as distinct from each other and seeming to be logical and progressive.

- Co-design- The process of designing with people that will use or deliver a product or service (Vargas et al., 2022).
- Co-production- This process involves delivering services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours (Boyle & Harris, 2009).
- Co-creation- The process of creating and delivering new solutions with people not for them: involving citizens and communities in design and delivery (Bason, 2018).

In other words, Co-design is an attempt to define a problem and then define and develop a solution with people, co-production is the attempt to implement the solution with people and co-creation is a combination of both co-design and co-production, i.e. designing and implementing with people (McDougall, 2012). Therefore, co-design was best suited to the aims and objectives of this research, as implementing the solution was beyond the scope and resources of this PhD research.

3.3 Co-design

Co-design has been selected as the best suited methodology, embracing participatory techniques and tenets but also enabling the implementation of solutions from professionals. Unlike co-production which can happen naturally and incorporate the process of implementation or co-creation which incorporates both the process of design and implementation, co-design enables collaborative design with a view to implement recommendations or solutions beyond the co-design process. Therefore, co-design was the most appropriate method of the three Co-s for the purposes of this study, i.e., to design a behaviour change intervention for older adults living with and beyond cancer. Ultimately co-design implores that the user and provider work together to optimise the content, form and delivery of services and involves service development with those who will use and provide the service, as well as other professionals (e.g. the researcher (Bradwell & Marr, 2008)). It is anticipated those involved will be treated and respected equally, creating a power shift (Bradwell & Marr, 2008)).

Co-design has many links with health and health care, as well as the capacity to facilitate social change. Based on these facets and the above definition outlined (Design Council, 2021), co-design is suited to the design and development of a behaviour change intervention. When the intended outcome of the co-design process is a behaviour change intervention, it is also helpful to consider the MRC framework for complex intervention development (Medical Research Council, 2006) as discussed in Section 3.6.3. Co-design is therefore, expected to sit within the development phase of the MRC framework and will satisfactorily achieve the necessary components of this phase (i.e., identifying the evidence base, theory development & modelling processes and outcomes).

Co-design can be embedded in the double diamond structure of design (Figure 5). This process incorporates four stages, discover, define, develop, and deliver. Each of these stages have a distinct purpose:

- Discover: Exploring the problem or area of interest
- Define: Homing in on key areas of focus
- Develop: Exploring potential solutions and recommendations
- Deliver: Providing solutions that work

The double diamond was developed to explore the necessary work required to understand the problem as presented and use an iterative process to develop solutions (van Beusekom & Amann, 2021). Essentially designing the right thing but also designing the thing right, be that a product, intervention, or service. The process has in some instances been criticised as it seems to present in a linear fashion, yet it is acknowledged that co-design is rarely linear (Drew, 2022). This is something I was less aware of at the time of setting out this research and something that now in hindsight makes sense and was enabled through the adaptive approach employed.

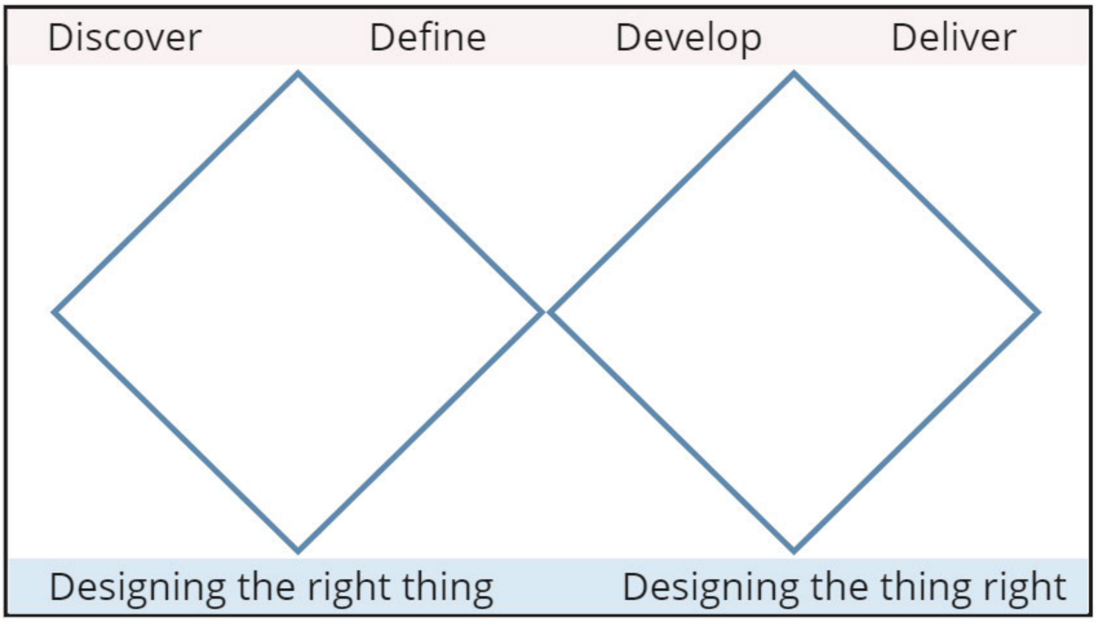


Figure 5: Double diamond of design
(Adapted from (Ball, 2019))

Co-design generally fits within the broader realm of qualitative and specifically participatory research. Qualitative research allows for in depth study to understand the why of things, it is often used to improve interventions and evaluate acceptability, essentially encompassing and embracing the subjective (Aspers & Corte, 2019; Busetto et al., 2020). Further, in qualitative research data can include, transcripts, videos, audio recordings, field notes and mediums, associated with participatory research i.e. photographs, storyboards and drawings, emphasising a good fit with co-design as a person-centred collaborative approach (Lester et al., 2020). I intended to embrace this throughout the PhD, however, I also chose to take a somewhat pragmatic approach to ensure the process worked at a practical level for everyone involved, with a focus on adapting to the needs and practical challenges of the project.

Pragmatism first coined by Peirce (1839-1914) and later affiliated with James (1842-1910) and Dewey (1859-1914) strives for an "integrated interpretation of human life" (Scheffler, 2012) and emphasises the necessity of practicality over the search for truth, therefore, "an ideology or proposition is said to be true if it works satisfactorily...and that unpractical ideas are to be rejected" (McDermid, 2017). Pragmatism is also said to highlight the consequences of actions, as well as being problem-centred, pluralistic and real-world practice oriented (Creswell, 2014).

> *"To a pragmatist, the mandate of science is not to find truth or reality, the existence of which are perpetually in dispute, but to facilitate human problem solving."*
>
> (Powell, 2001)

To inform this research and investigate the aim in the manner most appropriate, a qualitative approach was undertaken, drawing on the practical and adaptive nature of pragmatism to enable an iterative and adaptive co-design process, as has been done previously (Steen, 2013). The necessity of this process and the associated pragmatic underpinnings were also emphasised in the systematic review (Chapter 2) wherein it was evidenced that intervention studies primarily focussed on quantitative evaluations, with limited evidence exploring the acceptability of interventions. Thus, a pragmatic, adaptive and iterative co-design process was deemed most suitable to consider interventions from a new perspective and in turn work to build an acceptable intervention, suited to the needs of those who will use it and those who may provide it.

Co-design puts those who may use and/or provide a service, intervention or product at the core of its design, be that design from the outset or improvement work. This move towards participant control and collaboration can be reflected in Arnstein's ladder of participation (Figure 6 (Arnstein, 1969)). Arnstein's ladder of participation is one of the pillars of community engagement practice and is used to detail the relationship between the community and the government. Arnstein's ladder of participation indicates three levels of participation which each capture a variety of methods/actions. Depending on the study and level of participation research is expected to fall into either tokenism or citizen power (Arnstein, 1969), with co-design expected to fall towards citizen power.

A similar ladder Figure 7 incorporating the key approaches used and discussed in this thesis, (i.e., co-design), has also been developed by the New Economics Foundation (McMillan, 2019). This ladder reflects the key premise of Arnstein's ladder, in that participation is progressive from “doing to” or “non-participation” to “doing with” or “citizen power” (McMillan, 2019). This idea of “citizen power” or “doing with” effectively represents the key benefits of participatory research and in terms of the New Economic Foundation, co-design and co-production specifically. Both ladders enable the consideration of level of participation, with a remit to move away from tokenistic or consultative behaviour. It is this move towards collaborative working, in a person-centred way that I sought to achieve in this research. Essentially striving to do with and not to, but also acknowledging that, for the purposes of this research and the resources available, co-design and not co-production was the intended level of participation.

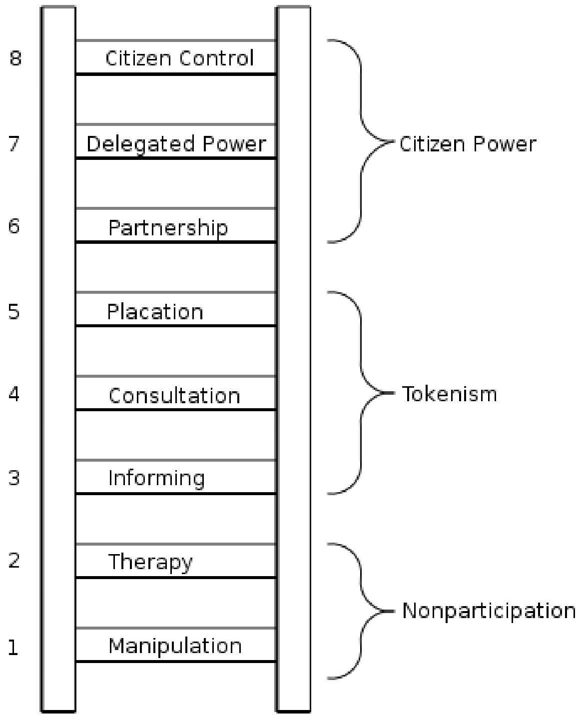


Figure 6: Arnstein’s ladder of participation

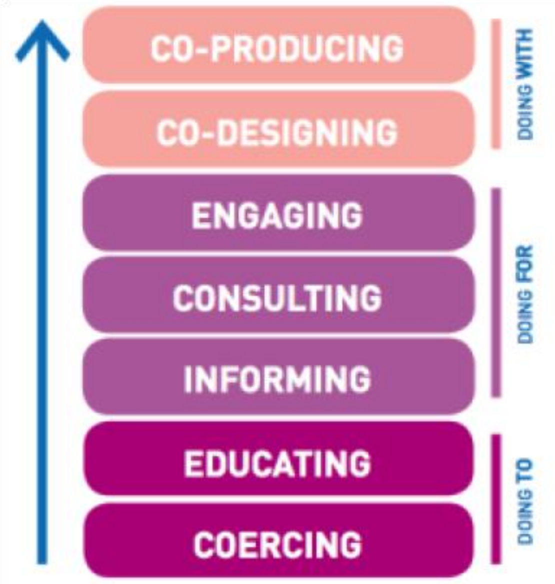


Figure 7: New economic foundation, ladder of participation

Figure 8: Metaphor for the necessity of participatory research
(Adapted from (Swaminathan, 2021))

To portray my understanding of the necessity and benefits of co-design, Figure 8 can be considered. The image is of a recently built train station in my hometown. The land the station is on had been houses and there had always been a path through to the houses from the main road that meant people did not have to walk all the way round the wall. However, when the station was built, a fence was erected blocking this path through as highlighted with the no entry sign in the image. After only a week or two this fence was knocked down and people continued to use the path that had been there, as shown in the bottom left image or the desire path, as discussed elsewhere (Swaminathan, 2021). I propose that interventions that are designed in a top-down way are akin to the path paved by the developers in this scenario, effectively taking people the long way round to achieve their goals. Whereas I propose we use participatory methods and in particular co-design to pave the path preferred by users in this instance that which was blocked off, to ensure we are meeting their needs, enabling empowerment and facilitating what it is they wish to achieve. Consequently, ensuring an approach to paving the most practical path that suits the needs of the users/participants, rather than a path to suit the perceptions of others. To understand this premise further, it is first necessary to understand the key aspects of participatory research.

The origins of participatory research derive from emancipatory theory and social action research (Macaulay, 2017), dating back as far as the 1940s. Kurt Lewin's (1940) proposal for a continuous cycle of inquiry, action and evaluation, undertaken with or by as opposed to on or for society's marginalised individuals, explicitly emphasises the promotion of social equity evident within participatory research (Macaulay, 2017). Similarly, Paulo Freire (1970) identified individuals as full participants in inquiry, indicating the necessity of participatory research. Evidently, within these fields of thought and participatory research itself, there is a rejection of the traditional components of research, specifically the focus on objectivity (Martin & de Konning, 1996). Such rejection is further evidenced in the development of partnerships and all-encompassing person-focused research, wherein, all involved exhibit personhood and an equitable footing within the research (to include all stakeholders and users). Thus, knowledge or knowing in participatory research captures three domains:

1. Learning
2. Action/change
3. Experience

(Martin & de Konning, 1996)

Researchers and organisations began to embrace participatory research, with the term being initially derived from an educational project (Tandon, 1998). Since participatory research has been used in a variety of projects. Such focus has led to the development of the fundamental principles of participatory research, being:

> "equitable co-ownership and co-decision making with full partner engagement with academic researchers, locating power and ownership at every stage of the research process." (Macaulay, 2017)

3.3.1 Exploring contemporary literature of co-design

Recently the use of co-design and other participatory methods has become increasing popular. This has led to an increase in the literature around this area and emergence of key advocates for such methods. One such advocate is KA McKercher who has written widely about co-design, how and when it should be used and has been vocal about the current focus on this method as a potentially tick box and tokenistic exercise that does not really constitute co-design. McKercher states that there are four key tenets to co-design, these are,

1. Mutual learning
2. Designing
3. Co-deciding
4. Recognising lived experience

(McKercher, 2020)

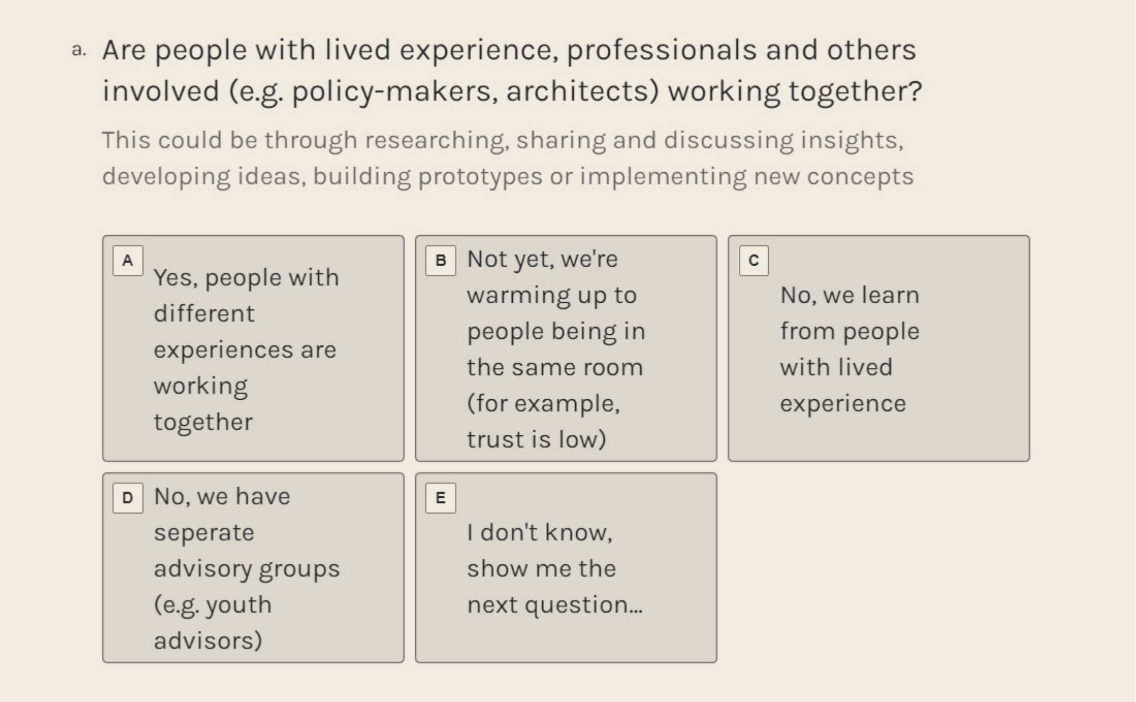
McKercher (2022) has also developed a tool to explore whether work is in fact co-design, this is a small questionnaire which encourages researchers and practitioners to think about the process, what they are doing and the extent to which it is indeed participatory and co-design. In essence this tool reflects the ladders described in section 3.3 and encourages individuals to situate their views and process within this. The tool provides four questions with multiple response answers available for each. These answers align to an extent to the ladders of participation, with a clear progression from inclusive and collaborative co-design to more tokenistic and consultive projects. Screenshots from the tool can be found in Figure 9 and Figure 10.

But is it co-design? by Beyond Sticky Notes

This learning tool is designed to help you think about co-design. Your responses are anonymous.

There are **four sections.** Prompts appear after each section based on your answers. You can exit anytime or return to a previous question.

Figure 9 Example shots from McKercher tool


a. Are people with lived experience, professionals and others involved (e.g. policy-makers, architects) working together?

This could be through researching, sharing and discussing insights, developing ideas, building prototypes or implementing new concepts

A Yes, people with different experiences are working together

B Not yet, we're warming up to people being in the same room (for example, trust is low)

C No, we learn from people with lived experience

D No, we have seperate advisory groups (e.g. youth advisors)

E I don't know, show me the next question...

Figure 10 Example question and answers from McKercher tool

From the literature, attendance at conferences and events, and discussions with others working in the field it was clear co-design methodologies were becoming more popular as my PhD progressed. It was also clear this has become a buzzword of sorts and that the methods were often being employed poorly. Although, I had already set on my definition and understanding of the three co-'s, as described in Section 3.2.1. it was important to reflect on how this had progressed since I started my PhD and to explore contemporary literature around this issue, to enable reflection on the process I implemented. Four key reviews are currently available regarding the definitions, implementation and theoretical underpinnings of co-design as is being currently used. These are the reviews of (Blomkamp, 2018; Greenhalgh et al., 2019; Masterson et al., 2022; Messiha et al., 2023).

These reviews have one thing in common, being the acknowledgment that there has been an influx of co-design and other co- methodologies in research and that these need to be will defined and evaluated. Messiha et al (2023) explored the use of theories to inform co-design processes, concluding that further work is needed to determine how and what theories are suited. While Greenhalgh et al (2019) concluded that a variety of methods and approaches implemented together through iteration is key to the success of co-design. Regardless of these reviews and the progress made, a recent editorial by Dudau et al. (2019), emphasises the possibility of disenchantment with such methods for the design and improvement of public health services, as evidence evolves and evaluation improves. However, the others are more optimistic in the potential of co-design and its future use. It is intended that this thesis can contribute to this debate and build on the evidence base for co-design.

In addition to these reviews concerning the definition and general use of co-design there are also a number of reviews exploring the use of co-design with a variety of populations. A brief search of the literature identified 14 such articles. I am aware this is not an exhaustive list of reviews conducted regarding co-design, however, the purpose here is to explore and learn about available evidence for co-design, as time has progressed, rather than conduct a full systematic review or review of reviews after the research is complete. These reviews were primarily conducted after the completion of this research, as co-design became more popular, with only two being conducted and published before the data generation for this study began, being those of (Mulvale et al., 2016; Tsekleves & Cooper, 2017). However, it is important to consider these within the thesis and explore how co-design has been implemented and in what populations. An overview of these reviews can be found in Table 5. Reviews specifically regarding EBCD have been excluded from this section as these are explored in Section 3.4. However, some of the reviews explored included EBCD articles, amongst other co-design methodologies.

Reflection box 3-Reflections on co-design, then vs now

I set out on my PhD journey in 2016, at this time co-design was a fairly novel concept although I was aware it had its roots in historical literature and research, as described in Section 3.3. From this reading I was aware that co-design was a relatively new way of thinking and working in research, especially around intervention design. From the beginning I had been interested in understanding what those who may use or need a service/intervention would like to see for that service or intervention. Therefore, co-design was well suited as it provided a platform to work collaboratively in a slightly different way to the usual relationship of researcher and participant but also work to develop something useful. Thus, co-design a general concept seemed especially suited to the aims and questions as raised in the systematic review.

However, since then I have noticed that at almost every single research event I attend there is a profound focus on co-design and other participatory methods. This is exciting to see, but also worrying considering the fact that co-design is an intensive, resource heavy process. It is also possible however, that this apparent increased focus is synonymous with co-design becoming more of a buzzword than a philosophical perspective. I therefore feel it is important to advocate for authentic co-design that is not tokenistic and believe that using the framework which McKercher (2022) has developed is an possible way to do this.

Table 5: Overview of reviews regarding co-design

Reference	Aims	Key findings and recommendations
(Bevan Jones et al., 2020)	To explore the use of co-design for the development of digital technologies to support children and young people's mental health	Need for guidelines for the use of co-design in intervention development. Recommendations include need for consideration of diversity in populations and necessity to evaluate co-design processes.
(Butler et al., 2022)	To identify optimal approaches to co-design in health, specifically for First Nations Australians. To ensure approaches used are safe and acceptable for this population.	Six key themes identified with 28 practical sub themes exploring the use of co-design with the First Nations Australia. The 6 key themes were First Nations Australians leadership; Culturally grounded approach; Respect; Benefit to First Nations communities; Inclusive partnerships; and Evidence-based decision making.
(Carroll et al., 2021)	To determine the necessary components and methods of co-design for the development of assistive technologies for older adults.	Determination of set recommendations and mechanisms for the use of co-design for this purpose, including mutual awareness, mutual learning, trust, and reciprocity. In addition, emphasis was placed on the need for power restructuring for effective co-design.

(Cole et al., 2022)	To understand the use of co-design for the development of electronic healthcare tools with older adults.	Gaps identified around the involvement processes, levels of participation and stages of the process. Future work is needed to ensure engagement and empower individuals in the process.
(Constantin et al., 2022)	To determine how co-design has been used to develop physical activity interventions for older adults.	Frameworks and methodologies, logistics, relationships, participation, and generalizability, were identified as barriers and facilitators to co-design. The majority of studies identified involved users only in a consultative way. Large variability between processes was identified and a need to evaluate the effectiveness of the process was recommended.
(Cwintal et al., 2023)	To explore the use of co-design in the development of MHealth tools, with the aim of developing a similar tool for paediatric surgery.	Co-design can be useful for the design and development of MHealth tools, but it relies on the use of clearly defined terminology, activities to be involved and evaluation of the process and outcome.
(Grindell et al., 2022)	To understand how if at all co-approaches can achieve knowledge mobilisation in healthcare.	It is suggested that researchers are relying on co-approaches to develop interventions to enable knowledge mobilisation. However, the interventions developed are poorly evaluated and little evidence is available for their effectiveness and impact on health outcomes.
(King et al., 2022)	To understand how or if co-design works for socially marginalised groups, including but	Limited information regarding the effectiveness of co-design for indigenous children and young people, and other marginalised groups.

	not limited to indigenous children and young people.	There is a need for quality reporting regarding co-design with these groups and more generally. Limited evidence regarding the impact on health inequalities, indicating a need for more detailed evaluation of processes and outcomes.
(McGill et al., 2022)	To explore the literature regarding the use of co-design for the development of chronic disease prevention initiatives.	Acknowledgement of the slippage of terms when used to describe co-design and the impact of this on research. Co-design was generally described as a formal process using interviews and focus groups. No information was available about the effectiveness of the interventions developed and a call for improved evaluation was evident.
(Nusir & Rekik, 2022)	To understand how co-design methods are used to improve existing technology-based health systems under the pressure of the COVID 19 pandemic.	Co-design may provide a useful method for the improvement of technology-based systems. However, there may be issues around bias of certain patient groups, and specific methods are needed that can be used to enable these improvements, incorporating the already used systems.
(O'Brien et al., 2021)	To explore the use of co-design with culturally and linguistically diverse populations, with a specific focus on these populations in mental health services.	Additional research is needed to better understand the use of co-design with this population. It is understood that co-design can influence the relationship with these communities and so partnerships and

		understanding of the communities must be ascertained when using co-design, to ensure these are empowered and not disrupted.
(Sanz et al., 2021)	To understand the implementation of co-design methods in health and social care services for the development of digital technologies for the provision of people centred care.	Co-design can be beneficial for the delivery of people centred care. Future studies should trial and implement some of the methods and key tools identified in the review, to enable the participation of end users in service design.
(Talevski et al., 2023)	To explore the use of co-design for the development of cardiovascular disease secondary prevention interventions, within both the community and healthcare settings.	Acknowledgement in use of various terms to mean co-design. Co-design methods seem formal and focus on consultative methods including interviews and focus groups, with limited mention of creative methods. Limited evaluation of interventions developed, or processes implemented to develop these but a recommendation that co-design could be useful for future development of interventions.
(Tay et al., 2021)	To explore co-design techniques used in the development of interventions for improved nutrition in adult populations.	A variety of co-design methods or components of co-design were implemented for intervention design. However, none implemented a full co-design process, drawing more on participator research, again highlighting the issue around slippage and overuse of these terms. No evaluation of the co-design process or impact of the co-design process

		on the intervention determined. Future work should implement the full co-design process and evaluate throughout and after implementation of the intervention designed.

From these reviews it is possible to see the breadth of the implementation of co-design. Co-design has been used to develop a variety of services and interventions, with various population, both within healthcare and the community. In addition specific studies expand on these areas, with co-design having also been used to develop educational curricula, a telehealth programme, quality indicators and public services, among other services and interventions (Avram et al., 2019; Banbury et al., 2021; Heiss & Kokshagina, 2021; Manalili et al., 2021; Mulvale et al., 2019; Munoz et al., 2017). However, it is clear there are key limitations in the use of co-design, with two key themes evident from these reviews, 1. That there is slippage around the term and use of co-design methods, with some falling into more consultative than collaborative processes, and 2. That there is a need for improved evaluation of both co-design processes and how these processes impact the outcomes generated.

Furthermore, a recent systematic review of reviews focussing on the use of co-design found several instances in which co-design has been used in research, specifically in healthcare, highlighting the potential for benefit and need to include stakeholders to build acceptable services and interventions. However, this review also concluded further work is required to develop and evaluate such processes, emphasising the role of continued research using co-design as a developing tool (Slattery et al., 2020). From this reading I was aware of the need for evaluation of the process, regardless of outcomes and so worked to embed such an evaluation in my study. Detail of this can be found in Chapter 6.

Specific examples of co-design for the development of behaviour change interventions are also available in the current literature. One is that of O’Brien et al (2016) wherein the aim was to develop a lifestyle intervention for adults transitioning to retirement, targeting physical activity and diet. However, it is key to acknowledge this study did not in fact take all considerations expressed by participants on board. For example, participants cited a preference for a face-to-face intervention, but it was intimated that this was beyond the scope of the research and was therefore overlooked. It is necessary to ensure the process is not merely tokenistic consultation but is instead as true to the philosophy of co-design as possible, working collaboratively and equally.

In addition to these specific examples of co-design for intervention development, two of the reviews briefly explored earlier in this section are of specific interest for this project and will therefore, be expanded on further. These are the reviews of Constantin et al. (2022) and Tay et al. (2021) and are of interest due to their focus on intervention development for diet and physical activity, two of the behaviours selected for exploration within the current study. Tay et al (2021) explored the use of co-design for the development of nutritional interventions, while Constantin et al (2022) explored the use of co-design for the development of physical activity interventions for older adults.

Tay et al (2021) identified 22 studies to be included in the review regarding co-design for the development of nutrition and diet interventions. The articles encompassed a variety of populations including Aboriginal communities, Type 2 diabetes patients, older adults, healthy adults, healthcare professionals, and other marginalised or disease populations. Of the 22 studies included few used creative methods, a key component of co-design and few enabled shared decision making. The majority used only consultative participatory methods and not co-design to inform design. Moreover, the interventions developed or improved varied greatly and were often poorly evaluated. The authors also noted that the intervention development processes were often poorly reported, indicating a need for improved reporting of co-design and participatory methods. As such there is scope for the use of co-design for nutritional and diet intervention development but there is a need for improved methodology, reporting and evaluation.

Constantin et al (2022) identified and included a total of 29 articles exploring co-design for the development of interventions for physical activity in older adults. This review was comprehensive and explored many components from the definitions and terminology used, the methods implemented and stage of the research projects, the means of process evaluation and the identification of barriers and facilitators to the use of co-design for the intended purpose and population. Results identified 10 different terms to describe co-design, with analysis of operational definitions identifying five key components of co-design necessary when working with the specific population of older adults. These were 1. A user centred approach, 2. Collaboration with researchers, older adults and other stakeholders, 2. Tailored to specific needs, 4. Active involvement of all stakeholders and 5. Iteration and continuous reflection. However, not all articles achieved each of the identified components, emphasising room for learning and improvement when using co-design with older adults.

As with the review of Tay et al (2021) the processes reported by the articles included in the review by Constantin et al (2022) were predominantly consultative and tokenistic as opposed to collaborative. In addition, there were also issues with a distinct lack of evaluation in that none of the included articles reported any evaluation of the processes implemented. This review does, however, add to the evidence based in that barriers and facilitators to co-design are determined. These focus on framework and methodologies, logistics, relationships, participation and generalisability. Aspects such as these are explored further in Section 3.5, where benefits and challenges of co-design are discussed. Regardless of the issues raised as with Tay et al (2021), Constantin et al (2022) pointed to the potential of co-design for intervention development, specifically with older adults and targeting physical activity. This emphasises the extent to which the current project was needed and novel.

From this overview of contemporary literature regarding co-design in both healthcare and community settings, it is clear there is potential for the method for the development of interventions. However, it has also been useful to identify some key issues around the use of co-design for such development. Primarily the slippage around the use of the terms; co-design, co-creation, co-production and in some cases general participatory research. This is where the set definition of co-design as described in Section 3.2.1 is key. In addition, there are calls for improved evaluation and the creation of empowerment of individuals, with a move away from consultative methods, which were often dominant in the previous literature.

Reflection box 4-Setting expectations

From reading it was clear that co-design could sometimes lead to the development of services and interventions that are not accurate representations of the process, as in the case of O'Brien et al (2016). The extreme of this is distrust in research and a sense of being used when the researchers exit the field. Therefore, it was important that I set expectations from the outset. Those involved were aware of the aims, aware that I was a PhD student working to complete my degree and most importantly aware that the process was not going to result in a new service or intervention they could participate in. Instead, they were contributing to recommendations for best practice for a service or intervention that may be developed further in the future.

When attending a conference, I was asked what I might do if someone suggests something that I know does not work or that is not feasible. At the time this was difficult to answer but after discussions with my supervisors it was agreed again that setting expectations would be key. However, I did not want to restrict the process too much and allowed for flexibility within these expectations. For example, discussing an idea that may not be feasible could be important and agreeing together as a group that this is not feasible, rather than overstepping and creating an unequal power dynamic would be important. Therefore, I aimed to set out expectations from the outset but allowed for discussion as opposed to shutting down ideas. An example of an idea that was not feasible is explored in Section 5.13.7.

3.3.2 Actively learning about co-design methods

After selecting co-design as the appropriate approach for this work, I acknowledged that I was inexperienced in these methods and more broadly qualitative methods. I, therefore, sought out relevant training which contributed to developing the design of the study and the tools used in the process. The training I attended can be found in Table 6.

Table 6: Training attended

Title	Provider	Topics and considerations for PhD
Spring into methods-Introduction to co-design and co-creation methods	Scottish Graduate School for Social Sciences	Considering personas and storyboards, trialling these methods on a sample project.
Experience based co-design	Point of Care Foundation	Exploring the underpinnings and process of EBCD. Opportunity to trial emotional mapping, realised at this point it is likely not suitable for the project I built, as it is too focussed on a service that already exists.
Conducting focus groups	Social Research Association	Opportunity to learn and try out focus group facilitation techniques, a method I had not used before but was aware of the importance of the facilitator-Learned it is best practice to have 2 facilitators and use an ice breaker/open question wherever possible.
Participatory research	Queen Margaret University	Discussed and built on skills around participatory research. Some of which were quite abstract but interesting to learn and consider the level of participatory I was comfortable with.
Reflexivity-Why does it matter?	Scottish Graduate School for Social Sciences	Exploring the concept of reflexivity, important as I had to acknowledge my own role and interpretation of the process throughout.

3.4 Experience based co-design

I selected experienced based co-design (EBCD) as the best suited approach to co-design for this research, due to calls for use in community settings and potential for adaption. The primary components of EBCD can be found in Figure 11. In essence EBCD enables the process akin to the double diamond structure. The process moves from preparation and observation, to interviews, then groups and workshops, first separately with both stakeholder groups (users/patients and providers/staff) and then jointly, before culminating in a celebration event (Donetto et al., 2015). The key focus of EBCD is experience both of those using and/or providing services/interventions, making it particularly suited when considering chronic illness populations, as in this case being individuals living with and beyond cancer. There are also often implemented tools within this procedure being interviews, videos and emotional touchpoints. However, the method is also touted for its flexibility and adaptability (Donetto et al., 2014; The Point of Care Foundation, 2022a) There is also ample support for those using EBCD, through the toolkit and via a number of case studies e.g., The Point of Care Foundation (2013).

Unlike co-design, EBCD is often facilitated by non-professionals/non-designers (i.e. someone working in the service (Robert, Donetto, & Williams, 2021)). However, as there was no service yet available in this instance, I was the facilitator of the process. This is not unheard of in EBCD but is certainly less common, and a point to be aware of. I was aware of this due to the impact of my role and the potential of creating power imbalances. However, I was also aware that I could use my role to empower and reduce power imbalances, as an outsider and not part of the community or usual hierarchy of patient/professional.

3.4.1 Underpinnings and application of EBCD

EBCD was developed by Bate and Robert (2006), as a means for quality improvement in healthcare. Having its roots in experience based design (Bate & Robert, 2006), EBCD sought to explore the experiences of both service users and providers. However, this was to be understood through storytelling based on emotion rather than attitude and opinion (The Point of Care Foundation, 2022a). To do this EBCD works to distribute power equally between healthcare staff and patients, to build a joint venture of improvement (The Point of Care Foundation, 2022a).

An interesting perspective to consider when determining the need for methods such as EBCD in healthcare quality improvement is that of (Dale, 2016). This premise emphasises the notion that when people are creating products they have to sell or services they want to attract people towards, they have to understand how people will experience or use them. This has meant design science and tools such as co-design have been used often in business and product development. However, this is generally not the case for healthcare, as people need healthcare services regardless of the quality and standard of this. There is no or little competition, which has meant healthcare services have been designed with the system at the heart and not the individuals, be it patients, carers or staff. This has led to frustration from many regarding the services provided (both staff and patients). EBCD looks to turn this on its head and incorporate design science, putting user and providers at the heart of healthcare services, to empower and build acceptable, effective and useful services, through collaboration. This is conducted through design or redesign of existing services. In essence that enables healthcare to catch up with other service provision, product development and business services.

In addition to the above need for quality improvement there was also an acknowledgement of the need for a move from potentially expert or often relied on patients, and instead a move to involving patients who reflect the general user of healthcare services (Bate & Robert, 2007a). This move to understanding the experience of your average service user was expected to reduce frustration and improve the services available, through similar methods as those used in business and design science. It was also expected to contribute toward the development of patient centred services, an area where the UK was lacking (Bate & Robert, 2007a).

In the development of EBCD it was acknowledged that healthcare improvement and patient involvement practices had been a focus for some time, while patient centred services had not been achieved. However, it was also said that the term “patient centred” was grossly overused, indicating a need for something more (Bate & Robert, 2006). And, so EBCD was developed, a method of quality improvement that was expected to put the patients and healthcare professionals at the heart of initiatives (Fylan et al., 2021). Evidence suggests that approaches such as EBCD can benefit research processes and outcomes, as well as those involved in the process. For example, it is said to lead to well suited solutions and improved knowledge production (Messiha et al., 2023).

EBCD is a set structure and methodology embedded in the broader paradigm of participatory research and co-design more generally. EBCD draws on ethnography, particularly in the earlier stages of the methods, as well as design sciences, participatory action research, learning theory and narrative based approaches to change (Donetto et al., 2015; Girling et al., 2022). This method places a particular focus on emphasising the benefits of and potential for co-designing services within healthcare, to policy makers, professionals and other decision makers (Robert, Donetto, & Williams, 2021). Experience based co-design is a multi-stage cyclical process Figure 11, generally involving patients, healthcare staff and carers (Fylan et al., 2021). The method was initially piloted in a head and neck cancer service (Bate & Robert, 2007b).

3.4.2 EBCD in healthcare

EBCD has been developed with health care service improvement in mind and many of the previous projects utilising this method have focussed on such improvement (Green et al., 2020). A recent review identified 65 studies implementing EBCD either in its full form or an adapted version (Green et al., 2020), across a number of healthcare services and systems. Another review focussed specifically on the use of EBCD with child and youth mental health services, emphasising the scope for the method with potentially vulnerable populations (Mulvale et al., 2016). While, (Donetto et al., 2014) reviewed EBCD via a survey method gaining insights on the specifics of its use in a variety of healthcare settings. More recently the application of EBCD has been explored further by (Robert et al., 2022), emphasising the benefits and challenges of the approach.

Specific examples of the use of EBCD include, healthcare systems improvements, safer medical use, means to reduce domestic violence and other quality improvement projects (Chisholm et al., 2018; Dimopoulos-Bick et al., 2019; Fucile et al., 2017; Fylan et al., 2021; Gander-Zaucker et al., 2022; Robert et al., 2015), with others specifically exploring adaptions of the methods (Raynor et al., 2020). EBCD has also been used in a variety of cancer care service improvement projects, these will be discussed separately in Section 3.4.3.

As mentioned, EBCD was designed specifically with health care improvement in mind which means it is generally effective in achieving this aim, through collaboration, empowerment, and often simple changes. However, the method is also time consuming, and the literature would suggest it is difficult to get health care professionals to engage sufficiently with the process at times (Bowen et al., 2013). The literature also indicates many teams and projects deviate from the intended process, often omitting the development of a trigger film or the non-participatory observation, again due to time and resources available (Donetto et al., 2014). Owing to these issues an accelerated form of EBCD has been developed, where standard trigger videos are available for research teams to use within their process. This is intended to ameliorate some of the issues associated with the method, particularly the fact that it is resource and time intensive. Regardless of these issues the benefits are clear, and the impact of the process can be great, even through the smallest changes.

Reflection box 5: When is EBCD appropriate?

When learning about EBCD I became aware of the issues around the time and resource intensive nature of the process. However, it seemed the most suited method to the aims of the work and provided a platform to use a somewhat standardised method in a unique and novel way (i.e., intervention development as opposed to service improvement). I, therefore, felt it necessary to embrace the potential issues and adapt and manage these as I progressed through the process. Exploration of how I did this is threaded throughout the thesis.

I was aware of the accelerated form of this method when setting out with the research, however I did not think this was suited to the project, as the sample videos weren't relevant to intervention development in the community. Another reflection regarding EBCD more recently is the perspective of funders. I was involved in a grant application where EBCD was the chosen method. However, the feedback was that this method was too time consuming and resource intensive, and so the bid was unsuccessful. This to me was interesting as so many funders are calling for participatory methods, yet in this case, resource and time issues outweighed the perceived benefits. I think we have to be careful in implementing these methods and ensure they are not cutting corners to meet requirements. It is not possible to harness the full benefits of these methods without the time and resources required.

3.4.3 EBCD in cancer care

Current literature suggests EBCD is becoming more common in the improvement of cancer care strategies and services. A rapid search of literature using PubMed and EBSCO databases with the search terms 'Experience based co-design AND cancer' in title only identified six articles reporting six independent studies, with a focus on a variety of elements of cancer care and populations (Brady et al., 2020; Hiatt et al., 2022; Moser et al., 2021; Tang et al., 2020; Tsianakas et al., 2012; Weston et al., 2018). In addition to these six articles which provide a snapshot of EBCD in cancer care, it is also important to acknowledge that EBCD was indeed initially piloted in a head and neck cancer service. However, this study will not be explored here as no full text or report was found. Therefore, this overview will focus on these six articles. These studies will be briefly appraised below and considered in light of the strengths and limitations in the previous section to ensure I am fully aware of the uses and potential challenges of using EBCD with this population.

Reflection box 6-Practicalities of a PhD

I am aware this is potentially only a snapshot of the material focussing on EBCD and cancer care due to the methods employed to identify the literature. However, it was only realistically possible to conduct one lengthy systematic review during the PhD (Chapter 2). I am also content with the literature included at this stage, as it sufficiently informed my thinking and enabled progression of the co-design process. Moreover, as I was using EBCD for a slightly different purpose to that intended (intervention development vs service improvement) an onerous review of this topic would not have informed the process to any greater extent than that of the writing already included here.

The six studies identified focussed on a variety of topics in cancer care and specifically service improvement in these areas, including lung cancer, breast cancer, prostate cancer, older adults and younger adults. One article reported the development of a pre-habilitation programme, while the rest reported service improvement (Table 7). The articles identified drew on EBCD in different ways, with some utilising the entirety of the process and others only certain components (Table 7). Most of the articles described did not manage to include or conduct the co-design groups, facilitate change and evaluate this. Reasons for this were not noted, however, it was assumed these will be reported later, this emphasises the resource and time intensive nature of the process. Again, most of the articles identified did not cite the use of non-participant observation. However, it was recommended that increased effort at the setup is useful to ensure recruitment and engagement (Brady et al., 2020). Few articles mentioned or reported a celebration event, likely as the process was not complete in most. One article (Moser et al., 2021) did not develop a trigger video, instead the researchers identified and reported touch points to participants. This is likely due to the time and resource intensive nature of this aspect. A brief overview of each of the articles can be found in Table 7. Although some limitation and deviations are evident, it is clear that EBCD is a useful tool in cancer care service improvement and development. It is adaptive and collaborative, creating insights that might not otherwise have been evident.

Similarly, to EBCD more broadly there are some criticisms evident from this literature focussing on cancer care. EBCD is an adaptive process, and it is clear from the articles included that few have followed that process to the letter. However, of most concern is the fact that the majority of processes did not progress to the co-design small group stage or implement any changes. Instead, the majority of articles developed recommendations and priorities for change. This was likely due to the time and resource intensive nature of the process. In addition to this it was clear there were issues with recruitment and engagement, with some of the articles reporting very low participant numbers, to the point that multiple co-design working groups would not have been physically possible. From this I was aware that engagement, recruitment, retention and ensuring I have time and resources were going to be vital to the success of my research.

Also, in support of the current study and use of EBCD for this study I was aware that EBCD had not been used in community settings with cancer patients, with all studies working in a healthcare setting. Thus, in all EBCD is suited when working with cancer patients, the implementation within a community setting is new and unique to this study and considering previous work has provided an overview of potential challenges and pitfalls I may have faced when conducting the process.

Table 7: Overview of articles reporting EBCD in cancer care services

Title/author	Setting	Population	Methods	Limitations and recommendations	Changes prioritised or implemented
(Brady et al., 2020)	Pre-treatment head and neck radiation clinic	Head and neck cancer patients, oncologist, speech and language therapist, dietician, clinical nurse specialist	Standard EBCD methods but no evaluation, celebration event or observation	Small patient and staff numbers (n=7 each), poor engagement and attendance at meetings. Increased engagement at setting up stage.	Not implemented as yet, priorities set- 1. Revised information methods/content, branded for patient/relatives 2. Patient experience video for patients starting treatment 3. Information on timelines on onset of timelines and recovery 4. Buddy system for patient support 5. Flexibility of appointments 6. Seamless transfer of care between institutions 7. SLT rebranding
(Hiatt et al., 2022)	Head and neck cancer journey-diagnosis to survivorship period	Head and neck cancer patients, carers, health care professionals	Standard EBCD method but no evaluation, celebration event, or observation	Limited engagement with joint meeting and co-design workshops, use of personas instead of more varied demographic, limited understanding of	Not implemented but priorities set- 1, improve head and neck information on hospital website 2, create videos and/or podcasts with

				demographics of patients. Evaluate process to address barriers and enablers to participation	information and patient experience
(Moser et al., 2021)	Breast and colorectal cancer pathways	Older patients with breast or colorectal cancer, carers, health care professionals working in these pathways	Interviews with patients and carers, focus groups with health care professionals, no trigger video, experience mapping instead, separate prioritisation workshops, joint prioritisation workshops, co-design working groups. No evaluation, celebration event or observation.	Power imbalance still evident, with processes not possible without buy in from health care professionals. Unable to set up all co-design groups for all priority touchpoints identified due to engagement and resources available. Future work to engage more older adults and provide this population a voice.	Colorectal cancer- Availability of contact person during diagnostic, treatment and aftercare phases Collaboration between clinicians and different hospital departments, enabling information transfer. A continuous relationship with the same doctor. Breast cancer- Comprehensive information package and information provision Care planning based on preferences of patients. Outcomes and improvements still ongoing.
(Tang et al., 2020)	Pre-habilitation service	Prostate cancer patients, carers, health care professionals	Interviews and video development, individual workshops with each	Very low participant numbers and engagement. Possible	Development of a guide for a 2-week group pre-habilitation class.

			group, joint workshop. No observation, no co-design groups, no evaluation, no celebration event. Touchpoints as priorities (often practical) rather than emotional.	selection bias, as only included if participants were willing to tell their story.	Priorities identified were format, duration and frequency, referral, content and advertising. The model was finalised by the research team and is yet to be implemented.
(Tsianakas et al., 2012)	Breast and lung cancer services in hospital	Breast and lung cancer patients, health care professionals	All stages and methods of EBCD	Possible underserved populations are not represented.	Breast cancer service-changes to appointment provision, information provision, communication and structure of clinics. Lung cancer service-changes to improve communication at diagnosis, improved information and support, Improvement of continuity of care, and improved IT and out of hours services. Only sample of improvements.
(Weston et al., 2018)	Adolescence and young adult oncology service	Adolescent and young adult cancer patients, health care professionals	All stages of EBCD but co-design groups and celebration/evaluation	Small number of individuals recruited 6 per population group. Limited resources and	A number of recommendations and priorities determined but these were

			not conducted or reported yet	knowledge/experience of the process in staff. Healthcare professionals should be supported to run and be involved in similar studies in the future.	individual to each group. The process is still ongoing to prioritise, develop change and implement these.

3.5 Benefits and challenges of co-design and EBCD

There are several benefits and challenges when using co-design as described in section 3.3. I will explore these in turn below. It was important for this PhD to consider and understand these before setting out to conduct my own co-design project. These challenges and benefits are generally reflective of those identified in the previous Sections focussing on EBCD in healthcare and cancer care.

Co-design more broadly has been found to have a variety of benefits and strengths, particularly for service design and improvement. A previous literature review by Steen et al (2011) identified these benefits as sitting in three categories, being;

1. Benefits for the service design project
2. Benefits for those who will use and/or provide the service
3. Benefits for the organisations involved

With regards to benefits for the service design project it is intimated that co-design can give voice to often underserved individuals, as well as identify needs from service users and providers, which can then lead to creative and 'out of the box' solutions and designs (Steen et al., 2011). As for benefits for those who will use and/or provide the service it is suggested that those involved can actively benefit from the changes to services and services developed, as these are the intended population groups (Steen et al., 2011) . However, it is also possible those who contribute to co-design may not see or be a part of the services or improvements made for a variety of reasons, leading to tensions and hesitancy in participating in future similar projects. It is important for us a researchers to ensure that expectations are managed throughout to avoid this, a key challenge in conducting co-design projects (Tindall et al., 2021).

As for co-design in healthcare in particular benefits are expected to centre on the improved experience of staff and patients, as these individuals will contribute to improvement and ultimately use or provide the service. In addition to this co-design is expected to lead to improved care and service quality, with previous mention of patient safety and clinical effectiveness (Robert et al., 2022). Such benefit emphasises the scope for co-design in health care.

Yet, another dominant criticism of co-design is the likelihood of facilitating only the goals and needs of those who are most vocal and actively engaged in services, often expert patients who may be desensitised to the needs of others less fortunate than themselves due to immersion in such research, i.e., seeing things from the perspective of the researcher, rather than the population of need (Moll et al., 2020). In addition to this another potential issue is the recent necessity to include and facilitate PPI by grant calls and funders, for example the recent call of Cancer Research UK (2022). Such points may lead to more tokenistic projects, and ultimately miss trust in the process, and poor engagement in future similar projects. I, therefore, felt it important to manage expectations, both for participants organisations, and myself based on resources and time available. This need to be pragmatic is also reflected in the deviations and adaptations to the intended methods, further detail can be found in Chapter 5. Broadly these challenges and benefits can also be applied to the specific technique of EBCD. As well as these benefits and challenges there are also ethical considerations, these will be discussed in Section 3.6.4.

3.6 This study

Having explored different participatory methods, specifically the three Co-s, co-design was selected as the most suited collaborative method, due to the aims of the research (i.e., to design an intervention and then implement it beyond the process). Alongside this due to the learning process of a PhD and my background in quantitative methods a more structured approach to the process was deemed suitable. Although designed to improve current health care practices, there has also been emphasis on the potential to use EBCD in other instances. Donetto, Tsianakas, & Robert (2014) indicated future research concerning the use of EBCD should focus on broader community-based interventions, particularly the development and improvement of these. This move to a focus on community-based interventions further cements EBCD as a suited method for the current study, as it was decided from the outset that the process would take place in the community as described in Section 1.5. Thus, the current study will contribute towards this focus, emphasising the novel, yet necessary nature of the study. Moreover, at the time of conducting this work, co-design was a novel method and using EBCD in this way was unique.

More recently a review by Green et al (2020) indicated EBCD has been used in some instances for intervention design (Green et al., 2020), indicating that this approach has become more common over time. An example of current work drawing on EBCD has also focussed on the development of interventions, in line with the MRC framework for complex interventions. This project led to the development of a DVD and support package for carers of individuals undergoing chemotherapy (The Point of Care Foundation, 2013). However, as yet no other studies have focussed on the use of EBCD for the development a behaviour change intervention or service for older adults living with and beyond cancer.

Thus, due to the links with healthcare and the call to expand the use of EBCD within community and intervention design projects, EBCD was selected as a suitable method. However, due to the distinct focus on quality and service improvement some adaptions and alternate tools were used within the overarching process of EBCD. I am also aware a number of toolkits for co-design have been developed, which is in turn in part why I selected the specific method EBCD. This was the most prevalent at the time of the research, most suited to the question with scope for new learning and provided the most support. Having a quantitative background, that sense of structure in the process and potential tools was vital to ensure I felt confident in the research. Another point of consideration in selecting EBCD was the way in which relationships and confidence were built over a set period of time, with a means to facilitate this. For example, it is suggested patients and professionals are first interviewed individually and then feedback events carried out with both groups, to allow for people to meet and have a backing when coming together as whole (The Point of Care Foundation, 2022a). This is also expected to redistribute the power dynamic within the groups, something which I felt would be key to the success of this work.

This all falls in line with my desire to work pragmatically and really do what suits the question, as well as and perhaps more importantly so, the individuals involved in the process – both the participants and me. This study was completed over a 12-month period from June 2018 to June 2019. It is common for such studies to take this long, with these usually taking 9-12 months (Donetto et al., 2015). A description of the methods used in each Part and Stage of the co-design process are detailed in Chapter 5, including any adaptions made.

3.6.1 Aims & objectives

The overall aim of the study was to use co-design to develop intervention recommendations with and for older adults living with and beyond cancer to improve the behaviours diet, physical activity, and sedentary time.

The objectives were:

1. To engage the community of those who may use and or deliver a future behaviour change intervention for older adults living with and beyond cancer
2. To understand the needs, requirements, perceived barriers and facilitators of major stakeholders, with regards to behaviour change interventions targeting physical activity, diet, and sedentary time, for older adults living with and beyond cancer
3. To determine an appropriate theoretical basis for behaviour change intervention design for older adults living with and beyond cancer
4. To evaluate the experience of using co-design from the perspective of both the participants and researcher.

3.6.2 Design

A co-design process following the flow as detailed in EBCD (Figure 11) but also drawing on other co-design methods and tools suited to the aims of the research was used. This was in line with the adaptive nature of both the study and the method, any adaptions will be described in each of the methods sections for each Part and/or Stage of this study. The flow of EBCD was selected due to the expected ability to build rapport with the participants and ensure they are comfortable with the process but also the structured nature of the process, as this provided me with a focus and distinct process to move through. I felt this was necessary at the time as this was the first time I had worked on a project like this and although I knew I wanted to work in a collaborative way I also felt at the time I needed some structure and guidance to support my progress and learning (i.e., moving from primarily quantitative research to qualitative). Some adaptations were made as the toolkit and the process is designed with health care improvement in mind rather than the development of behaviour change interventions. Therefore, I used the primary components of EBCD (Figure 11) but omitted some of the specific techniques, for example non-participation observation, as it was not suited to the purposes of this design process and emotional mapping. The tools employed were adapted to suit the process and often differed to those recommended in EBCD. This was deemed necessary to consider the aims of the work and move through the process, details of adaptions and tools used can found in Chapter 5. The process moved from a preparatory phase to interviews, then focus groups with both groups separately and finally a workshop bringing all participants together. The process was evaluated throughout from the perspective of the participants and the researcher. Therefore, there were three key parts of the research: A: Preparing, B: Co-designing and C: Evaluating. Each of the three parts were expected to build towards the aims and objectives of the research by informing the proceeding work (Figure 12). The second part (Co-designing) was split into a further three stages:

- Stage 1: Interviews
- Stage 2: Focus Groups
- Stage 3: Workshop

This process was carried out over a year long period, with some additional time for Part A-Preparing, a detailed timeline of the process inclusive of all Parts & Stages can be found in Figure 13.

[redacted]

Figure 11: EBCD cycle
(Adapted from (Donetto et al., 2015))

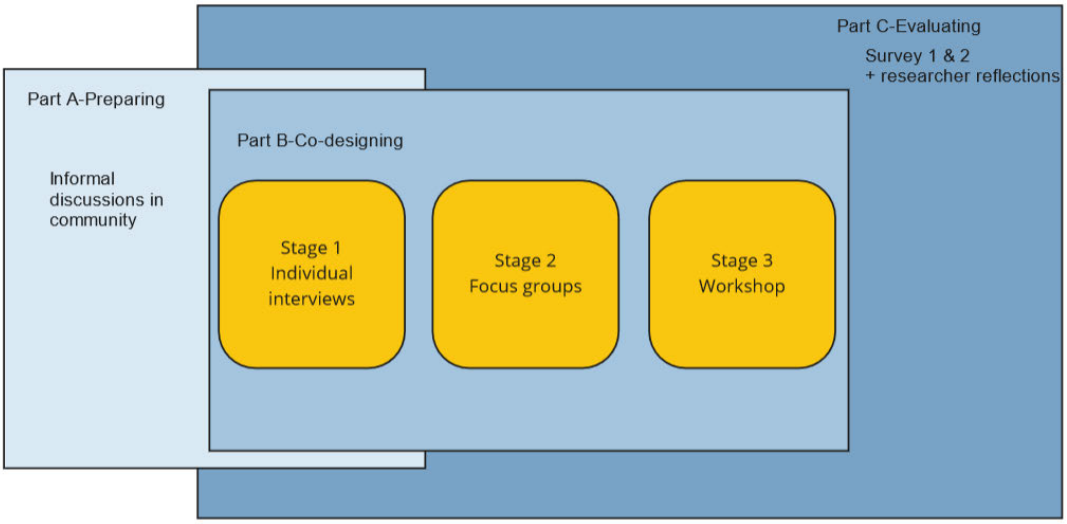


Figure 12: Research process

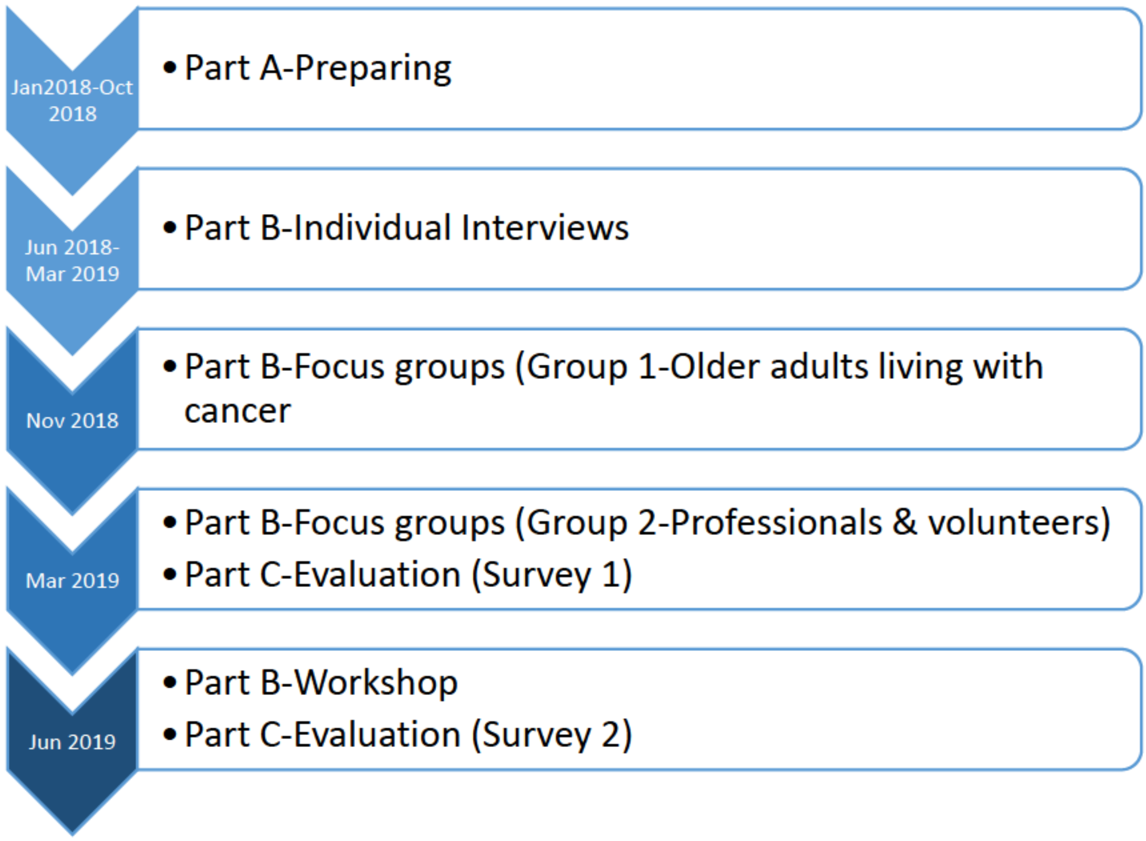


Figure 13: Study timeline

3.6.3 Adaptive approach to theory

In order to consider objective 3 (To determine an appropriate theoretical basis for behaviour change intervention design for older adults living with and beyond cancer), an adaptive approach (Layder, 1998) was applied to the selection of a theoretical basis for the intervention. The MRC framework for intervention development highlights the necessity of a theoretical basis for interventions (Medical Research Council, 2006) However, selecting the basis from the outset seemed counterintuitive and restrictive considering the study design. Instead, I reflected throughout on the theories available, and components discussed in light of these. The adaptive theory approach was developed by Layder (1998) in order to enable an iterative process of theory use/development, incorporating both what is already known and what will be learned from data collection, using both inductive and deductive processes (Layder, 1998). Such an approach was deemed necessary due to the collaborative nature of the work. Incorporation of this adaptive approach furthered the pragmatic nature of the work, enabled the process as was intended but also added an additional layer of knowledge creation.

3.6.4 Ethical considerations when using co-design

As with all research key ethical considerations were explored and risks reduced or omitted where possible. Each of these key risks and considerations are explored in the following section. These include anonymity, consent and exiting the field. The impact of power and the prospect of shifting power is also discussed in the below, as this is a key facet of co-design, as well as participatory research more broadly. In addition, the means used to maintain engagement throughout the process are considered, although not specifically ethical considerations, the tools used had to be ethical and not coercive, and so these are also discussed in this section.

Ethical approval for this study was granted by the Edinburgh Napier University Research Ethics Committee (SHSC/0018).

3.6.4.1 Anonymity

Ensuring anonymity and confidentiality was a key ethical consideration of the process (Liabo et al., 2018; Nijhawan et al., 2013). Due to the participatory nature of the study, anonymity in some ways was not feasible, in that those who participated throughout the process met and interacted with each other often on more than one occasion. However, measures were taken to reduce the impact of this, the main measure being the development of a group agreement. Instead of inflicting rules upon the groups throughout the process, which would not be in the spirit of co-design it was decided the groups would have the opportunity to actively participate in the development of a group agreement. A set of statements the group felt were necessary to feel comfortable and enable engagement with the process made up this group agreement. A group agreement was created for each interaction, generally covering the same key points (i.e., confidentiality, giving everyone an opportunity to speak and respecting others).

In terms of data generation, analysis and presentation anonymity was key. To limit any concerns regarding anonymity of data, a data management plan was created in line with university ethics practices. This plan intimated the coding process to be applied to data to ensure anonymity. Data generated was stored in pseudonymised form, meaning names were replaced with a coding number and a key retained to ensure data linkage through each stage of the process, similar to the use of pseudonyms (Saunders et al., 2015). Pseudonyms were not used at this point, as they may have caused issue when linking data, numbers were used solely for ease and organisation. However, people's real names were used throughout the process and when interacting with others in the process. The pseudonymisation was only used for the purposes of data storage. Place names, family names and any other identifiable data were removed from transcripts during the data cleaning process. Data collected was stored in a secure University drive, with only the lead researcher having access. However, for the purpose of write up, to enable understanding but also to humanise the process, pseudonyms were ascribed to participants.

3.6.4.2 Consent

Obtaining informed consent is key in all research. It is necessary to ensure participants understand the aims and processes of the research, the way their data will be stored, processed and used, and their rights regarding withdrawal (Owens, 2010). Considerable thought was given to the consent process of this study to ensure it suited the study process and gave participants opportunity to engage as and when they liked, without feeling a pressure to withdraw from the process.

Throughout the study a form of process consent (Dewing, 2018; Usher & Arthur, 1998) was employed. Process consent involves obtaining consent at each interaction point, as opposed to requiring participants to consent to the full process from the outset. Process consent was selected as the means of consent for this research as although participants weren't expected to be vulnerable it was acknowledged that their health status may change and influence their ability to participate, especially as the process was expected to span 12 months. This also ensured participants understood the necessary commitment to each stage and were willing to participate. It also removed any need to consider withdrawal of data from previous stages, should participants decide they no longer wish to participate as each stage was discrete in the consent and data collection. Therefore, participants were asked to participate in and consent to each stage of the study process, when that stage was due to begin and were debriefed at the end of each stage.

3.6.4.3 Exiting the field

After investing in the project and creating relationships within the group, it was anticipated that some may find it difficult to detach from the group/process. Therefore, a celebration event was hosted to thank the participants for their efforts and ensure a distinct sense of disengagement from the process and group for both the participants and the researcher (The Point of Care Foundation, 2022b). Details of the celebration event can be found in Chapter 5.

3.6.4.4 Power

A final ethical concern considered was the dynamic of the relationship between the various participant groups, including the research team (Farr, 2017). I endeavoured to create an environment and process where everyone was acknowledged as an expert of their own experience, therefore, alleviating the usual influence of power evident in relationships of professional/service user or patient. Reducing this sense of one group or groups leading the other/s was key to enable the participatory process of co-design but also to ensure all participants were comfortable in their participation.

To further reduce the unnecessary influence of uneven power dynamics measures were taken to identify and work with participants to identify appropriate settings for each of the phases of the process. A concerted effort was made to ensure settings associated with “experts” or professionals i.e., Universities and hospitals were avoided unless discussed with participants. It was expected that this would ensure all participants were comfortable in the setting provided.

Moreover, EBCD lends itself to creating relationships, encouraging confidence and building up to a point of cohesion and comfort before bringing parties from other groups together. This was key in alleviating any possible power imbalances. Regardless keeping check of ourselves, and others throughout the process was key to ensure the balance of group dynamics throughout, ensuring there is no opportunity to revert to the naturally assumed roles of expert and participant. The primary purpose of this study was to collaborate with all of those potentially impacted by the development of the intervention and therefore, special attention must be paid to group dynamic, to ensure all voices are heard in a comfortable environment.

3.6.4.5 Maintaining engagement

Throughout the co-design process maintaining engagement was key. Participants were involved in the study for up to 12 months. Key measures were implemented to ensure engagement, for example contact was maintained with participants briefly outwith the study interaction periods, including one email acknowledgment of the time delay and one Christmas card. The Christmas cards seemed to be very well received and instigated an insightful conversation with one participant re behaviour but most importantly acted as a reminder to participants of the study process and the ongoing nature of the study. Most useful in maintaining engagement was the process itself, several measures were taken to ensure the process was enjoyable, people felt heard and able to contribute. The impact of these measures and results regarding the evaluation of the process itself can be found in Chapter 6.

3.7 Chapter Summary

Chapter 3 has detailed the methodological considerations of the research. The ethical considerations associated with co-design were also explored, as well as the means employed to maintain engagement throughout the process. The following chapter will explore the first Part of the co-design process, Part A Preparing. This will set the scene for the following chapters, exploring each of the consecutive Parts and stages as they were conducted. At this point the thesis deviates somewhat from the norm as each chapter explores the methods and results of each Part.

Chapter 4. Part A-Preparing

4.1 Chapter overview

In this chapter I will explore the first Part of the co-design work, being Part A-Preparing (Figure 14). First, I explain the rationale of Part A-Preparing, as well as note the aims of this. This Part primarily focussed on learning about services in the community and building relationships with these to facilitate the research, as well as improve my understanding of the current landscape. I discuss how I carried out this preparation, the services involved and the results in reference to the four key aims of this Part. Finally, I describe how the results were considered and carried forward into the next Part of the work, highlighting the importance of preparation in co-design.

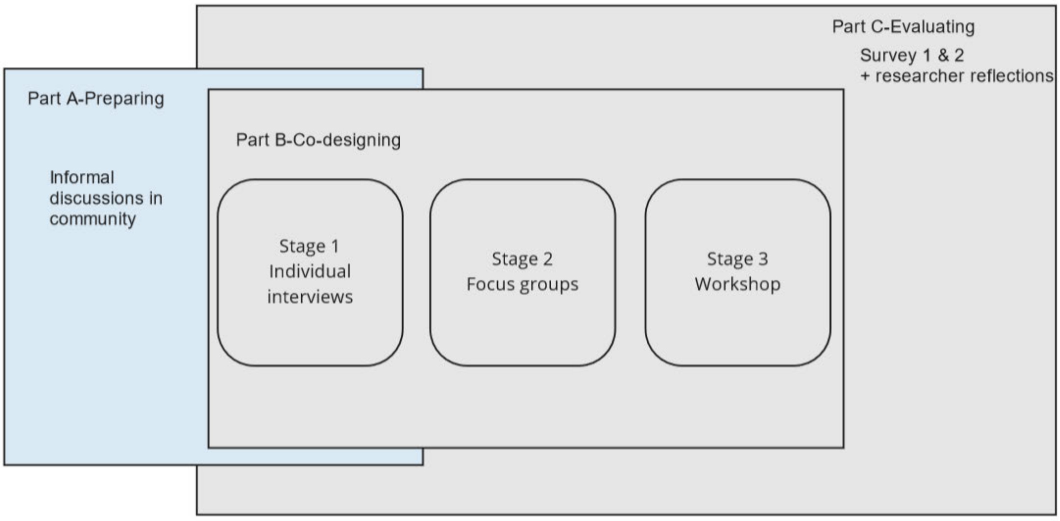


Figure 14: Research process highlighting Part A-Preparing

4.2 Rationale & aims

Part A-Preparing, the first step of the co-design process (Figure 14) was designed and implemented, embedded within the co-design process, incorporating components of the setting up and observations phases of EBCD (Point of Care Foundation, 2022). At its core this Part focussed on engaging the community (Objective 1 of this research: To engage the community of those who may use and or deliver a future behaviour change intervention for older adults living with and beyond cancer). The community included both those who may use the intervention in the future (i.e., Group 1-older adults living with and beyond cancer) and those who may provide it (i.e., Group 2-

Professionals/Volunteers). These groups were defined as a community as a whole due to their expected shared experiences and shared use/provision of services due to the geographical area. All cancer types were included, as although some experiences might be different depending on cancer types, the overarching characters of interest were cancer diagnosis and age (i.e., 65+). This is an important distinction as it allowed greater inclusion of participants than has often been seen in previous intervention studies, that are generally targeted at the most prominent cancer types.

Reflection box 7-Need for support from the community

At this point for me it was important to get out and meet people who had experienced cancer or worked in services supporting these individuals. This was a new area where I had little previous experience and so I wanted to make sure I had support from the community but also understood what was already available to people. I felt it was important to actively engage with services and groups, unlike the recommended non-participation observations in EBCD. As, I wasn't improving one service and instead sought to build or inform something new, engaging with services and individuals seemed more suited and enabled greater insight into what worked and what was available more generally, instead of an in-depth snapshot of one service.

This Part was also used to gain a broad but not exhaustive understanding of the services available locally for older adults living with and beyond cancer, with a specific focus on community-based services. In addition to this, Part A was used to facilitate initial discussions with service leads/facilitators around what has worked and perhaps not worked in their service to begin the exploration process and inform future steps, as well as identifying means of recruitment for the research.

Ultimately Part A-Preparing enabled and informed the remainder of the work, specifically contributing to the development of recruitment methods, and materials. To do this, four key questions were the focus of the Part, along with Objective 1 of the research:

1. What programmes and activities are available for older adults living with and beyond cancer?
2. What aspects of the programmes/services approached are said to "work"?
3. What are common barriers to participation in the programmes/services?
4. What recruitment methods are recommended for both target populations (i.e., Group 1-older adults living with and beyond cancer and Group 2-Professionals/Volunteers)?

4.3 Design

Part A-Preparing incorporated setting up the project and engaging the community (i.e., Group 1-Older adults living with and beyond cancer and Group 2-Professionals & volunteers). Setting up is a usual component of EBCD, as is non-participation observation (Point of Care Foundation, 2022). However, the setting up or Part A-Preparing of this work was conducted slightly differently to that of EBCD, drawing on the adaptive nature of the toolkit and intended pragmatic, flexibility of the study (Donetto et al., 2014). Instead of non-participant observation, active participation in current programmes and services was conducted to embrace the community and discuss the research with those already involved in similar programmes. This was done as it was agreed with the supervisory team that non-participation observation was more suited to service improvement. Whereas, for service development and the necessity to determine buy in to the work from the outset, being an active participant in the community was deemed as more appropriate. To do this community groups and services were approached, these were attended, and discussions or participation were facilitated to ensure both service providers and those using the services were included and consulted. Another slight difference to the EBCD toolkit was in the setting up component. Usually this would involve setting up the team etc, however, this was already in place due to the nature of the PhD project. Therefore, this setting up focussed more broadly on the study but did incorporate means expected to identify information necessary for the project plan and future design, including recruitment and material/activity development. Details of the procedure for Part A-Preparing follows.

4.4 Services approached and engagement

Individuals working in a variety of services who have regular contact with older adults living with and beyond cancer were approached to discuss the proposed study, as well as the service they provided. Of the 18 services and organisations approached, 14 programmes/services (67%) provided by 7 different organisations agreed to participate in the preparatory discussions (Table 8 for details of participating services and programmes). More than one discussion was held with services where they were provided in more than one geographic location within the study area, being Edinburgh and the surrounding areas (i.e., Edinburgh, the Lothians (Mid & East) and Fife (Figure 1)). One group stretched the boundary being in Dundee and was only used as a means of discussion, as it was a community led group, just starting up and so it was anticipated interesting insights around this process could be gained. Recruiting from this group was not considered, as it was not practically feasible.

Table 8: Services involved in Part A-Preparing

ID No	Service scope (as described by service material e.g., website)	Contact	Participation
S01	Information and Support Centre for people living with cancer, offering a variety of services onsite.	Discussion with project co-ordinator	
S02/S03	Programme working to improve cancer care- covering a variety of areas in Scotland	Discussion with project co-ordinator for 2 areas	Attendance at Christmas event
S04	Support service offering a variety of services for people affected by cancer	Discussion with centre manager	
S05	A service for people affected by cancer	Discussion with	Attendance at a local committee meeting.

	providing assistance with travel, complimentary therapies and support	organisation founder	
S06/S07	Physical activity service for people living with cancer	Discussion with the project manager of 2 areas	Attendance and participation in 3 classes within the Edinburgh area.
S08	Peer-led physical activity service for adults aged 60+		Attendance at a local peer-led walk.
S09	Practical home-based support for people affected by cancer	Discussion with project co-ordinator	
S10	Community based sign posting service	Discussion with project co-ordinator	
S11	Walking group for people affected by cancer	Discussion with walk leader	Attendance and participation in 2 walks
S12	Support service for people experiencing a variety of issues and difficulties, including chronic illness	Discussion with health and well-being practitioner	
S13	Physical activity service for individuals who have a chronic illness	Discussion with project lead	
S14	Support and information service for people affected by prostate cancer	Discussion with service lead and assistant	

4.5 Facilitating the discussions

Participants were approached and invited to meet the researcher to discuss their service and the intended study. Most of these discussions occurred before an ethical application was submitted, as this was preparation, embedded in the setting up and observation phases of the co-design process, as set out in the EBCD toolkit (Point of Care Foundation, 2022). Although ethical approval was not required as these were informal conversations expected to inform the research process, ethical good practice was observed with only my field notes being drawn on for examples, no direct quotes, as I did not make individuals aware direct quotes may be used for the purpose of the thesis. As well as this, individuals identified were kept confidential, so only an understanding of the types of services approached was evident. As this process was iterative in nature some discussions took place during the co-design phase to identify further links and means of recruitment. These discussions generally lasted around 30 minutes to 1 hour, with a focus on the questions detailed above but with the discussion generally being led by the participant, to ensure they were at ease.

A total of 12 discussions with service professionals were held during this Part. All discussions were with those leading and/or facilitating the service. Participants generally led the conversations, expressing their experience of the service and the aspects they deemed important. Participants were initially asked "Can you tell me a little about the service?", the discussion then naturally flowed, incorporating the facilitators/barriers, tips for service development and co-ordination, as well as recruitment methods and buy in to the proposed study. To facilitate these conversations example questions were drawn on where necessary as prompts, these questions were developed for each discussion to ensure they were relevant. Questions could be general or specific, with specific questions only asked where it would be relevant. Table 9 for example prompt questions.

In some instances, I also actively participated in the service delivery (e.g., by attending physical activity classes, joining walks, and joining group lunches or meetings). I, therefore, had the opportunity to discuss the scope of the study, as well as other aspects of cancer care and provision with both service leads/facilitators and service users, enabling a broader sense of the benefits of attending these services. This also facilitated an immersion in the services and greater understanding of their workings.

This period of community engagement was embedded within the co-design process as Part A-Preparing. However, owing to the flexible and adaptive nature of the process there was some overlap in Parts. Consequently, this Part ran for approximately 10 months, at times simultaneously with the proceeding process, to ensure progression of the research and effective recruitment. Although recruitment is a common issue in many projects, I anticipated it may be more difficult due to the numerous interaction points and length of time people were asked to be involved for.

Table 9: Example questions used to facilitate discussion in Part A-Preparing

Question type	Question
Specific	How are people referred to the service?
General	What other services are available in the local area?
General	Who normally uses your service?
General	Why do people come to your service and/or drop out?
General	What do you think of my proposed study, is it feasible?
General	Would you be willing and/or able to assist with recruitment to my study?
Specific	Can you tell me a bit about your previous experience using co-design or developing services in a participatory way?

4.6 Reflecting on Part A-Preparing

A reflective process was employed, consisting of note taking during and after the discussion (i.e., fieldwork notes), focussing specifically on the objective and aims of this

Part. This also provided a forum to consider how others reacted to the proposed study, as well as potential points of follow up to discuss recruitment. This reflective process drew heavily on my own experience and worked to understand the perspective of participants without adding any additional meaning. The benefits of reflections and the use of field work notes has been widely reported in the literature (Maharaj, 2016; Tenzek, 2017). A simple procedure was conducted for this reflection, wherein, fieldwork notes were read and re-read with key findings points and information relevant to the four key questions posited in this Part were grouped and considered to determine answers and insights where possible.

4.7 Methodological reflections

Part A-Preparing encompassed the observation and setting up elements of EBCD. However, I am aware the manner in which this was conducted was different to that specified in the literature and manual for EBCD (The Point of Care Foundation, 2022a) It is common for non-participatory observation to be conducted as part of the setting up component of EBCD. This is expected to give an insight into the service and can be conducted by staff and health care professionals working in the service or by researchers (The Point of Care Foundation, 2022a). However, many omit this stage of the process, likely due to time and resource constraints. Regardless it is identified as a key stage and within the context of my study led to a variety of insights that might not otherwise be evidenced. These insights included potential recruitment methods, areas of focus, including social interaction and potential barriers to participation in a future service or intervention, for example travel.

I became aware of the importance of this component of EBCD and the way in which it was often omitted in other research, and this was highlighted within the review by Donetto et al, (2014). I was also aware that I would likely find it difficult to recruit cancer patients, firstly, due to my own past experience of recruiting to research studies and, secondly, following an awareness informed by literature concerning the use of EBCD in cancer care (Section 3.4.3) detailing co-design projects, where recruitment and engagement was a key challenge (Kirk et al., 2021; Moser, 2016). I, therefore, made the decision to adapt the observation to enable discussion and a sense of embedding myself in the community and local services. I expected this approach would help to build trust with the community, which would be beneficial for recruitment and engagement with the process. Instead of non-participatory observation, I actively participated in classes, groups, discussions and meetings (as described in Chapter 4) to build my understanding of the services available and any gaps prevalent but most importantly to engage with those who may be involved in the forthcoming co-design process. This adaption demonstrated the flexibility of the methods in conjunction with the pragmatic approach taken when setting out on this research journey. Following this adaption, the data generated was also somewhat different to that generally generated at this point in EBCD studies and therefore, it was treated slightly differently, yet the outcomes were similar (i.e., initial insights of potential priorities for intervention development). The data collected was fieldwork notes primarily focussing on conversations with individuals, as opposed to fieldwork notes regarding observations. These notes were analysed thematically with a focus on the conversational content.

I am aware some may criticise this decision as a departure from EBCD, however, I am confident this was this correct decision and ultimately it enabled important insights that may not have otherwise been possible. These insights included reflections on the importance of social interaction and the necessity of ensuring practical access, for example easy transport and access to toilets. This would have been raised later in the process, but it was good to hear about this first hand early on in the process. In addition, I was always mindful that the aim was to build or develop recommendations for a new service or intervention, as opposed to improving an existing service. This is an important distinction to make when considering my methodological decisions, as a sole focus on non-participant observation may have yielded interesting insights regarding necessary improvements of the services observed, but the discussions due to the adaptions made were key in enabling insights regarding key components or barriers to be tackled for effective new services.

4.8 Key insights from the reflection on data and discussions

Conversations with service leads/facilitators, and often service users themselves, were illuminating. Having successfully engaged 14 services and several service users/facilitators it is possible to conclude the community was successfully engaged at this point, with this engagement continuing throughout the process. All of those involved saw merit in the work and in co-design more generally, with some service providers indicating they felt this was the way forward in service design and provision. Further insights regarding each of the key questions to be addressed in this Part are detailed in turn below.

4.8.1 Question 1: What programmes and activities are available for older adults living with and beyond cancer?

A total of 14 services from 7 organisations were involved in Part A-Preparing. Most services/programmes provided general support, primarily putting the person at the centre of their service. One provided practical support within the home (S09) and another two were primarily signposting/information provision services (S10 & S14: Table 8). The remainder focussed on physical activity (N=5), with brief discussion regarding sedentary time when the opportunity arose. No services specific to diet were identified. However, these were offered by services of wider support for example one of the programmes available (S04). None of the services or programmes involved were specifically for people aged over 65 but all worked with those over 65, as part of the general population of individuals living with and beyond cancer. One service targeted older adults but did not have a cancer remit (S08). (Table 8 for brief overview of services involved)

4.8.2 Question 2: What aspects of the programmes approached are said to "work"?

From reflections on the conversations, as well as consideration of the fieldwork notes, two key facilitators of participation or engagement with services and programmes were identified. These were 1) Tailoring to the individual and 2) Social interactions.

All services and programmes involved focussed on the individual, ensuring support and/or activities were tailored and suitable to their abilities. All programmes and activities involved were available face to face and extra measures were in place in some instances to ensure those who were particularly vulnerable and/or isolated could attend or at the very minimum had a source of contact, for example home visits/telephone calls/meetings before participation in any activities. In fact, this was quite common across the board, with most services or programmes putting the service user at the fore. This sense of tailoring to the individual seemed to be at the core of all services/activities involved and was deemed as a key facilitator by many, making the programme or service "work" and work specifically for the service user. Evidence from fieldwork notes reflects this core tenet and likely facilitator to participation and engagement in Table 10.

Table 10: Evidence for Tailoring to the individual

Fieldwork notes excerpt	Source (Service ID)
S05 is person centred and intends to plug gaps in services	S05
Need to make sure exercises are tailored	S13
S07…covers most activities and is tailored/person centred.	S07
People want what's important to their recovery	S03
A variety of programmes and activities available from counselling to tai chi and nutrition, with individuals able to discuss these and chose what may be best, individuals can also be referred.	S04
The individual discussed at length the benefits of having an exercise specialist come round to the house to get her back in to the swing of things	S03

Another key component that seemed to contribute to the success of the programme and/or activities by acting as a key facilitator to participation was the provision of a social aspect or the possibility to interact with others throughout the activities Table 11. Throughout this Part, I also witnessed the incorporation of social components when participating in services. For example, I attended a Christmas event and a few different socials after classes and activities. It was clear in attending these that participants enjoyed the social aspect, and really had fun at both the activities and the social events afterwards. Sitting down and having a coffee and chat after the activities was clearly enjoyed by all and seemed to facilitate the camaraderie evidence within the activities. This focus on social interactions was evident throughout the discussions with all those involved and incorporating a social component was deemed integral.

This was reported not only by those leading the activities and services but also those who took part, evident in the discussions when participating in the activities alongside those who participate regularly. Evidence of the importance of this social aspect was clear throughout the discussions and can be found in Table 11, which draws on fieldwork notes.

Table 11: Evidence for need of a social aspect.

Fieldwork notes excerpt	Source (Service ID)
Exercise and nutrition can create a little community…To sustain motivation people need to have a social framework as it is easier to commit to other than yourself	S04
It's important to have social events, e.g., Christmas events to build social support and engagement.	S02
Individuals had an interest in meeting regularly to discuss ways things can be changed and new ideas, as well as create a support system for each other…There was a definite lean towards having fun and enjoying life but also supporting others. It's interesting that one individual pointed out that those who attended were supported by each other but that there is many who don't attend groups like this who are struggling.	S03
Social support was also identified throughout as very important. Individuals mentioned the fact that the activity was planned, and other people were relying on them to turn up meant they did turn up. Others stated that they looked forward to seeing their friends at the group. There was a real sense of social support throughout the group and many of the participants mentioned social support within the group and within the wider service. It was clear social support was important in the group and the way the group run. The group leader also contributed to this. Most of the attendees had been referred by the psychologist at services which was very interesting to note. One individual indicated there was a sort of balancing act between the social and physical benefits of the group. On some days he looked forward to seeing the others after a rubbish week, while others he looked forward	S11

to the work out when he had had a better week. Whenever I mentioned the term community this seemed to resonate with the participants but not just in terms of the walk, at a broader level, perhaps a community.	
Tea and coffee were provided after exercise classes in most instances. This was seen as an important part of the class to allow people to get to know each other, create bonds and a community, which influenced motivation to attend the classes.	S06, S07, S08 S11, S13
It's an effort just getting to S13, but people find it worth it for the social side…The social aspects are very important there's a snowball effect from the physical activity in to mental and social well-being.	S13

4.8.3 Question 3: What are common barriers to participation in the programmes approached?

Information regarding barriers was limited as discussions generally focussed on positive aspects of the services, as would be expected in the circumstances. However, two points were raised as potentially influencing participation and engagement with services and programmes, regardless of their scope. These were: 1) Timing and 2) Access.

Conversations emphasised a difference in services attended depending on timing in the individuals' cancer journey (e.g., during or after treatment). For example, services such as S06 and S07, as well as S11 were generally attended by those who had finished treatment, the length of time post-treatment varied greatly from very recently to years previously. Other services were often attended during treatment (e.g., psychological/support services provided by S02, S03 & S04). However, all services and programmes that were engaged offered services suitable throughout the cancer trajectory, again ensuring the individual is considered. When considering the purpose of the current study i.e., to develop a behaviour change intervention, it was noted that time point in the individuals' cancer journey may impact future participation or engagement with such an intervention (i.e., timing may be a barrier for some).

Timing of the day was also briefly mentioned with a distinct lean towards daytime classes or events for people aged over 65 from both the participants and leaders/facilitators of current programmes. Therefore, timing in the cancer journey and time of day could be potential barriers to participation.

A further barrier identified was access/transport, particularly in more rural areas included in the study catchment, (e.g., Midlothian and Fife). One individual discussed this at length during the meeting (S03). While attendance at a class provided by Macmillan (S06) highlighted the difficulties people may have in attending due to access, evidenced by the poor attendance rates observed (N=4).

4.8.4 Question 4: What recruitment methods are available for both target populations?

Nine of the 14 discussions with service leads/facilitators resulted in the identification and expected implementation of means of recruitment for both or one of the target populations (Group 1-Older adults living with and beyond cancer, Group 2-Professionals and volunteers working with group 1 in community settings). The recruitment strategy identified for all was the facilitation of a gate keeper, commonly the individual involved in the preparatory phase. Those who agreed to act as gate keepers, shared information with individuals working and/or using their service or programme, who met the criteria for group 1 or 2 depending on the scope, timing and agreement made. One of these services (S04) also agreed to put a poster up in their main space. A 10th (S02) agreed to display a poster at their venue, however, the project had ended before the study recruitment period started, so this was no longer possible. An 11th (S05) offered to assist with recruitment, but it was decided their service was both too far away to feasibly participate and had little interaction with older adults at the time. One of the groups attended as a participant (S08) was not consulted re recruitment, as the group was for older adults more generally and had limited means for identifying those who had cancer. Another (S01) was not willing to act as a means of recruitment. Table 12 for details of recruitment opportunities from discussions. Some places offered to recruit to Group 1 (Older adults living with and beyond cancer), but this was not required as the target number had been reached by the time of these discussions (i.e., S06, S07, S09, & S12).

Table 12: Means of recruitment identified through Part A-Preparing

ID	Population	Recruitment method
S03	Older adults living with and beyond cancer	Gatekeeper to distribute information to network
S04	Older adults living with and beyond cancer & professionals/volunteers	Agreed to display poster in centre to recruit older adults living with and beyond cancer and distribute an introductory email to professionals and volunteers working in the centre
S06	Professionals & volunteers	Agreed to distribute introductory email to professionals and volunteers working in the service
S07	Professionals	Agreed to distribute an introductory email to professionals working within the service
S10	Professionals & volunteers	Agreed to distribute information email to professionals and volunteers
S11	Older adults living with and beyond cancer & volunteers	Agreed to distribute information with walking group and fellow volunteers
S12	Professionals	Agreed to distribute introductory email to professionals within the service
S13	Older adults living with and beyond cancer	Gatekeeper to distribute information with network
S14	Professionals	Agreed to distribute introductory email to professionals within the service.

4.9 Informing Part B

The findings from Part A-Preparing were used to inform and facilitate Part B-Co-designing in three distinct ways 1. Recruitment methods, 2. Interview schedule, 3. My understanding of research vs practice.

4.9.1 Recruitment methods

The main means by which Part A informed Part B was through the identification of recruitment strategies. Gate keepers for the recruitment of Group 1 (Older adults living with and beyond cancer) were identified within this Part. Identifying gate keepers as a means of recruiting to the process was deemed necessary due to the anticipated difficulties in recruiting (Payne & Hendrix, 2010) and the benefits of using gate keepers for this through direct access to the community (Andoh-Arthur, 2020). This expected use of gate keepers for recruitment, as well as the build-up of relationships within the community, and in particular the build of trust between myself and services/service leads was also to be drawn on to facilitate recruitment of both Groups 1 (Older adults living with and beyond cancer) and Group 2 (Professionals/Volunteers).

4.9.2 Materials and the process

The findings of Part A pointed towards the influence of social support and the necessity of social components in programmes and interventions. Therefore, an element of and discussion around social elements was included in the interview schedules developed for Part B-Stage 1-Individual interviews, highlighting the root of the social aspect throughout the process. In addition to this it was clear timing (both within the cancer journey and of the day) may influence participation in future intervention/programme. This was not raised explicitly in the interview schedule, as it did not seem appropriate in the exploratory phase, however, it was retained as a point to consider within the process, should it not be raised by participant.

In addition to the influence of materials this Part influenced my own belief in the study and cemented my focus on the use of co-design, as well as the necessity to “do with and not to”. It was clear throughout the discussions that these services were generally collaborative, with some deriving from consultation etc. It was also clear community services were beginning to invest in co-design more generally, and therefore, I felt comfortable in my decision.

4.9.3 My understanding of research vs practice

Throughout this preparation part it became clear things were done differently in practice when compared with research. Having completed the systematic review and identifying a number of issues with acceptability, I reflected that if we used some of the tools employed in practice these issues might not be so prevalent. It was clear services and programmes provided in the community were working to put the person at the core and make sure the provision suited their needs, whereas this was less evident in the studies identified in the systematic review (Chapter 2). For example, in the community many programmes were group based and often delivered through peers as opposed to professionals, while the review reported on primarily home-based interventions. I took this learning to my process and explored the different options with participants. I also took this to support the necessity for co-design in intervention development, as it was clear from practice ensuring provision suits those who may use and/or provide it was key.

4.10 Chapter summary

This chapter has explored Part A-Preparing. Part A was the first Part of the co-design process, giving time to purposefully get to know the community I intended to work with. This chapter described the rationale and aims for this Part, as well as the services approached and those that participated. Four key questions were asked in Part A, each of which were answered through the reflection on field notes. Finally, this chapter explained how this Part fed into the next Part of the work, Part B. Part B Co-designing will now be discussed in the following chapter. Again, this chapter is slightly different to a traditional thesis chapter in that it first explores the Part generally before discussing the methods and then results of each of the three stages.

Chapter 5. Part B-Co-designing (Stages 1-3)

5.1 Chapter overview

This chapter explores Part B of the research, being the main co-design process. Firstly, the rationale and aims of this Part are considered, before I describe the design and participants to be recruited. As this Part is made up three stages (Figure 15), I then explore the methods and process each of these in succession, being Stage 1-Individual interviews, Stage 2-Focus groups and Stage 3-Workshop. Next the results and findings are described, moving from getting to know the participants, exploring barriers and facilitators to participation in an intervention and then finally identifying potential elements for an intervention that would be acceptable to older adults living with and beyond cancer.

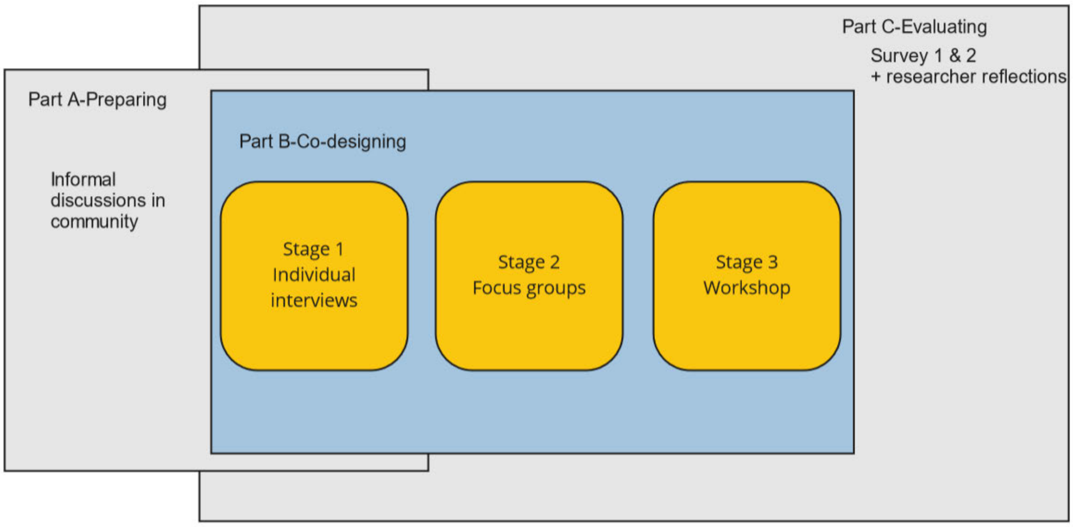


Figure 15: Research process highlighting Part B-Co-designing (Stages 1-3)

5.2 Rationale & aims

Part B tackled the main aim of the study i.e., to use co-design to develop intervention recommendations with and for older adults living with and beyond cancer to improve the behaviours diet, physical activity, and sedentary time. Part B also worked towards achieving aims 1-3:

1. To engage the community of those who may use and or deliver a future behaviour change intervention for older adults living with and beyond cancer

2. To understand the needs, requirements, perceived barriers and facilitators of major stakeholders, with regards to behaviour change interventions targeting physical activity, diet, and sedentary time, for older adults living with and beyond cancer
3. To determine an appropriate theoretical basis for behaviour change intervention design for older adults living with and beyond cancer

This co-design process was used as it was expected to effectively achieve the aims and objectives set out, creating a structured process flow, while also enabling the adaptability necessary to progress toward intervention development.

5.3 Participants & recruitment

This section describes the participants and recruitment processes for this part, Part B: Co-designing. It is recommended a minimum of five participants are required to run co-design workshops. In EBCD it is common for approximately 50% of participants to drop out at each stage (Donetto et al., 2014), therefore 10 was selected as the target for each group, Group 1 (Older adults living with and beyond cancer) and Group 2 (Professionals/Volunteers), total n=20. This was expected to ensure a minimum of five participants were likely to participate to the end of the process (i.e., Stage 3), as all participants were invited to each of the three stages of the process.

Two groups were identified as key participants in this work. These were Group 1, older adults living with and beyond cancer and Group 2, professionals & volunteers (hereafter Group 1 and Group 2) Professionals and volunteers were expected to have experience of working in community settings with older adults living with and beyond cancer. These two groups were expected to reflect the users and potential providers of a future behaviour change intervention for older adults living with and beyond cancer. Full inclusion and exclusion criteria for each Group can be found in Table 13 and Table 14.

Table 13: Inclusion and exclusion criteria Group 1

Inclusion Criteria	Exclusion Criteria
Aged 65 and over	Individuals aged 64 and under
Current or previous diagnosis of cancer	No diagnosis of cancer
Self-reported as physically well enough to participate	Self-reported as incapable to participate

Table 14: Inclusion and exclusion criteria Group 2

Inclusion Criteria	Exclusion Criteria
Aged 16 and over	Under the age of 16
Individuals in a paid or voluntary role providing care and support for older adults living with and beyond cancer, working in a community setting.	Individuals working in such roles in a health care setting

Most of the recruitment methods implemented were identified in Part A-Preparing, as described in Section 4.9.1. The following section will explore how these recruitment methods were used for both Groups.

5.3.1 Group 1-Older adults living with and beyond cancer

Participants in Group 1 were recruited through several gate keepers identified in Part A (Section 4.9.1) and/or through word of mouth or direct contact with services. Gate keepers were identified as the most likely means to effectively recruit to Group 1 in Part A-Preparing (Section 4.9.1) as they have been shown to be an effective means of recruitment in previous research due to the sense of knowing and trust this enables (Andoh-Arthur, 2020; Eide & Allen, 2016). Gate keepers were individuals who worked directly with older adults living with and beyond cancer, in a variety of community settings. Potential gate keepers identified worked primarily in third sector organisations. Four individuals agreed to act as gate keepers and distributed the study information to those eligible to participate in their network (Appendix 5 for an example of information distributed). Participants were also recruited through word of mouth and through an advertisement in a local support group's newsletter (Appendix 6).

5.3.2 Group 2-Professionals and volunteers

Participants were primarily recruited to Group 2 using a snowballing technique (Tanzek, 2017), whereby initial contacts from Part A-Preparation were invited to participate or disseminate information about the study to their colleagues and networks. Contacts were provided with participant information sheets as well as brief email invitations (Appendix 6/7), introducing the project and the researcher. These contacts were asked to share the information with their colleagues/networks.

Participants from both Group 1 and Group 2 who had taken part in Stage 1 (i.e., individual interviews) were invited by telephone or email to take part in Stages 2-Focus groups, and 3-Workshop. No new participants were recruited to ensure the development of the relationship between the participants and researcher, as well as enable the development of the relationships between participants, and build-up of findings throughout the process.

5.4 Design

A 3-stage co-design process was implemented. Each of the three stages reflected one of the steps in the EBCD flow (Figure 16). In essence this part consisted of:

- Stage 1: Individual interviews
- Stage 2: Focus groups
- Stage 3: Workshop

Throughout the process adaptions were made and implemented to enable sufficient exploration of the aims and objectives. It became clear some of the methods used in EBCD, for example, videos and emotional mapping (The Point of Care Foundation, 2022a) were not suited to the purposes of this research. This was due to the focus on service improvement in the use of these methods, and instead methods that enabled intervention and service development were required. Therefore, in addition to EBCD, other more general tools and activities often used in co-design and participatory research were implemented. Some of these were drawn from the training I attended during the PhD (Section 3.3.2) and other toolkits available, for example the Institute for innovation and Research in Social Sciences (IRISS) co-production project planner (Vallely, 2018), as well as Evidenced Based Co-design (O'Brien et al., 2016). Thus, the process was an amalgamation of tools and activities all derived from co-design, with a specific flow set through EBCD. This flow was deemed as important, as it was expected to create a safe and comfortable environment for people to share and build relationships, as well as give a platform for the exploration of experiences, which is a key focus of this method. However, the small co-design group stage of EBCD was not carried out, as participants felt they had contributed enough at the first point of bringing both Groups 1 and Group 2 together, i.e., the co-design meeting. A celebration event was also held after the end of the workshop. This is common practice in EBCD and was deemed important to navigate an appropriate means of exiting the field, which is a key ethical consideration, as described in Section 3.6.4.3. Setting up was incorporated into the process and is discussed in Chapter 4. Evaluation of the process was conducted (Chapter 6), however, evaluation of the outcomes was not conducted, as these were not implemented.

[redacted]

Figure 16: EBCD cycle with steps highlighted that are reported in this chapter
(Adapted from (Donetto et al., 2015))

5.5 Stage 1: Interviews

Stage 1 of Part B – Individual interviews (Figure 17) - sought to explore the overarching aim of the study as well as objectives 1 & 2. This Stage was primarily used to develop a rapport with participants, learn of their experiences and behaviour participation, as well as begin to consider barriers and facilitators to both behaviour participation and intervention participation. It was key that the relationship between the researcher and participants was successfully built up at this point, to enable the proceeding stages of the process, in line with EBCD methodology (The Point of Care Foundation, 2022a).

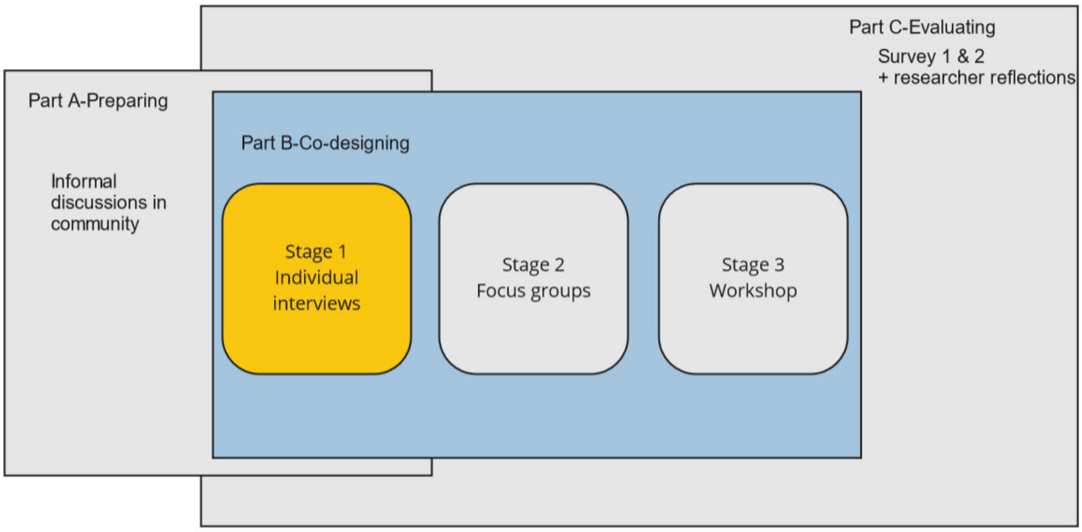


Figure 17: Research process highlighting Part B-Stage 1

5.5.1 Process

Part B-Stage 1 consisted of individual interviews with those in both participant groups, as recommended in EBCD methodology (The Point of Care Foundation, 2022a). These interviews were semi-structured, enabling some focus on key aspects of the research but also providing room for participants to discuss and explore points important to them (Fylan, 2005), as well as being evidenced in previous EBCD work (Wright et al., 2017). To further explore participants experiences in Group 1, of the target behaviours (physical activity, diet, and sedentary time) single item questions were used to determine their perspective on their own participation in these behaviours. In addition to this a set question was included in the design of this stage to explore individuals' perspectives on health, as it was possible this perspective could influence the process. The SF-36 was also used at this time with Group 1-Older adults only, as a means to explore quality of life (Ware & Sherbourne, 1992). This measure was selected as it has been previously used and validated with older adults and those living with and beyond cancer (Hayes et al., 1995; Tan et al., 2007; Treanor & Donnelly, 2015; Walters et al., 2001).

Participants were invited to take part in an individual interview (Part B: Co-designing-Stage 1), at a location that suited them. Participants received the participant information sheet (Appendix 7/8) at least 24 hours before the interview. Before proceeding with the interview participants were given the opportunity to ask any questions about the information sheet or otherwise in advance by telephone or email, and again at the time of the interview. When participants were happy with the information provided and felt they had any questions answered they were asked to complete the informed consent sheet (Appendix 9). Consent was always obtained before the interview took place, in line with process consent (Dewing, 2018). Interviews were primarily participant-led, to build rapport and create a relationship with the participants but a semi-structured interview schedule was developed and consulted by the researcher throughout to ensure key topics were considered (Appendix 10). Interviews lasted between 40 minutes and two hours, and most were approximately 60 minutes long for participants in both Groups 1 and 2.

At the point of agreeing to participate in the interviews, individuals were asked where they would like the interview to take place. It was key to ensure all participants were comfortable discussing their experiences, especially as a key objective of the interviews was to develop rapport and establish the relationship between the participants and researcher. Previous research has emphasised the influence of location on interviews, and in particular the extent to which this can create a power imbalance (Elwood & Martin, 2000). Therefore, interviews were conducted in several different places, at the request of participants, to enable practical participation and empowerment, including:

Group 1-Older adults living with and beyond cancer

- Participants’ homes (n=5)
- Private rooms at the University (n=2)
- Local libraries and community centres (n=3)
- Local café (n=1)

Group 2-Professionals & volunteers

1. Local café (n=1)
2. Workplaces (n=8).

5.5.2 Materials

A variety of materials were used throughout Stage 1-Individual interviews, these were designed to lead the conversation without imposing on participants. Materials used throughout Stage 1 with both Groups can be found in Table 15 and Table 16.

Table 15: Materials used to interview participants in Group 1

Material	**Use & purpose**	**Appendix**
Participant information sheet (PIS)	To provide details regarding the study, data collection, storage and use, as well as alleviate any concerns re anonymity etc.	8
Consent form	To ensure participants are freely consenting and understand the PIS.	9
Semi-structured interview schedule	To facilitate discussion around a number of key points expected to progress the study and move towards achieving the key aims and objectives set out. Topics included: experience of cancer, perspective on health, health behaviour participation and barriers/facilitators to participation.	10
SF-36 (Ware & Sherbourne, 1992)	To create a greater understanding of participants' health and well-being. A standardised measurement of quality of life.	11
Behaviour participation questions derived from (Gill et al., 2012)	To compare levels of behaviour participation with their peers, i.e., in comparison to others similar to you, would you say you are more active, less active or about the same, with this being repeated for diet and sedentary time.	12
Demographic questions	Age, gender, cancer type, year of diagnosis, co-morbidities	13

	and any ongoing treatment (e.g., hormone therapy).	
Debrief sheet	Due to the use of process consent participants were debriefed after each interaction. The debrief sheet reiterated information in the PIS and provided key contact information should there be any worries after the interview.	14

Table 16: Materials used to interview Group 2

Material	Use & Purpose	Appendix
Participant information sheet	To provide details regarding the study, data collection, storage and use, as well as alleviate any concerns re anonymity etc.	7
Consent form	To ensure participants are freely consenting and understand the PIS.	9
Semi-structured interview schedule	To facilitate discussion around a number of key points expected to progress the study and move towards achieving the key aims and objectives set out. Topics included: exploring their role to create rapport and further understand services available, as well as consider their perspective and understanding of the barriers and facilitators to participation in both the behaviours, as well as interventions/services.	15
Demographic questions	Service, role, age and gender	16
Debrief sheet	for the purposes of ensuring the process of each group was the same participants in group 2 also followed a process consent procedure, and therefore, received a debrief sheet at the end of the	14

	interviews reiterating the contents of the PIS and providing contact details.	

The interviews were guided using a structured interview schedule. Although this may not be usual as part of EBCD, as interviews are generally very open (The Point of Care Foundation, 2022a), I opted to create and draw on the schedule throughout, as it increased my confidence in being able to guide the process – a pragmatic decision. Looking back on the processes involved in the interviews it transpires that they were more unstructured than perhaps would have been anticipated in view of the pre-determined schedule. The schedule was used more as a means to ensure I covered the points I had identified as important from both the literature and Part A-Preparation. However, it is important to reflect on the benefits of having the interview schedule available throughout the interview, and the confidence this gave me in conducting the interviews, albeit that in the end it was used less than anticipated.

In addition, I would like to reflect on the use of the SF-36 (Ware & Sherbourne, 1992). When setting up the project and the methods used, I was aware of the necessity to evaluate the process itself, as this had often been a criticism of previous similar projects. I, therefore, included the SF-36 as a means of evaluation, with the intention of comparing scores before and after the co-design process. However, I am now aware this was a somewhat misguided decision and is reflective of my past experience in quantitative methods. The SF-36 is a quantitative measure of quality of life. However, it was useful to have attempted this as it contributed greatly to my learning and although no comparison was made, as this was not possible or necessary, the data generated around quality of life from the interviews is insightful. In retrospect, the use of this tool did change the tone of the interviews and is therefore, not something I would do or recommend in the future.

5.6 Stage 2: Focus Groups

Stage 2 consisted of focus groups (Figure 18). The focus groups were conducted in line with the flow of EBCD methodology (The Point of Care Foundation, 2022a), and incorporated in the engaging staff and patients steps (Figure 16). The focus groups were expected to contribute to the overall aim of the research, as well as Objectives 2 and 3 (Findings regarding Objective 3 are reported in Chapter 7).

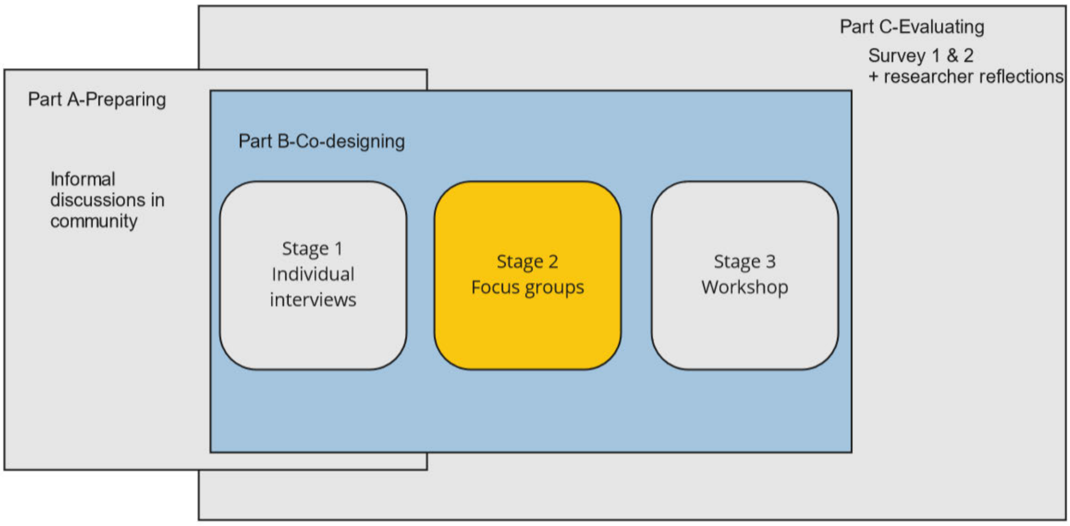


Figure 18: Research process highlighting Part B-Stage 2

5.6.1 Process

Two focus groups were conducted with those in Group 1, to ensure as many individuals living with and beyond cancer could contribute as possible by offering a choice of dates and times. Another focus group was conducted with those from Group 2. In line with EBCD methodology groups were kept separate at this stage to facilitate rapport and confidence within the group before coming together. This was particularly key for those in Group 1 to ensure they were confident with their peers and felt comfortable discussing with the group and myself before taking this to Group 2. A number of tools and activities used commonly in EBCD, and co-design more widely were used to facilitate this stage.

The focus group process followed a similar structure for both groups, with the addition of a barrier ranking tool for Group 2. The focus groups (Part B-Stage 2) lasted approximately 90 minutes. A second PhD researcher was present during the focus groups to assist with facilitation, take notes of interest and discussion points and act as means of debrief and discussion for myself, as this is recommended best practice (Kreuger, 1998). The second facilitator mostly took notes and emphasised any points they felt were important in the group. The second facilitator also enabled an opportunity to debrief, discuss the group interaction, the notes, and the means in which the process should be moving forward, as well as highlighting any issues that emerged e.g., participants' difficulty using the stickers. The full procedure is detailed below in the order in which it was conducted with participants at the time.

Consideration was made regarding the settings of the focus group. When considering the potential influence of power not only between the two groups of participants but more importantly between the researcher and participants, it was deemed necessary to ensure the initial focus group with those in Group 1 was conducted in a neutral space. Also, after conducting the interviews and consulting the literature it was clear access and transport would be key (Nyumba et al., 2018). Therefore, the selected location for the focus groups had to be within 30 minutes of all participants, have free car parking and be on a local bus route. A local café was selected as the best location for the focus groups, with both focus groups with those in Group 1 being conducted here. It was anticipated the focus group with Group 2 would also be conducted in the same location. However, many from Group 1 expressed a dislike for the café, particularly that it was cold. Therefore, the decision was made to hold the focus group with participants from Group 2 at the University Campus.

5.6.2 Materials

Materials required to run the focus groups, included: flip chart paper, pens, and stickers. Information sheets (Group 1: Appendix 8, Group 2: Appendix 7), consent forms (Appendix 9), and debrief sheets (Appendix 14) were also used to comply with the process consent procedure. Five tools were created to facilitate discussion and progress the process.

5.6.2.1 Tool 1-Topic guide

A schedule regarding the flow and tools was developed for both Group 1 and Group 2, containing the three key points of focus for discussion: focus of intervention, timing of intervention, and format of intervention (Appendix 17/18). This also included detail and instruction regarding the use of the other tools employed. The three key questions were relayed to participants as below:

1. What should the focus be? i.e., should we focus on promoting all three behaviours diet, physical activity or reduced sedentary time, just one or two or something completely different?
2. For an intervention or programme what time in your cancer journey or the cancer journey of clients you support would be most appropriate to hear about this and/or take part?
3. What format would you prefer the intervention/programme to be in? Online, face to face, group individual, peer-led, professional-led?

These three questions were derived from the analysis of Stage 1-Individual Interviews. Before proceeding with the questions and tools an 'ice breaker' was used as noted in the topic guide. This was used to enable the group to get to know one another and understand each other's goals (Kilanowski, 2012). A group agreement was also developed, primarily focussing on confidentiality and the freedom to speak, i.e., not talking over each other.

5.6.2.2 Tool 2-Social network mapping

As it had become clear social interaction and support were important to the participants and perceived as a facilitator to participation in both the behaviours and any intervention/programme it was decided to understand further about the social networks of participants living with cancer. It was possible perceptions of current social circles may influence any need or interest in future social interactions and influence the cancer journey experience and, therefore, influence any future participation in interventions or programmes. It was also observed in the interviews that some of the participants may be lonely, while others had a varied social circle. It was, therefore, necessary to establish whether these field observations were accurate. This tool was essentially used as an additional means to get to know the participants and understand the perspective from which the intervention was being designed. Therefore, participants were asked to draw out their close social contacts, i.e., people they see or speak to regularly, indicating how they interact with each other and how close they are by sketching maps of these, all of which was to gain an understanding of their social network, drawing on previous similar work (Donath, 2020; Tracy & Whittaker, 2018). Only participants in Group 1 were asked to use this tool, as the social networks of Group 2 were not relevant to the process. Due to time constraints within the session, and the fact the map was only to be used as a crude description of people's social circles, the full mapping process out to acquaintances was not conducted; only brief description of close contacts was required. This description was expected to convey their relationship to the individual i.e., friend, son, wife etc but omitted their name to ensure anonymity. In addition to this, participants were asked to indicate the strength of the relationship by placing those they are closer to, nearer themselves on the map. This reflects the pragmatic nature of the research, as only data needed to progress and understand the process was collected, ensuring the acceptability of the process. To help explain the process to participants I showed them a rough example of my social network map, explaining it included those I felt were close to me and who I could rely on. (Section 5.12.3 for results of mapping exercise)

Reflection box 8-Choosing the best time to implement social network mapping

Initially I had planned to conduct the social network mapping in Stage 1-Interviews. However, at the time it didn't seem like the best place for this type of activity and so I made the decision during the first interview to conduct this later in the process. This was primarily to ensure I could build my relationship with the participants and move away from a dynamic where I was solely extracting information from them and move more toward working with them. When discussing this adaption with others who are more quantitatively minded it was suggested that this was bad practice and that I should have stuck to my original plan. At the time this really worried me, but on reflection, I know I made the right decision and consequently advocate for the ability to adapt processes, and actively work to enhance understanding from colleagues and ethics committees of the benefits of such flexibility moving forward. I am also aware it may have been interesting to consider engagement in light of the initial social mapping to identify patterns between social networks and the likelihood of engaging to the end of the process. However, this was beyond the scope of the study.

5.6.2.3 Tools 3/4-Key concept maps and barriers (Prioritisation)

Prioritising is key to progressing design and specifically co-design processes, as evidenced via the define component of the double diamond and necessity to prioritise issues in EBCD (Ball, 2019; The Point of Care Foundation, 2022a). Two prioritisation tools were developed and implemented for use in Stage 2. One named ‘key concept mapping’ was used by both Groups to consider mainly facilitators of participation in a future intervention. The other named ‘barrier ranking’ was used only with Group 2 to consider barriers to participation in a future intervention. Both ranking tools were derived from data collected in Stage 1-Individual interviews. Key concepts and barriers were selected as it was expected these would significantly influence the development and/or potential success of any future intervention. With regards to Tool 3-Key concept map, participants in each Group were presented with copies of the map on A1 sized sheets of paper (Appendix 19/20) and asked to identify which aspects they felt were most important to be considered in the development of a future behaviour change intervention, keeping a focus on physical activity, diet, and sedentary time. Participants were encouraged to mark as many items as they wished but asked to make sure they were very important to them. Discussion was also facilitated throughout the use of this tool to encourage participants to explore why they were choosing certain items. Stickers were used to mark preferences on the sheet with the first focus group. However, it very quickly became clear participants struggled with the stickers and found them fiddly. Due to these issues future focus groups were provided marker pens to complete the same exercise.

The second was a barrier ranking tool. As noted, the barrier ranking tool was implemented only with Group 2. This tool was designed to rank the barriers to participating in a behaviour change intervention targeting the behaviours physical activity, diet, and sedentary time. After identification of the barriers to be included in this tool from the analysis of Stage 1-Individual interviews these were mounted on small cards (Appendix 21). These cards were then used to rank the barriers. Participants were permitted to rank the barriers in whichever way they saw fit. The cards were deemed the most suited to this tool, as they enabled a hierarchy to be developed where more than one barrier could be ascribed the same level of importance by repositioning the cards.

These tools were used in place of emotional mapping the suggested process at this stage in the EBCD. Moreover, due to a variety of reasons (explored in Section 5.9) a trigger film was not developed, and emotional mapping was not conducted. Briefly this was due to the aims set at the start of the research project and the intention to develop a new service or intervention instead of improving something that already exists. Prioritisation of outcomes and goals is a key process in co-design and is reflected in the double diamond structure through the define component (Ball, 2019).

At this point behaviour change theories were drawn upon when considering the concepts, and in the decision to rank these as barriers or key concepts. This is a common technique used when considering behaviour change as it enables consideration of barriers and challenges we must help and empower individuals to overcome to achieve effective and sustainable change. This is also often a key component in consideration of behaviour change theories and in this instance in particular consideration was given to the COM-B model (Michie et al., 2011). This model was used, as it is common to identify barriers and attribute these to one of the three components of the model (capability, opportunity, motivation) to make an informed decision about intervention requirements. However, as the research progressed it became clear that the behaviours of focus were perhaps more of a catalyst to achieve higher level goals.

5.6.2.4 Tool 5-Persona development

Personas are a commonly used tool in co-design processes (Miaskiewicz & Kozar, 2011; Neate, 2019; Pruitt & Adlin, 2006) and were a considerable component of some of the training I attended. However, personas are not generally used in EBCD, as the purpose of EBCD is the focus of the individuals' experience. In this instance I wanted to maintain that individual focus but also open up conversation beyond the experience of participants in each of the groups, especially as they generally had high levels of motivation for participating in local groups and programmes, as well as the target behaviours (Section 5.12.2).

Personas allow the consideration of the “thing”, such as a product or intervention to be considered from the perspective of individuals who may have a slightly different outlook to those in the co-design group. These personas are still however, expected to represent the target population. Personas are sometimes developed before the process begins to be used in the early discussions and often considered by professionals to understand the target audience but are also often developed in the process and used throughout (O'Brien et al., 2016).

In this instance personas were used to reflect participants’ experiences and understanding of who might use the intervention in the future and why, but also who might find it difficult to engage with the intervention and the reasons for this. Therefore, creating personas was going to be key to facilitate discussion in Stage 3. To support this, sheets with key questions were developed that prompted participants to consider for each persona:

1. What are this person’s goals?
2. What does this person enjoy?
3. What motivates this person?

The data collected to inform personas was limited due to practical concerns including time constraints but also as I did not want to overrun the process with outside experiences. From meeting and interviewing the participants I was aware that the participants involved were generally motivated and that I would have to take steps to facilitate discussion around those who may not be motivated. I chose personas as the best means to do this, after discussion and trialling these at a training event.

Other projects have developed the personas with participants, as opposed to developing them in isolation from the process (O'Brien et al., 2016). This way of developing personas was more in keeping with my understanding of co-design and the necessity to incorporate participants throughout. Bringing in personas developed by myself or others would not have fitted with the process and would have added an additional abstract element, removed from the group itself. However, in asking participants to develop or contribute to the development of the personas I was also aware of the additional burden of this and kept questioning around this to a minimum, only focussing on areas that are relevant to working through the issue that those involved in the process were generally motivated. Therefore, I was aware the personas would be simple but accepted this as the most useful and acceptable manner of development and use to ensure limited burden on participants, through inclusion of only relevant components and not a full persona.

5.7 Stage 3: Workshop

The final stage of Part B-Co-designing was the workshop. After the preceding stages it is recommended in EBCD that all participants come together to develop ideas and solutions, as it is likely that at this point in the process they will be comfortable in doing so (Figure 11, (The Point of Care Foundation, 2022a)). The other stages of this work were building to this point and this idea of gathering individuals from both groups is core to EBCD. Part B-Stage 3, Workshop (Figure 19) was designed to contribute to both the overarching aim of the research as well as Objectives 2] and 3 (Findings regarding objective 3 are reported in Chapter 7).

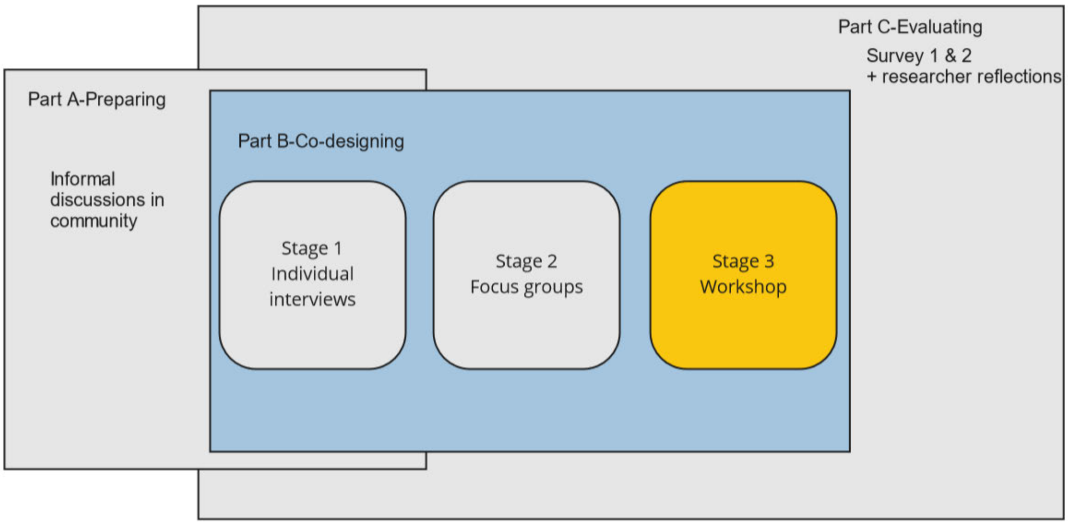


Figure 19: Research process highlighting Part B-Stage 3

5.7.1 Process

To consider the aims and objectives set out it was also necessary to use other general tools and techniques associated with co-design. At this point in EBCD it would be common to watch the video, consider points to be improved and work to improve these, however, this was not possible in this case, as no video was developed, and so instead other methods were used. These methods were used to effectively 'carry forward' the data and findings from the previous stage, as well work towards achieving the aims set out and build up solutions to overcome any issues or gaps identified in the previous stage. To facilitate the development of an intervention, at this point the Template for Intervention Description and Replication (TIDIER) checklist was broadly drawn on (Hoffmann et al., 2014). The TIDIER checklist provides a set of key questions to consider when describing and reporting an intervention. Therefore, it was seen as fitting for this task, as it would provide a standardised layout for description of the intervention. The checklist had not been used in this way at the point of conducting this study, and therefore this use was novel at the time. This was used to support the structure of the workshop and focus discussion. The workshop (Part B-Stage 3) lasted 3 hours. A second PhD researcher was present during this workshop to assist with facilitation, particularly representing the idea generation, note taking, and to act as means of debrief and discussion with me.

After difficulties with the local café selected as the setting for Stage 2-Focus groups with Group 1, discussions were held by telephone/email with the participants to agree on an appropriate setting for Stage 3-Workshop. It was suggested by the researcher that the University could be used as the setting for the workshop. All participants agreed this was a good idea and, indeed, some were very keen to come to campus as they had previously attended college on the premises before its refurbishment. Although initially this setting was seen as a potential negative influence over the process, establishing a asymmetric power dynamic, particularly at the interview stage (Elwood & Martin, 2000), by the point of the workshops I had established a good relationship with participants and felt that the influence, while not eliminated, was reduced.

5.7.2 Materials

Materials required to run the workshop included: flip chart paper, pens and giant post-it notes. Information sheets (Group 1: Appendix 8, Group 2: Appendix 7), consent forms (Appendix 9), and debrief sheets (Appendix 14) were also used to comply with the process consent procedure. Three tools were also created for the purposes of the group, which are detailed below.

5.7.2.1 Tool 1: Topic guide

A topic guide was developed for the workshop (Appendix 22). This included a summary of the results to that point in the process to facilitate discussion regarding the final focus, format, and timing of the intervention. To do this, a script (appendix 23) was developed, and participants were periodically asked during its reading if they agreed with what was being said. Visuals were also created to describe the findings, for example outlining the barriers as ranked by participants. Validating this ranking was important as this exercise was initially only conducted with Group 2, as the older adults living with and beyond cancer recruited, insofar as they were motivated and exhibited few barriers. The results from the three main questions of the previous stage, i.e., focus, format and timing were also included in the topic guide and time was allocated to discuss these in more detail where necessary. As with Stage 2-Focus groups, a group agreement and ice breaker were included in the topic guide. The topic guide also described the tools and tasks to be carried out in this Stage, as detailed below.

5.7.2.2 Tool 2: Idea generation and prioritisation of intervention components

Storyboarding is a common tool used in co-design (Ayrton, 2020; Cross & Warwick-Booth, 2016; Macken-Walsh, 2019). Storyboarding was also a key element in training I attended regarding co-design and had been used previously in the development of an intervention for retired adults, through evidence-based co-design (O'Brien et al., 2016). Storyboarding involves drawing out the sequence of events necessary for the delivery of the intervention. I drew on this concept to generate potential intervention ideas and components with participants before grouping and prioritising these based on my reflections. I had planned to work with the group to prioritise these ideas and work through them using a persona, however, the participants indicated they would prefer I took away their ideas and worked through this later. All participants were keen to develop and generate ideas but less interested in set decision making, it was clear they felt this was my role in the process. This potentially indicates there was still some sense of a power imbalance which is discussed further in the Limitations (Section 8.6). To create and provide a format for intervention development the key elements of the intervention were considered in light of the TIDIER checklist (Hoffmann et al., 2014). The TIDIER checklist provides a set of key points to consider, which were used to facilitate the idea generation discussion. Again, this further emphasises the need to adapt tools and methods throughout this research process.

Set questions were developed to enable idea generation for the intervention and to reflect upon the expected and necessary components both through the TIDIER framework and those identified in previous stages of this research. To enable the idea generation process each of these questions were written up on flipchart paper and stuck to the wall. Participants were asked to think more about the form the intervention would take, now the key constituent components had been determined. Therefore, participants were asked to discuss:

1. What do you want to see in a lifestyle programme designed to improve diet, reduce sedentary time and increase physical activity for adults aged 65+ living with cancer? (activities and focus)
2. Who is running it? (peer- or professionally led)
3. What are the activities? (linked to the focus of different behaviour)
4. Where is it being held? (setting)
5. How do people find out about it? (communication)
6. How do we get people through the door? (accessibility)

Notes were taken regarding the discussion and pictures were drawn on the giant post-it notes depicting ideas to develop an overview of ideas and key elements, progressing from how people find out about the programme to what the activities are and who is running it (Figure 20). This was conducted by a second facilitator, while I facilitated discussion. A broad story board of ideas and potential intervention elements was developed (Figure 20). These were later scanned and condensed where overlap was evident in the images and added to a final sheet depicting each of the categories for presentation (Figure 21).

Figure 20: Examples of ideas build up from process

5.7.2.3 Tool 3: Personas

Building on from Tool 5-Stage 2 (Section 2 5.6.2.4) and the analysis of Stage 1 and Stage 2, personas were developed to be used in the Workshop (Stage 3). Two personas were developed, reflecting the discussions of the previous stages, as evidenced in Table 17 and Table 18. One persona was motivated, the other unmotivated. Motivated vs unmotivated was selected as a contrast of interest as most of the individuals in the group were motivated and therefore, it was expected to create more discussion around those who may be less likely to engage with services. Due to the focus on gender and the potential influence of gender (Section 5.13.1.6) the personas developed were not ascribed a gender and any gender specific descriptions were omitted. Instead, the personas focussed on location (town vs out of town), past behaviour, current behaviour, attitude, goals, social support available, facilitators and barriers to participation, all of which had been previously raised in the process. The two personas described contrasting individuals to facilitate discussion and develop an understanding of how each would interact with the intervention components considered in Tool 2-Idea generation and prioritisation. This was expected to ensure the process outcome was potentially transferable beyond the group involved (Miaskiewicz & Kozar, 2011; Neate, 2019; Pruitt & Adlin, 2006). The personas developed were simple forms of the usual persona format, as described above. Only information necessary to facilitate discussion regarding the intervention was detailed.

Specific decisions were made for example to make the personas gender neutral, subsequently limiting the amount of information available to be relayed. However, it was agreed with my supervisors that this decision was important as gender had been identified as having a significant impact on participation. Yet, this had and continued to be discussed at length in the groups, so I chose to use the personas to move away from this discussion and focus more on motivation and access, both of which were also identified as important points. The personas were presented to participants as seen in Appendix 24 and 25. Participants were asked to discuss what we need to do to ensure these people can engage with the intervention.

Table 17: Persona 1 details: Motivated

Item type	Item for persona	Evidence for item
Demographic	Location: Out of town	Barrier ranking/interviews/key concepts (Part B-Stage 1 & 2: Interviews &Focus groups)
Past behaviour	Individual led an active life and has always made an effort to take part in activities, particularly team sports. Has never enjoyed or been able to sit still and has always loved trying new foods and recipes.	Part B-Stage 1: Interviews
Current behaviour	Plays golf regularly and tries to keep steps up, often heading out for a walk when just missing the step count.	Part B-Stage 1: Interviews
Attitude	Being active is important to keep fit and healthy and keeping healthy is individual's responsibility.	Part B-Stage 1: Interviews Persona building Part B-Stage 2: Focus groups
Goals	To keep as fit and healthy as possible for as long as possible by getting function and ability to as close as it was before diagnosis and treatment	Part B-Stage 1: Interviews Persona building Part B-Stage 2: Focus groups
Social support available	Wide social support network of close family and friends	Social network mapping Part B-Stage 2: Focus groups Part B-Stag1: Interviews
Facilitator	Enjoys socialising	Persona building Part B-Stage 2: Focus groups
Facilitator	Past behaviour	Part B-Stage 1: Interviews Persona building Part B-Stage 2: Focus groups

Facilitator	Encouraged by family	Part B-Stage 1: Interviews Persona building Part B-Stage 2: Focus groups
Barrier	Treatment effects and fatigue	Barrier list Part B-Stages 1 & 2: Interviews & Focus groups
Barrier	Finding info	Barrier list Part B-Stages 1 & 2: Interviews & Focus groups

Table 18: Persona 2 details: Not motivated

Item type	Item for persona	Evidence for item
Demographic/Facilitator	Location: City	Barrier ranking/interviews/key concepts (Part B-Stage 1 & 2: Interviews &Focus groups)
Past behaviour	Individual focussed on career in younger years, so wasn't very active and has generally stuck to foods familiar to them. Past career involved sitting at a desk.	Part B-Stage 1: Interviews
Current behaviour	Leads a generally sedentary lifestyle. Doesn't cook much, as only cooking for one.	Cooking for one-barrier from Part B-Stage 1: Interviews
Attitude	Finds the advice re diet confusing and contradictory, isn't fussed about being active.	Part B-Stage 1: Interview Part B-Stage 2: Focus groups
Goals	To maintain independence	Persona building Part B-Stage 2: Focus groups
Social support available	Limited social support-few close family members nearby and distant family members living far away	Social mapping Part B-Stage 2: Focus groups
Barrier	Lack of motivation	Barrier ranking Part B-Stage 2: Focus groups
Barrier	Fear (new activities and groups)-getting through the door	Barrier list Part B-Stages 1 & 2: Interviews & Focus groups
Barrier	Social isolation	Barrier list Part B-Stages 1 & 2: Interviews & Focus groups
Barrier	Cost	Barrier list Part B-Stages 1 & 2: Interviews & Focus groups
Barrier	Lack of knowledge	Barrier ranking Part B-Stage 2: Focus groups
Barrier	Dislike/individual preferences	Barrier ranking Part B-Stage 2: Focus groups

5.8 Celebration event

A key ethical consideration of co-design is exiting the field (Section 3.6.4.3). This is important to demarcate when a process spanning a considerable period of time has ended, both for participants and the researcher (The Point of Care Foundation, 2022b). To mark this ending, a celebration event was held immediately after the final stage of the process, Stage 3-Workshop. This celebration event lasted approximately one hour and involved informal discussion over tea and cake. Celebration events are recommended within the EBCD framework, as a suitable means of ensuring effective means of exiting the field but also as a means to thank and celebrate the process with everyone involved (The Point of Care Foundation, 2022b).

5.9 Methodological reflections

Throughout the process I was aware I was slowly drifting further and further from the usual methods and tools of EBCD. However, throughout I also maintained the defined flow and general methodological approach of EBCD. I found it difficult to implement the usual methods and tools of EBCD in this instance, primarily as I was working to build something new, as opposed to improving something that already exists. There are three main deviations of this process from that of EBCD in this Part, each of which I will discuss in turn, providing rationale for the decisions made. These are (1) No video, (2) Less reliance on emotive tools and more use of practical data/prioritisation, and (3) No small co-design groups.

Firstly, I would like to address the omission of a trigger video. When I set out to conduct this study, I had intended to develop a video. However, as time progressed it became clear this was impractical as I did not have the skillset to conduct this or the resources/time to have a company develop this but also impractical in terms of shooting the footage. It was not possible to film all interviews and those that were filmed were poor quality. In addition to this I became aware that in a pursuit to create trust and build a rapport with individuals, particularly those in Group 1-Older adults I had facilitated a wealth of discussion on the cancer journey more generally. In hindsight I think this was necessary for the success of the project but also meant developing a trigger film relevant to the aims of the PhD was not possible, as it would have focussed on the full cancer journey. Other studies have also omitted the video component, primarily due to time/resource constraints (Donetto et al., 2014). Therefore, this is something to be aware of as a deviation but also something that is common and in this instance was the best decision to progress the PhD effectively.

Secondly, due to the developmental nature and behavioural focus of the PhD and co-design process, I am aware that I leaned more heavily on practical and prioritisation tools or mapping as opposed to emotional responses or mapping as is common in EBCD (The Point of Care Foundation, 2022a). I had initially planned to use the emotional mapping tool suggested in EBCD. However, I attended training on EBCD and was given the opportunity to work on an example of the emotional mapping tool. This experience led me to consider how this would actually work in my research, as it was clear at the training that the mapping was used to identify pain points in a service that was already running. As I was intending on developing a new service/intervention, I was hesitant about using this tool, as it would likely focus on the full cancer journey as had been the case in the interviews. Therefore, I chose to adapt this tool to prioritisation and ranking tasks targeting the intended development of a new service or intervention focussing on the behaviours.

Before making this decision, I decided to trial it once more at a tutorial with PhD students. This also provided ample discussion about my proposed use and how this may or may not work. It was agreed at this meeting and in later discussions with my supervisors that it would be too difficult to ask individuals to map emotional touchpoints to a hypothetical service, especially as the purpose of the process was to design the service. Therefore, instead prioritisation of key components perceived as necessary for the success of an intervention or service was conducted. It still had a semblance of the mapping and prioritisation but also enabled creative discussion about service or intervention development.

Finally, the process ended at the joint workshop phase or Part B-Stage 3, whereas it is common during EBCD projects to set up a number of small working groups to tackle the priorities identified (The Point of Care Foundation, 2022a). Initially I had planned to run additional smaller co-design groups, however, this became unfeasible for three set reasons. First, I did not have the time, capacity or resources to progress the project further under the constraints of completing a PhD. Second, the participant number was low by this point and would have likely only constituted one or two small groups, meaning this would be a lengthy process. Moreover, it is suggested in the literature that where a key design question or point of change is determined one co-design group may be sufficient (The Point of Care Foundation, 2022a), although I am aware these would be expected to meet more than once. But most importantly participants indicated at the end of Part B-Stage 3 that they felt they had provided enough information and generated enough ideas; their role in the process was now complete. They indicated they were happy for me to progress and develop recommendations or a service based on the information already generated. This is an important point to consider as it emphasises the potential burden of such processes on participants, as well as myself as the researcher, something that I had perhaps overlooked at the outset of the PhD but reflect on further in Chapter 6. It is, however, common for EBCD and co-design processes more generally to stall at the point that I reached, many of the articles evaluated regarding EBCD in cancer care report only to this point, Section 3.4.3.

5.10 Analysis

Data was analysed throughout the process thematically, drawing on the procedure detailed by Braun & Clarke (2006). Each stage was analysed at the time of data collection or shortly after to ensure this could effectively inform the next stage, creating an iterative process, as is common in co-design. This was a rapid process and so, primarily consisted of the first three steps of Braun & Clarke's process:

1. Familiarising yourself with your data.
2. Generating initial codes.
3. Searching for themes

The remaining three steps of the analysis were conducted after completion of the entirety of Part B-Co-designing. This allowed for a layering of the analysis, enabling reflexivity. Thematic analysis was selected as it has been used before in EBCD studies (Fylan et al., 2021).

Generally, audio recordings and/or transcripts were listened to and/or read and re-read to ensure familiarity with the data. Next initial codes were identified and noted as relevant to the process and necessary to inform the next stage, these may, for instance, be barriers or facilitators to participation, gaps in the discussion, questions to carry forward or intervention elements to carry forward. This process was conducted by hand at all stages. An initial code file was created and was expanded on by colour coding of data, ultimately creating code and evidence files which were retained as is or condensed to broader themes, for example ‘motivation’. An example of such a file can be found in Appendix 26. This process was also informed by notes taken by the second facilitator during each Stage, to ensure rigor and validity in the information carried forward to the next Stage. Data from each Stage was treated in the same way, with the only difference being the questions asked of it, as detailed via the materials employed. Descriptive statistics, reported as n and %, were also conducted to present findings from ranking and prioritisation tools.

Following the co-design process, the files derived from this process were stored in NVivo to facilitate organisation. This also enabled overarching reflexive analysis, essentially the latter three steps of Braun & Clarke’s (2006) thematic analysis to identify key recommendations for future interventions based on the entire, now completed, co-design process.

Reflection box 9-Difficulties conducting the analysis

Due to time constraints imposed by the PhD journey, I had to analyse the data quickly throughout and so as described had decided to reflect back on the data at the end of the process. This is common in co-design, as it is necessary to work in an agile manner to progress and develop ideas. Regardless of the need for swift analysis, I would like to reflect on the difficulties I experienced while conducting the analysis.

Due to the emotive nature of the topic of living with and beyond cancer I initially found it difficult to separate data relevant to improving the cancer journey more generally and data relevant to the research aims. In fact due to this struggle, I considered adapting my aims as discussed in Section 5.12.2, however, after discussion with my supervisory team and the participants we decided this was not a good idea, and it was important that the original aims were maintained. This meant it was important to focus on relevant data only and has possibly led to more descriptive analysis. However, I feel this accurately portrays the process and suits the aims and objectives of this research.

5.11 Section Summary

This section has explored the methods of the co-design process, emphasising the iterative nature of this, and exploring how each stage informed the next. First the overall design of the process was described, next each of the stages were described in succession, Stage 1-Interviews, Stage 2-Focus groups and Stage 3 Workshop. Finally, the analysis procedure was explained. The next section will explore the findings from this process, through considerations of the aims and objectives of the work.

5.12 Findings 1: Getting to know the participants

The following section addresses objective 1, i.e., engaging the community. A total of 20 participants were recruited to the co-design process from Edinburgh, the Lothians and Fife: 11 older adults living with and beyond cancer (Group 1) and 9 professionals/volunteers working with older adults living with and beyond cancer (Group 2).

In Group 1 participants were aged between 66 and 89, with a mean age of 72 at the time of recruitment in June-September 2018. Most participants were male (n=8), and all participants identified as British. The majority lived alone (n=7), while the remaining four lived with family. Seven of the 11 participants were diagnosed with cancer less than five years ago at the time of recruitment, while the remaining four were diagnosed more than five years ago at the time of recruitment. For seven of the participants this diagnosis pertained to a primary cancer, while the remaining four were secondary, with an original diagnosis between five and 20 years earlier. The majority had been diagnosed with prostate cancer (n=6), while the other five had been diagnosed with bowel, ovarian, breast, brain or bone cancers. At the time of recruitment, the majority of participants (n=7) indicated they had finished treatment, while four indicated treatment was ongoing and in all cases this consisted of medication. However, due to the length of the data generation period this changed for some participants. At the time of the final co-design session (one year after initial recruitment), five participants were undergoing cancer related treatment in a clinical setting (i.e., hospitalised; n=3) or due to other health issues (n=2). Eight of the 11 participants had also been diagnosed with a further chronic illness or health issue (e.g., heart attack, arthritis, hypertension, arthritis). Overall SF-36 scores ranged from 40-95, with a mean of 78, indicating most participants deemed themselves as physically capable, with a good quality of life, as the maximum score is 100. Comparison with a population norm was not possible, as the participants had a variety of different cancer types. A total of eight participants from Group 1 took part in Stage 2-Focus groups, while four took part in Stage 3-Workshop Table 19.

Group 2 consisted of nine professionals and volunteers working with older adults living with and beyond cancer. Participants worked and/or volunteered at a variety of services supporting those living with cancer in the community. Seven participants worked or volunteered at cancer support services, three of which had a focus on physical activity provision for those living with and beyond cancer. The eighth was a nutritionist working at a local community food centre and the final was a well-being practitioner working for a local charity focussing on chronic illnesses and general support. Most participants in this group were female (n=5). A total of three participants took part in both Stage 2-Focus groups and Stage 3-Workshop Table 20.

Demographic data was only collected at Stage 1-Interviews and so only brief demographics are presented for both Groups 1 and 2, for Stage 2 and 3 due to changing circumstances.

Table 19: Demographic characteristics Group 1 (Stage 1-3)

Variable	Interviews N=11	Focus group 1 N=5	Focus group 2 N=3	Workshop N=4
Age	72 (mean)	72 (mean)	69 (mean)	70 (mean)
Gender				
Male	8 (73%)	4 (80%)	2 (66%)	3(66%)
Female	3 (27%)	1 (20%)	1 (33%)	1 (33%)
Cancer type				
Prostate	6 (55%)	4 (80%)		3 (66%)
Breast	1 (9%)	1 (20%)	1 (33%)	1 (33%)
Bowel	1 (9%)			
Bone	1 (9%)			
Brain	1 (9%)		1 (33%)	
Ovarian	1 (9%)		1 (33%)	
Treatment				
Ongoing (medication only)	3 (27%)			
Completed	8 (73%)			
Time since diagnosis				
>5 years	4 (36%)			
<5 years	7 (64%)			
Living status				
Alone	7 (64%)			
With family	4 (36%)			
Additional chronic illness	8 (73%)			
QoL (measured via SF 36)	78 mean			
Recruited from				
Physical activity service for chronic illness	3 (28%)			

Cancer specific physical activity service	2 (18%)			
Local cancer support group	5 (45%)			
General cancer support service	1 (9%)			
Recruited via				
Gatekeeper	9(82%)			
Word of Mouth	1 (9%)			
Public Engagement	1 (9%)			

Table 20: Demographic characteristics Group 2 (Stage 1-3)

Variable	Interviews N=9	Focus group N=3	Workshop N=3
Gender			
Male	4 (45%)	1 (25%)	1 (25%)
Female	5 (55%)	2 (75%)	2 (75%)
Role			
Well-being practitioner	1 (11%)		
Physical activity instructor	1 (11%)		
Nutritionist	1 (11%)		
Walk Instructor	1 (11%)	1 (33%)	1 (33%)
Project Assistant	2 (22%)	1 (33%)	1 (33%)
Project Officer	1 (11%)		
Service provision (volunteer)	2 (22%)	1 (33%)	1 (33%)
Employment type			
Voluntary	3 (33%)		
Paid	6 (67%)		
Recruited from			
General cancer support service	3 (33%)		
General cancer support service with a focus on physical activity	4 (44%)		
Community food service	1 (11%)		
General support service	1 (11%)		
Recruited via			
Snowballing	5 (55%)		
Direct Contact	2 (22%)		
Gatekeeper	2 (22%)		

5.12.1 What is health?

Participants in Group 1 generally defined health as the ability "to do things that I want". For example, Shirley (66yo, Stage 1) indicated health is "Being able to do things that I want to do or being fit enough to do things that I want to do, having the energy to do them" emphasising the importance of doing what they want but also later stating "cancer changes that, in as much as well I want to do, sometimes I'm not able to do it. And I hate asking for help, unless I really have to". This definition broadly resonates with the idea of independence, in doing "what I want". For example:

> *"It means you can do things you wanna do, you're not tied in the home getting bored. I like to get out and about but if you're not able to do it, it severely restricts to what you can do… Cause I like going out photographing trains and going on holidays, well the 2 holidays I've had have been 3,000 miles by train and 1,800 miles by the plane in 6 weeks. So, if you're not healthy you can't do that." (*Dave, 68yo, Stage 1)

Others in group 1 identified health as "everything", including:

> *"Oh it can make an awfy [lot of] difference to you, you know if you wake up in the morning and you're not feeling that great, it can be well, a bit depressing, where if you've got your health you've got everything."* (Adele, 68yo Stage 1)

Similarly, Ted (68yo, Stage 1) stated "Well it's everything really (health), you know. I'm so lucky in that I'm here today talking to you, able to do most things," while Alfie (71yo, Stage 1) also suggested health is "Pretty much everything, actually, yes."

Participants in Group 2 generally determined health in a less philosophical and more practical way. For example, they tended to define what being healthy is, rather than what health actually means for them. The most dominant theme evident in the definitions of professionals and volunteers was, however, a sense of overall well-being, similar to that cited in the WHO definition of health i.e., "health is a state of complete physical, social and mental well-being and not merely the absence of disease" (World Health Organization, 2022) or aspects similar to this. For example, Isla (Volunteer, Stage 1) emphasised health as social well-being for the most part, in that she suggested:

> *"So, I think health is about feeling the best you can. So, feeling well, feeling content, feeling like there are opportunities to go out and meet people, and do things that you want to do. There are opportunities to relax in your home, and feel comfortable in your home, and contribute as much as you want to, to the goings on in your home. And yeah, I think health is about opportunity, having the opportunity to go out and be part of the community, feel involved, and do all the things that make life good, whatever that is for people."*

It was also apparent throughout this definition that there was an emphasis on both happiness and independence, similar to reflections from Group 1, i.e., the phrase "do all the things that make life good, whatever that is for people" (Elaine, Project officer, Stage 1). Such emphasis on the individual is important and links with the notion of identity expressed by Group 1. Hence, although the focus is on a component of the WHO definition in this instance, the phenomena evident in the definitions of Group 1 are still, to a degree, evident. Ryan (Nutritionist, Stage 1) also emphasised the social aspect of health, as well as the bio-psycho-social components within the WHO definition, when stating:

> *"Crivens [surprise]. You're making me think about health psychology now, what I learnt at uni. It's not just the absence of ill health but...Feeling like your body and brain are operating to the best of their ability and also free from ill health and coughs and colds and infections. But it's not just physical health, it's mental health as well and that includes social health. I know that's not a term but maybe social activity being a key feeder into good mental health as well. So, it's the kind of whole holistic picture, mind and body."*

Others focussed on this overarching sense of wellbeing but also incorporated the necessity of certain health behaviours, including physical activity and diet to maintain health:

> *"I think, the best way to describe health is probably just an overall wellbeing because I think so much of it comes down to lots of different factors, I think, what you eat and diet wise, whether you exercise or are physically active."*
> (Liam, Instructor, Stage 1)

Although there were some similarities across the two groups in terms of definitions, the sentiment was different between the groups, emphasising the importance and necessity to bring both groups together to better understand and develop behavioural interventions.

5.12.2 Understanding behaviour participation

Individuals in Group 1 shared their perspectives on participation in physical activity, diet and sedentary time in reference to others similar to themselves during Stage 1 (Interviews). These findings indicated that the majority felt they were more active (64%), had a better diet than others (72%), and spent less (36%) or about the same amount of time (36%) sitting than others similar to them. Participants recruited to Group 1 considered themselves to be already active and have a better diet than most of their peers and spent limited time in sedentary activities such as sitting.

All participants indicated that they took part in a variety of physical activities from walking to gym classes and gardening. Walking was the main means of physical activity for most. However, two of the participants (Adele, 68 and Mary, 89) indicated they could no longer walk due to health issues but participated in other activities, to ensure they remained active (i.e., gym classes and gardening). Gardening was also a primary form of physical activity for participants in Group 1, with 6/11 noting that they regularly worked on their garden. Other activities shared included cycling (n=1), gym classes/workouts (n=3), golf (n=2) and running (n=1). All participants recruited were generally active and participating in a range of varied activities, and even those who indicated they were less active than their fellow participants engaged in some form of activity, as mentioned above.

With regards to diet, 72% of participants indicated they had a good diet and deemed it as better than their peers (Table 21). This was further evidenced during the interviews, with participants indicating they *"eat healthily, very much…healthily"* (Mary, 89yo, Stage 1), *"eat well…and look after myself"* (Adele, 68yo, Stage 1), and that *"my diet's always been pretty good, pretty healthy"* (Ted, 68yo, Stage 1).

Although most participants deemed their diet to be good, healthy and better than others similar to them, there was also discussion from some regarding what they deemed as their bad diets, or in the words of Harry (69yo, Stage 1), an *"atrocious"* diet. When a perceived poor diet was discussed, this generally meant a perceived lack of fruit and vegetable intake (Shirley, 66yo, Stage 1) and/or over-consumption of sugary and fatty foods, e.g., *"then I have a pudding and then I have a packet of crisps and maybe a bar of chocolate as well and then I'll have an ice cream"* (Harry, 69yo, Stage 1).

Unlike physical activity and diet, sedentary time – or sitting time as it was described to participants – was considered difficult to determine, as participants found it challenging to assess how much time others spent sitting. However, for the most part (Table 21) participants perceived themselves as spending less or the same amount of time sitting as others similar to themselves. Participants also shared how they made conscious efforts to break up sitting time as well as an awareness of the harms of sedentary behaviour, e.g., Peter (68yo, Stage 1), who stated *"I've rigged up a system in my spare room where I can read my paper standing up. So, I'm wise to the fact that you mustn't spend too much time sitting down".*

Table 21: Perception of behaviour participation vs peers

Behaviour Level of participation	**More**	**Less**	**Same**
Physical activity	64% (n=7)	9% (n=1)	27% (n=3)
Sitting time (one participant answered unsure)	18% (n=2)	36% (n=4)	36% (n=4)
	Better	**Worse**	**Same**
Diet	72% (n=8)	28% (n=3)	

5.12.3 Social Networks

To further understand the outlook of participants recruited to Group 1, a social network mapping exercise was conducted at the beginning of the focus groups in Stage 2. An example of a completed map can be found in Appendix 27.

All participants indicated they had a close social network, consisting of a variety of individuals, including friends and family, emphasising that for the most part participants involved in the study were not isolated. However, Harry (69yo) indicated he was in fact isolated during the interview stage and this is to an extent reflected in his map, with the gym teacher closer to him than family members. Similarly, Dave (68yo) indicated limited familial social support during the interview in Stage 1, due to distance from one another but emphasised his involvement in the community and clearly actively sought out social activities, which was evident in the mapping exercise. Moreover, Arthur (79yo) – who had the smallest social network in this exercise comprising of only two components (wife & two sons) and three individuals - may not be deemed as isolated, regardless of this perceived limited social network. Throughout the interview (Stage 1) with Arthur (79yo) it was highlighted he was a bit of a "loner" but was happy and preferred this, indicating all individuals are different and context must always be considered.

5.13 Findings 2: Building the intervention

The following will explore the findings relevant to the development of the intervention. Presenting the barriers and facilitators identified, how these were prioritised and then the key elements proposed for the intervention design. These are represented broadly in the resultant idea prioritisation overview (Figure 21).

Figure 21: Full idea prioritisation overview

5.13.1 Facilitators and barriers

21 key concepts from Group 1 and 25 from Group 2 were identified in the analysis of Stage 1-Interviews. These could be facilitators and/or barriers to participation in a future behaviour change intervention based on participants past experience in groups, the behaviours or provision. Essentially these were potential influencers on and requirements for a successful programme (Table 22). Later these were condensed and prioritised through the process, with only 19 remaining across both Groups. Results of the prioritisation can be found in Figure 22. These were condensed further, resulting in 5 overarching themes (1. Motivation, 2. Tailoring to the individual, 3. Practicalities, 4. Learning from professionals, and 5. Social aspects.) and 15 sub themes, which were presented back to the Groups in Stage 3 (Appendix 23). All participants agreed with this output through validation in the Stage 3-Workshop.

In addition, 22 barriers to participation were identified from Group 2 (Table 23). Barriers were less commonly explicitly identified in Group 1, as this group was particularly motivated. Regardless the barriers identified by Group 2 were useful for consideration. These were later ranked by those in Group 2, to identify which would likely be most influential. The results from the ranking were validated with all participants in Stage 3-Workshops. The results of the ranking led to a hierarchy of barriers, with an overarching barrier of timing in the cancer journey identified (Figure 23).

Some interesting juxtapositions and key learnings or explorations of these results are now described.

5.13.1.1 Motivation

Throughout the interviews it was clear motivation, be it intrinsic or extrinsic, was likely to play a key role in whether individuals attended programmes, specifically behaviour change programmes. Many in Group 1 cited enjoyment as a reason to participate and more importantly sustain participation in past lifestyle programmes, and the target behaviours more broadly, specifically physical activity. Participants indicated the programmes they are part of are, *"good and most people look forward to it, that's why* *we keep coming back"* (Dave, 68yo, Stage 1). As expected, the flip side of this is the potential dislike of a programme for any number of reasons, i.e., uncomfortable with the group, dislike of the activities or fear at trying something new, which will likely act as a barrier.

Moreover, many cited goals as reasons to participate in the behaviours, particularly physical activity but more importantly in this instance goals were mentioned in light of participating in programmes, in particular a notion of using programmes to regain function and 'get back to me' was evident. Participants indicated they wanted to *"be the same person I was*" (James, 67yo, Stage 1) and highlighted how programmes had helped with this or at least helped in regaining function:

> *"but going to that class, it did help. And especially you know walking from side to side because at first, I did use my stick when I was there but then after a wee while, I stopped using it." (*Adele, 68yo, Stage 1*)*

This sentiment was also corroborated by professionals with conversation with individuals highlighting that need to get their identity back, get back to themselves but also working on building ways to do this. This emphasis on getting back to normal or regaining function highlights the need to understand the focus of the programme from the perspective of the participants.

5.13.1.2 Social Aspect

A social aspect was also identified as key to any future intervention. Initially this was seen as a motivator to participation and included in the overarching theme of motivation. However, this was later defined as a significant point on its own and later categorised as a key recommendation for future interventions, as evidenced in Chapter 7. However, it is important to understand the provenance this recommendation arose from. The benefits of social support experienced when participating in previous groups was expressed:

> *"They get a huge amount out of it, and it's more the socialising and the chatting, talking to other guys about what they've been through, what it's gonna be like, you know." (*James, 67yo, Stage 1*)*

This sense of social support also emphasised the need for cancer specific programmes, due to the benefits of discussing with peers when in attendance at the programme regardless of the behaviour targeted:

> *"It's a really important thing to feel, you know, if you get a cancer diagnosis of any kind, you can feel incredibly isolated. And there's something wonderfully liberating about just being with other people who are in exactly the same boat as you." (*James, 67, Stage 1*)*

Eating alone was again raised as influential on dietary habits. Participants who lived alone indicating they sometimes felt it was difficult to eat well, as it felt less important and more of a burden when only cooking for one:

> *"Aye, 'cause I know some days, myself, I can't be bothered, you know, wondering what I'm going to have for my dinner. I mean, I've usually got food in, but you know, there's times when I think, oh I can't be bothered making that." (*Adele, 68yo, Stage 2)

Within this discussion others recognised "it's more difficult when it's just one" (Alfie, 71yo, Stage 2), emphasising the potential impact of living alone on diet but also highlighting again the need for social interaction in the programme and the likely influence of social isolation.

5.13.1.3 Practicalities

Practical concerns were also raised, broadly these covered information available/knowledge, being available locally, cost, and practical concerns around running the programme (e.g., funding and organisation capacity). The majority of these could be both facilitators and barriers and were often cited as such throughout the interviews. The idea of information availability/knowledge also led to the idea of “how do we get the word out?” Participants in Group 1 indicated there was no services available locally. Yet, those in Group 2 indicated “Maybe not knowing what’s out there, what kind of organisations can be helpful,” (Kathy, Instructor, Stage 1) could influence participation, again highlighting the need for information and understanding of what is necessary to get the word out. It was also suggested by those in Group 2 that interventions and services were often competing for funding and therefore, less likely to refer people to other organisations, creating a further issue with getting the word out. This was also reflected in the discussion around the barriers:

> *“The main problem is actually getting the word out and it is, it’s just a matter of letting people know what’s out there”* (Calum, Volunteer, Stage 2).

Practical barriers were ranked as most influential on participation in a behaviour change programme for older adults living with and beyond cancer. These practical barriers included: transport, ensuring there is a toilet available, that the timing suits those expected to attend, and cost. What may seem small and simple could make the difference of people attending or not. Having access to a toilet was identified as necessary by most, particularly when considering certain types of cancer, such as prostate cancer. However, it was also suggested this should be advertised or mentioned in some way by group leaders, to minimise the need for potential participants to ask about this. As well as transport and facilities, cost was identified as a highly influential barrier, expected to prevent some from participating, with an emphasis on the necessary to provide free activities to ensure all can participate.

5.13.1.4 Peer vs professionally led

Throughout the process there was a distinct focus on both peer- and professionally led interventions, emphasised in the results of the prioritisation task (Figure 22). It was expressed there was a need for trust in a professional but also understanding and empathy from a peer, with motivation expected to be derived from both the authority of an expert, as well as the knowledge that someone else is speaking from their own experience.

5.13.1.5 Tailoring to the individual

Focus group 1 elected to add an additional aspect around tailoring to the individual, as it was acknowledged everyone is different. This was also reflected in the prioritisation results of Focus group 3 with Professionals/Volunteers who selected tailoring to the individual as a priority for the intervention. On reflection it was clear this was a key theme throughout the process and is discussed in depth as Considering the Individual in Chapter 7. An overarching barrier was decided as timing linked to cancer journey, which was expected to influence all other barriers ranked. This concept has been discussed elsewhere in terms of timing (Section 5.13.5), yet it is important to consider the significance of this on barriers and attendance. Again, putting the individual at the centre was emphasised as a way to overcome this issue.

5.13.1.6 Gender

Another potential barrier emphasised further outwith the ranking task and particularly by those in Group 1-Older adults living with and beyond cancer was the potential influence of gender. Gender was middle ranking in the prioritisation tool completed by Group 2. However, further emphasis was placed on this by those in Group 1-Older adults. Initially it was acknowledged that a class *"can be quite intimidating, if it's all women"* (Alfie, 71yo, Stage 2).

A further point raised regarding gender was the idea that men are more likely to *"bottle it up…and deal with it in their own way*" (Alfie, 71yo, Stage 3), which identified men as a key target population for a programme wherein social contact and tailoring to the individual are key. However, the opportunity to undertake activities to enable the conversation in a non-threatening environment with minimal expectation to participate in any discussion may also be required to encourage men to participate and alleviate gender as a barrier. Activities such as walking and talking (discussed further in Section5.13.3), were deemed as most suitable for this type of support. In the end it was agreed for the purpose of this study that mixed gendered groups were suited. However, there was also acknowledgement of the benefits of male only groups:

> *"it's difficult to get men to come in the first place so you really want to give them a safe environment where they want to come and they want to talk and*

*they want to share. So, you know, men only groups are great for that, they really are." (*Kathy, Instructor, Stage 3*)*

Table 22: Key concepts identified from Group 1 & Group 2 Stage 1-Interviews

Group 1-Older adults		
	Concept/theme	Evidence
1	External influences	*We are both well retired and emm, we are just on our own anyway, so we thought may as well just start to make changes [wife] (*Tim, 79yo*)* *Yes, you know, eggs are bad for you, eggs are good for you. It's all the time you're getting it, you know. Well, coffee's bad for you, oh, no, coffee will keep cancer away, oh, great. It's all mixed messages.* (Harry, 69yo)
2	Gender	Harry (69yo)*: Yes, if there were exercise groups for men as there are for women, that would be quite good.* Researcher*: What about the mixed ones, mixed groups?* Harry (69yo)*: Men don't go to them.*
3	Learning from professionals	*I feel a lot more should come from authoritative groups* (Alfie, 71yo) *And I dunno how you can motivate people to do things like that, unless you can tell them look, there's scientific evidence to say if you're active you're gonna boost your immune system, you're gonna help prevent, possibly prevent the recurrence and that's it the facts are there take it or leave it. Emm you can't force people.* (Arthur, 79yo)
4	Motivation-Goals	*I was struggling with my stamina, you know. Cause after an operation and I've had 2. I think it was after the 2nd one and it was really, you know,* (Peter, 68yo) *But I use that and again I think people being encouraged to do that sort of thing. I've seen me sitting in the house and I look at my phone and I go ohh I've only done a few thousand today.* (Tim, 79yo) *I enjoy the achievement.* (James, 67yo)
5	Fear of recurrence	*so I mean I still, well I found a lump a couple weeks ago when you phoned (R: yeah). And I thought Oh my goodness! It's came back.* (Shirley, 66yo)
6	Competition	*But the thing about a group of men together, it's much more competitive. I'm not really into all that male competitive carry-on.* (James, 67yo)
7	Social aspects	*and at the end of the group we would have a social, you know, you'd go to a café or something.* (Harry, 69yo)

		No, I tell you why they come along, they come along for the camaraderie. They come along because they want to be with people who are in the same boat as them. (James, 67yo) *because I was feeling very isolated.* (Alfie, 71yo)
8	Effects of treatment	*I wasn't going to go out at all until my hair grew and I sat here by the window looking outside and I thought, I cannae do this. I get stir crazy, especially going through chemotherapy, oh my goodness. (*Shirley, 66yo*)* *I did go to that. I dunno why I had to stop. Oh because I cracked my hip and then I fractured my foot.* (Shirley, 66yo)
9	Getting back to me	*I want to be the same person I was, without…[cancer]* (James, 67yo)
10	Emotional support	*So something like the support group, I think it's quite a surprise to people. And I think the guys absolutely love it, and I think it performs a really…but that's something about society as a whole*.(James, 67yo)
11	Fatigue	*I knew if I was feeling tired or not but I didn't, so if I do feel tired I know I've gotta go take things easy but I know now.* (Dave, 68yo)
12	Tailoring to the individual	*It's hard to go out and create. I want something thrown at me. I want to be given something to do rather than try and create something to do for myself.* (Harry, 69yo) *Every walk I lead or organise I tailor it to suit the group and you've always got to listen to the weakest member of the party. That's who determines what you can do and what you can't do in a day.* (Alfie, 71yo)
13	Confidence	*it's all to do with confidence and what's in your head really.* (Peter, 68yo)
14	Motivation-enjoyment	*And I hugely enjoyed it and got something out of it.* (Ted, 68yo) *Just health and enjoyment aye* (Arthur, 79yo)
15	Health benefits	*It's my health motivates me to be honest.* (Harry, 69yo) *And there is a lot of evidence, scientific evidence that suggests that the fitter you are the better your immune system is and if your immune system is good then you're going to hopefully prevent recurrence of any tumour, so you, your immune system your lymphocytes which are designed to kill foreign cells will recognise these are tumour cells and kill them off and that's there is some evidence that says that's what happens, and hopefully that's what's gonna happen with me (nervous laughter).* (Arthur, 79yo)

16	Learning from peers	*And instead of an expert saying oh this is what you should do, its people who have struggled saying this is what I've managed to do. There's a hell of a difference between an expert saying this is what you should do and everyone thinking crikey, you know and you listening and somebody saying I had a struggle but I managed to do this, that sort of thing, you know.* (Peter, 68yo)
17	Physical barriers	*I still couldn't rely on being an hour out without having to go to a toilet. Sometimes you're like ten minutes in between, you know, so it's still not regular and that's what happens with these things I believe.* (Harry, 69yo)
18	Education/information	*so it's a combination of social, physical and educational, if you like, and I think the formula works.* (Alfie, 71yo) *if somebody said to me now here's 2 stone weights, take them with you and golf, I'd be like no. And that's another thing is that, if people could just realise the benefits of it, things as simple as that.* (Tim, 79yo)
19	Regain function	*I got the diagnosis and all the rest of it and that fell rather by the wayside. So I've, I'm, I'm getting back to that you know* (Peter, 68yo) *and last Tuesday I was able to walk, and that's the furthest that I've walked since I had the operation.* (Harry, 69yo) *So, and I just thought, gosh, that's taken a year, February, that I had the operation, and you don't notice the improvements.* (Shirley, 66yo)
20	Available locally	*I don't think there's enough things in PLACE for people who have been through cancer.* (Shirley, 66yo) *Cause it's handy I can just walk down the road* (Arthur, 79yo)
21	Information availability	*But yeah the support is there, you just need to, I think you need to ask for it or you need to find out, it's not publicised* (Shirley, 66yo)

	Group 2-Professionals & volunteers	
1	Professionally led	*so it's almost like they're safe in the knowledge that they are with a trained instructor* (Kathy, Instructor)
2	Impact of tutor	*If you've got someone warm and bubbly and is like, hi, I'm NAME, this...you know, this is the class, and you'd be like, oh, I feel quite nice in here.* (Elaine, Project officer)

3	Relationship with tutor	*I think you have to be able to connect with lots of people.* (Kathy, Instructor)
4	Practicalities	*I think, for me, I would say that people like to be in a centre where they feel a bit more safe. There's a warmth, there's amenities.* *(*Carly, Project assistant*)* *Making things free overcomes cost as a barrier* (Liam, Instructor)
5	Funding	*But it's quite difficult and because we have modest funding and can't do older peoples groups at all often* (Ryan, Nutritionist) *So maybe something like that, I don't know but that costs a lot of money and a lot of time and you need to do, it's a huge amount of stuff.* (Kathy, Instructor)
6	Available locally/accessibility	*not ask people to travel or if there is travel involved, is it possible to have a minibus to bus people over? (*Ryan, Nutritionist)
7	Available facilities	*Importance of practicalities even as simple as chairs* (Elaine, Project officer) *They can just walk, sit down, there's loos there so you know.* (Kathy, Instructor)
8	Capacity of organisation	*One additional problem though is the capacity of the organisations who work with any given client group. So, it'd be wonderful if lots of people come forward for nutrition and cooking classes or exercise groups but if they don't exist... So, there's that. There's got to be both sides of it.* (Ryan, Nutritionist)
9	Education/information	*try and promote to them that this is the benefit of being physically active, particularly if you've gone through diagnosis and through your treatments.* (Liam, Instructor) *Yes, definitely, diet is a huge thing. You know, when I used to be a personal trainer it's...people are...they have no idea what to do whatsoever and they don't know where to start* (Liam, Instructor)
10	Prompts/nudges	*They want to be but I think you can almost drip feed people really, if you are, it's like that drip, drip effect.* (Kathy, Instructor)
11	Emotional support	*It's the usual balance of the world we live in where you don't have physical contact but it's the most natural thing in the world if a woman is weeping to want to just gently touch their shoulder or hold their hand.* (Isla, Volunteer)
12	Tailoring to the individual	*You know, cause there's some people who are restricted in what they can do and that's not going to change, no matter how much you would like it to change it's not gonna change.* (Kathy, Instructor)
13	Confidence	*definitely, yes, if you can get their confidence up* (Calum, Volunteer)

14	Intrinsic motivation	*Making it fun.* (Isla, Volunteer)
15	Social aspects	*then we are having a cuppa at the end or soup, so yeah communication is very important. Cause I think if someone was gonna come along and nobody spoke to them, they wouldn't come back, would they really. That's what it's about* (Kathy, Instructor)
16	Enjoyment	*the participants that are there they really enjoy it, they really enjoy it. They like the variety of it* (Calum, Volunteer)
17	Reducing isolation	*I think it's, when I'm having chats with people, who are maybe isolated, and they're kind of talking about potentially wanting to be more involved with things,* (Steve, Well-being practitioner)
18	Learning from peers	*…because they know that everyone's got it or had it and they've all been through the same thing or further down the line, so you've got someone here and you can ask that person, oh did you find this or what did you do* (Rebecca, Project assistant)
19	Extrinsic motivation	*And he just went downhill, obviously just getting more into a rut and then something happened, or he'd got the tracker or something or he went to classes, and he just tried to like increase his steps by so many hundred a week and now he's doing really well.* (Rebecca, Project assistant)
20	Goals	*it can be a motivating tool, trying to get back to…if a person has a clear goal of what it is they want to get from coming* (Steve, Well-being practitioner)
21	Getting back to normal	*sometimes, people talk about having a lack of purpose, so they're not able to do the things they used to do.* (Steve, Well-being practitioner)
22	Regain function	*There are people that do it and say, well that's good, it's got me back on my feet or whatever it is* (Calum, Volunteer)
23	Quality of life	*I think the health benefits, the social benefits, the mental health benefits probably just about encompasses everything.* (Kathy, Instructor)
24	Information availability	*It's in the book, so people can look through and see what's on (*Kathy, Instructor) *Well there's signposting and referrals from all sorts of agencies and staff and support staff but also, because it's a particular set of communities in the south east, there are posters up or it's going to parent evenings in schools and recruiting parents through that or, I'm trying to think, workers in GP surgeries. Just any old way.* (Ryan, Nutritionist)
25	Gender	*It's always surprised me that men don't want to come along to a group where there'll be women. You'd think they would but no they are more comfortable to come along to a group that's entirely male. So, that's a good way to get people on.* (Ryan, Nutritionist)

Table 23: Barriers identified in interviews Group 2

	Barrier	Evidence
1	Dislike/individual preference	*So they come to me and they can talk to me and that wee lady, the second one I spoke to there, she wasn't so… She said "Oh I don't think that I would like that." And I said that's absolutely fine, if you don't like it, you can say you don't like it, it's not for everyone.* (Kathy, Instructor)
2	Practical barriers	*they're saying, what happens if it rains, and what happens if I get caught short? All that kind of stuff*. (Calum, Volunteer)
3	Fear	*Other ones are maybe just, again, that fear of the unknown.* (Carly, Project assistant)
4	Impact of treatment	*sometimes it's overwhelming, if someone's been through treatment it can be overwhelming and there's lots of things going on, so it can be very overwhelming for them.* (Kathy, Instructor)
5	Fatigue	*if they feel not great that day; fatigue, that's usually quite a popular answer. Are there any barriers and they say, it depends on how I feel.* (Rebecca, Project Assistant)
6	Confidence	*if you throw a long-term condition into the mix you can see why people are terrified of trying to exercise and they've just not had the right advice, that's all, and it's putting them in touch with the right person so that they can then build...their confidence*. (Liam, Instructor)
7	Cost	*And I think some of the populations that we work with, sometimes are living on very minimal amounts of money, and don't have a lot of money to spend on things like that*. (Steve, Well-being practitioner)
8	Past behaviour	*I think people have to be predisposed to it almost though. I think it's really difficult to change people who really don't want to.* (Kathy, Instructor)
9	Gender	*So I think men are much harder to reach* (Steve, Well-being practitioner)
10	Deprivation/class	*I think there's a background social grouping thing going on as well. I think middle class people find it easier to come* (Isla, Volunteer)
11	Isolation	*so I think, when people are on their own, sometimes it's difficult.* (Steve, Well-being practitioner)
12	Timing re cancer journey	*I think it just depends at what point a person is at in their recovery.* (Steve, Well-being practitioner)
13	Readiness to change	*Barriers, I think the biggest one that I really ever see is that somebody's just not ready.* (Liam, Instructor)

14	Lack of info available	*Maybe not knowing what's out there, what kind of organisations can be helpful*. (Steve, Well-being practitioner) *But yeah, other than that, there's maybe not too much out there, to share with people* (Steve, Well-being practitioner)
15	Lack of knowledge	*they do not focus on pelvic floor, core and that, yeah. So if they focussed on that a lot more and people used it a lot more, then there'd be a lot less injury within particularly women and men too, men have a pelvic floor, they maybe don't realise it but they do.* (Kathy, Instructor)
16	Access/transport	*Transport and being able to actually get there sometimes is not always ideal for everybody.* (Liam, Instructor)
17	Motivation	*And I suppose, that leads to a lack of motivation, sometimes people just feeling like they don't really have the motivation to keep going, and they kind of think, what's the point.* (Steve, Well-being practitioner)
18	Mental health	*that's the nature of people's lives, they're chaotic, there's a lot going on, with these things. Especially if people are anxious as well* (Steve, Well-being practitioner)
19	Getting the word out	*they don't know about NAME and then they suddenly find out and say I wish I'd known about this years ago.* (Isla, Volunteer)
20	Preaching/lecturing	*But not force them, I think there's a fine line between if somebody shows an interest and wants to come along that's great.* (Kathy, Instructor) *if you start preaching about this and that. You know you end up people switch off* (Kathy, Instructor)
21	Getting through the door	*Had I not had a buddy, I'd be like, oh, I don't want to go through the doors.* (Carly, Project assistant)
22	Guilt	*I think the one thing that comes about with people that are a wee bit older, over 65, is if we are talking to them and we tell them about different things that they can do to help, they'll say things like, oh, give that to a younger person…There's that guilt of doing well and I don't think...I don't know how you would be able to change that.* (Elaine, Project officer)

Figure 22: Prioritisation task results

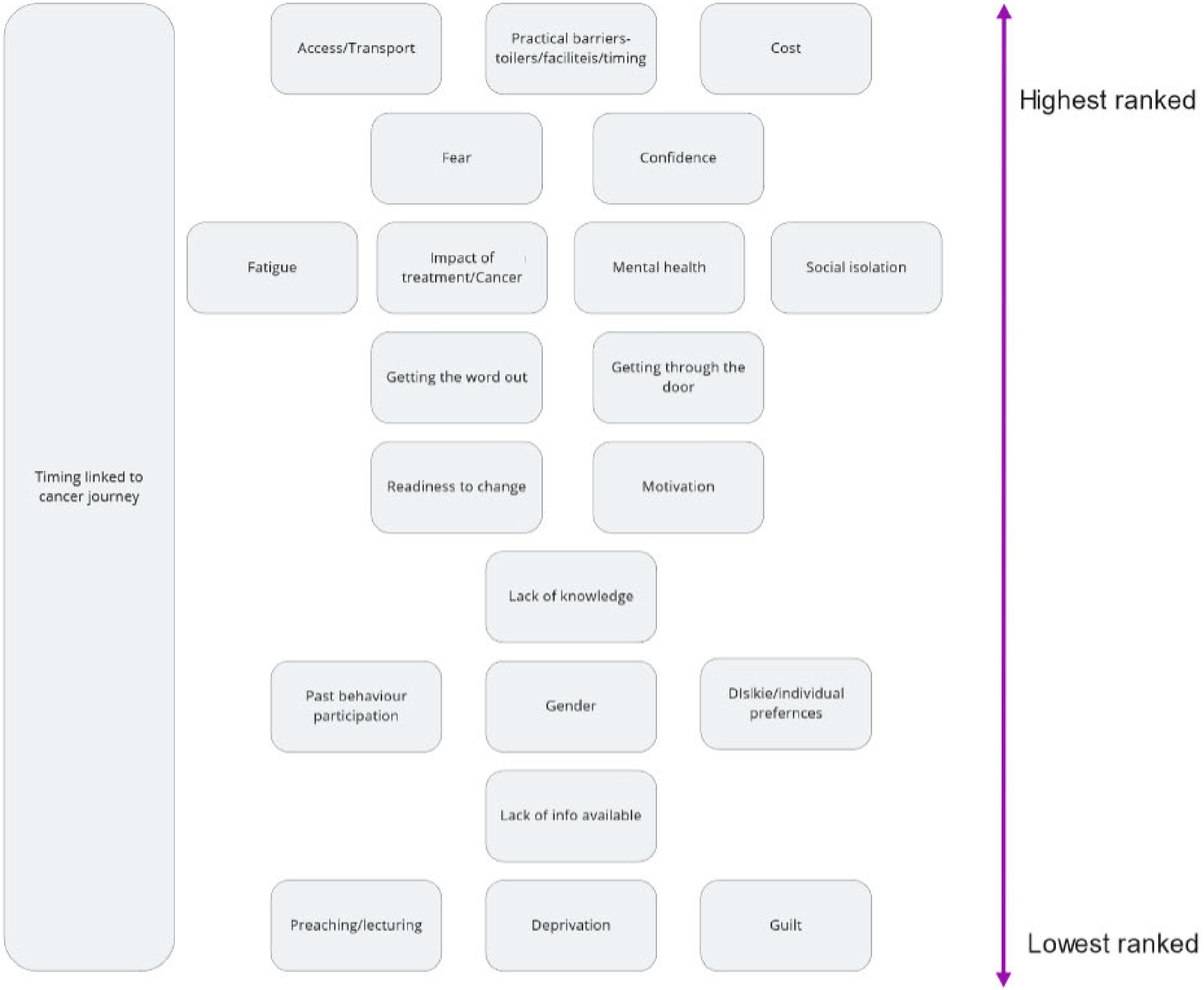


Figure 23: Barrier ranking results

5.13.2 Focus & Format

The focus of the intervention was explored as a key question due to the variety of discussion in Stage 1-Individual interviews and necessity to prioritise the scope. Throughout Stage 2-Focus groups, as with Stage 1-Individual interviews there was a definite lean towards physical activity with a great deal of the discussion centred on this. However, this is likely due to the participants recruited, most of whom were participating in some type of physical activity or physical activity programme, or professionals/volunteers leading a programme centred on physical activity.

There was a lack of interest in diet throughout. For example, in the Workshop one participant noted: *"I thought we'd given up on the dietary"* (Kathy, Instructor, Stage 3). However, it seemed there was also a need for education around diet and in particular the potential benefits of diet and dietary changes after cancer. Participants noted that the *"mind's boggling because you've read…you read about the usual greens and stuff like that and then you get to these super food things…"* (Arthur, 79yo, Stage 2), in reference to a book about diet after cancer. There was also a sense of resentment around the recommendation regarding diet with a view that the recommendations change often and feeling that experts can't make up their mind from one day to the next about what a good diet is. Participants, for example, felt they *"can't believe the information you're getting [about diet]"* (Harry, 69yo, Stage 2). Owing to this confusion it was agreed everything was okay in "moderation" and there was a need for common sense when it comes to diet.

Physical activity, by contrast, was often inadvertently core to the discussions which put greater emphasis on this behaviour for participants. It was clear, however, that there was a distinct focus on physical activity and at times diet or just general intervention/service participation as a means of getting back to normal and regaining function, in addition to the social aspects' activity enables. This was a clear thread throughout the process evidenced explicitly in the prioritisation of barriers, concepts and ideas (Figure 21 and Figure 22).

Aside from the clear interest in physical activity there was also a need for further understanding and/or education around sedentary time, as well as an acknowledgement of the necessity to change this behaviour:

> *"Sedentary time is an issue, because I'm conscious that with the lack of activity, I'm spending more time just sitting. And anything you can do to get, me personally, motivated to get up and do something would be appreciated."* (Ted, 68yo, Stage 2)

This was further emphasised by Dave (68yo, Stage 2):

> *"It's important to me because as I say, I live on my own. So, I don't have a wife to say, away and make me a cup of tea. So, you know, once I'm planted, I'm planted."*

Along with this there was brief discussion around sedentary time with the acknowledgement that balance in sedentary and active time is key; *"It's the balance thing, isn't it?"* (Calum, Volunteer, Stage 3) and a need in "wanting to avoid… people just having sedentary time the whole time" (Calum, Volunteer, Stage 3). Others asked what sedentary time is indicating a need for education around this behaviour, while others discussed what an appropriate length of time was to spend sitting, with a focus on breaking up sitting time at 30-minute intervals. Those in the third focus group (Professionals/Volunteers) felt sedentary was a good behaviour to target due to the difficulty in changing this behaviour and the prevalence of technology that facilitates this behaviour. Thus, there was some interest in sedentary behaviour and understanding of the negative impact this can have and need for *"people over 65… to push themselves, and do it, and get out,"* (Calum, Volunteer, Stage 2) but this paled in comparison to the focus on physical activity and other seemingly more important aspects that are discussed further in this section.

Although there were varying levels of interest in each of the target behaviours, there was also acknowledgement that these behaviours fit well together and are all important in terms of cancer and health, emphasising the need for inclusion of each:

> *"I think the three things are big things. That's what anyone talks about when…we're talking about cancer related issues just now. But if you're talking about any health-related issue, you know, exercise is top of the list, and what you eat is top of the list. And sitting down and doing nothing is up there, too. So they're all generally important issues."* (Group discussion, Professionals/Volunteers, Stage 2)

Reflection box 10-Are the aims right?

After conducting the interviews Part B-Stage 1, I considered redefining the aims of the study to capture more of the cancer journey and work to improve this. I considered this as it seemed although there was an interest in the behaviours (as set out by me the researcher), there also seemed to be something more evident such as an interest in higher level change or needs, particularly the need for social interaction. I discussed this with my supervisors, however it was agreed that I should stick with my original aims and continue the process as intended as is good research practice. It was posited that this would be expected had this been a research grant and also agreed that although there was potential to focus on the cancer journey more broadly, there was also a wealth of discussion and data generation around behaviours. Regardless I decided to explore my concerns with the group who alleviated them quickly stating focussing on the behaviours was enough and that they were happy with this moving forward. Even expressing that three behaviours was a lot to consider, a premise that is evident throughout this thesis.

However, there was also an acknowledgement that perhaps targeting each of the behaviours could be too much for both the programme and the individual with one participant speaking to me directly within Stage 2 to express this concern. Regardless, it is evident the behaviours are to a degree important and potential focuses of an intervention for older adults living with and beyond cancer. However, in the discussions with participants it became clear that although these behaviours are somewhat important other aspects are more so important and relevant and should be considered as the main focus of an intervention with the behaviours as secondary or indeed as facilitating this focus. These were: social interaction/support, regaining function, and getting back to normal/me, which was considered to be similar to regaining function but with greater focus on-seeking a return to an old identity not just function. All of which were ranked highly in the prioritisation tasks Figure 22.

Throughout the process it was evident implementation of any programme developed would have to be face to face, to incorporate the social aspect deemed necessary and evident throughout the process. For example, discussions focussed on the need to be able to talk to others and have that face-to-face contact, e.g. *"I like to talk to people…Yeah rather than a set of videos... or leaflets, aye"* (Dave, 68yo, Stage 2). Moreover, there were reservations regarding online services, in some instances attributable to age but primarily linked once again to the need for social interaction via face-to-face communication and services. For example:

> *"I mean, I know everybody…we would all be able to use a computer, but I've…I…what I've been reading is the younger people, when they're being diagnosed with cancer, they're right on a forum and typing back and forward. And I think, well actually that's not for me. I would rather talk to somebody."* (Shirley, 66yo, Stage 2)

However, there was an understanding that face to face may not always be practical, but it was still preferred, i.e., "If it has to be [Online], for some people who live further away, well, fair enough. But getting people together is better" (Alfie, 71yo, Stage 2). It is important to remember this work was conducted before the COVID 19 pandemic, when considering the results regarding format.

Those in Group 2 (Professionals/Volunteers) also emphasised the need for face-to-face programmes and instances the benefits of these with regards to recruitment and retention to programmes:

> *"I think people quite like face-to-face," (*Kathy, Instructor, Stage 2*)*

> *“I do find if I meet with them, they're more likely to actually…and I kind of build that rapport with them "(*Rebecca, Project assistant, Stage 2*)*

Participants also exemplified the need and benefit of social interaction and using face-to-face programmes to achieve this:

> *“And then, the activities themselves, as well, would be face to face as well, not like an online programme or anything like that…No…Because that’s so much easier just to fade out…If you ever do, like, online training, I always find if I'm sitting there doing it, I'm like, I'm bored with this now. But if somebody is actually talking, you're more, oh what am I gonna say next, I'm actually listening to you, but if you're just reading something, you're not taking it in…And I think a lot of people who go on a group, say a walking group or something, and they don't go one week, because you make friends, somebody might phone you to say, are you okay…Uh-huh, or you can text them, and they'll be like, oh I'm not coming this week. Or phone and say, I'm not coming this week, can you let them know…Yeah. But it just means that they feel that they're wanted within the group, you know, so they're part of something, (*Group discussion, Professionals/Volunteers, Stage 2*).*

As well as being face-to-face it was clear a group format was preferred as most examples and discussion focussed on a group format and the necessity/benefit of social interaction. This was cemented when “Group activity” was added to the prioritisation tool sheet Figure 22.

A further component of the programme format discussed was the regularity of it and the access individuals would have, i.e., is the programme only available and running for a set number of weeks or can individuals attend as and when they like and feel the need? During the focus groups (stage 2) it was suggested that a finite, goal-oriented programme may be better as people could achieve set goals within the set time period, with the time period acting as a motivator:

> *"But I think, it's good to commit yourself, I think, at the same time, just go for it, and sign up for the six weeks, or ten weeks, whatever. And if you can see a potential goal at the end of it, that would maybe encourage you to sign up"* (Ted, 68yo, Stage 2)

Yet, this group also acknowledged the disadvantages of a finite programme, stating:

> *"If it's finite, and you're dropping in and out, then you might miss important bits of it."* (Alfie, 71yo, Stage 2)

This necessity for an ongoing programme was also emphasised, particularly when considering those aged over 65:

> *"I think it would be quite harsh to sort of, at the end of that period say, well sorry, but that's it"* (Calum, Volunteer, Stage 2) *"[Especially over 65's]…It becomes part of their routine"* (Rebecca, Project assistant, Stage 2).

Therefore, the decision was made that a future intervention should involve group activities, run face to face and with no finite end, as these were most suited to the target population of older adults living with and beyond cancer. Moreover, emphasis was placed on the need for a cancer specific programme, with participants indicating:

> *"Well is that not the point of the exercise that you are together with like-minded people who have been through the same thing. If I was there, and nobody else had experienced what I'd experienced, or similar things, I think I'd feel a bit kind of, why am I here?"* (Ted, 68yo, Stage 2)

5.13.3 What activities?

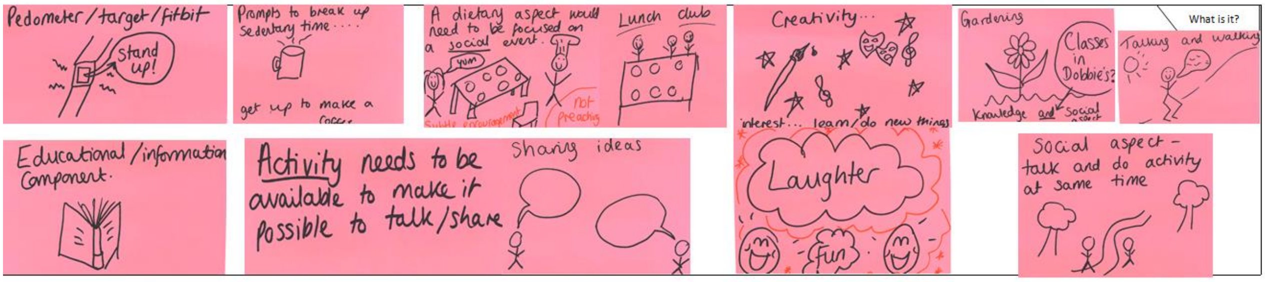


Figure 24: Idea generation overview section-What activities should be offered?

Results from the idea generation discussion in Stage 3-workshop indicated a need for activities that incorporate social interaction, fun and laughter, ensuring individuals can share ideas and be creative Figure 24. Some ideas of potential activities focusing on physical activity included walking and talking, and gardening. There was less of an interest in diet (Section 5.13.2). However, there was an interest in cooking classes, primarily due to the social interaction involved in the classes but more so in the idea to come together at the end to eat the meal prepared. With regards to sedentary time, although deemed important in Stage 2 (Section 5.13.2), little interest was evident and thus, a focus on the necessity of brief education was identified and agreed upon. It was also acknowledged technology could both enable and discourage sedentary time. Individuals cited the benefits of pedometers/fit bits in breaking up sitting time and suggested these may be a useful tool to incorporate in the programme, to determine goals and motivate but also to provide a further point of conversation.

Fun & Laughter

Participants highlighted the necessity for fun in laughter in programme and/or activities incorporated in any activity, highlighting the necessity of a social component. One participant exclaimed:

> *"Fun and laughter. Two words, that's the result of your whole study Lynsey - fun and laughter"* (Alfie, 71yo, Stage 3)

Others in the group agreed and emphasised this point stating, *"I'd go once and if it's not [fun] I'm away."* (Shirley, 66yo, Stage 3). In addition to this an emphasis was placed on social interaction with an acknowledgement that *"it's about individual* *relationships and that spark that you get when you meet somebody"* (Calum, Volunteer, Stage 3). It was therefore, recommended:

> "*That's why the group have a group because you have a choice, you know…"* (Alfie, 71yo, Stage 3).

Thus, in all it was clear whatever the activities included may be, they had to be fun, encourage and enable laughter and social interaction, and therefore, it was likely a group would be best suited to these needs. This sense that a group is necessary was evidenced throughout the process as discussed in Section 5.13.2 and prioritised in the ranking task Figure 22.

Walking and talking

In keeping with this need for social interaction, fun and laughter there was a great deal of discussion around walking and talking as an activity. This in part was due to the experiences of those in the group with some having participated and/or led walking groups previously. Therefore, there was an emphasis on the benefit of these groups, particularly concerning peer support and cancer specific support, with walking seen as a way to facilitate conversations which may otherwise be difficult:

> *Do you find that talking while you're walking…because you're not looking directly at a person might be why it's easier for the guys to off-load a little bit more and to chat because you're kind of walking straight forward and you're not necessarily looking and having direct eye contact?*
> *Possibly, yeah.*
> *Possibly, yes.*
> *That's an interesting…thought*
> *Because you're just chatting and you don't actually have to look at someone.*
> (Group discussion, Stage 3)

When asked directly if walking and talking should be a potential activity in the programme, participants responded *"yes, definitely"* (Group discussion-Stage 3). In addition to this the benefits again were emphasised based on past experience with an instructor indicating *"when they come back from their walk, they're on top of the world."* (Kathy, Instructor, Stage 3)

It was also acknowledged that walking and talking is *“a comfortable situation: you’re all out walking, so you’re enjoying the same activity, but you’ve all got the same condition”* (Alfie, 71yo, Stage 3). Thus, it was clear walking and talking could be a beneficial activity for older adults living with and beyond cancer, in terms of improving physical activity but more importantly creating a social interaction/group and enabling discussion around cancer experiences if desired. Such an activity also fits well with the barriers and key aspects identified in previous stages, with these being easily considered in providing such an activity. Moreover, it may be possible to individual tailor an activity like this, again creating a greater sense of acceptability for most. Thus, walking and talking could be a key activity in a future intervention for older adults living with and beyond cancer, incorporating a social aspect but also building on previously successful programmes, as discussed in the workshop.

Gardening

Gardening was suggested as a possible activity. With one participant exclaiming a garden programme *“is amazing”* (Alfie, 71yo, Stage 3), with another stating they *“would love to do it”* (Shirley, 66yo, Stage 3). Discussion regarding gardening as an activity focussed on gardening in local places, reinforcing the emphasis on having activities available locally as described in Section 5.13.6.

Cooking classes

Cooking classes were suggested as a means to explore diet but again with a greater focus on social interaction. It was suggested there could be *“a social outing but with somebody in making a meal, trying it out…”* (Shirley, 66yo, Stage 3). It was also acknowledged diet was a contentious topic, likely due to the personal nature of it with participants indicating:

> *“I don’t think people respond well to dietary experts saying, stop eating chips – really, I think that’s…people switch off completely, but if it came as part of a natural conversation, yeah.”* (Calum Volunteer, Stage 3)

After which it was agreed it would be more useful to explore healthier choices with friends rather than being given explicit advice and instruction, again highlighting the social component but also the potential for peer support. Thus, it was again suggested it would be *"better if it was like a cookery class or something like that"* (Shirley, 66yo, Stage 3). After this suggestion there was a move back to the idea of fun and laughter with participants stating "*if it's fun*" (Alfie, 71yo, Stage 3) people will come along, even through word of mouth.

Garden to plate

An interesting idea from garden to plate, wherein the intervention would consist of gardening and growing vegetables and fruits before harvesting and cooking with them was explored:

> *"Coming back to… the cooking, and being so appreciative of this food, from actually the ingredients, the basic ingredients, and producing something, making a meal out of it, it's a nice experience… An amount of gentle fitness, and then you altogether produce the meal, and then you eat it."* (Alfie, 71yo, Stage 2)

Others in the group seemed excited by this prospect and indicated if it were to come to fruition they would attend. From this initial idea it is clear it is not just a focus on the behaviours but something more than this, the social interaction and wider prospect of appreciation is really highlighted.

After this discussion I tried to sum up what we had so far, suggesting:

> *"it could be a cookery class and then physical activity could be about walking and talking and just talking all the time… no lecturing or preaching or anything?" (Researcher)*

To which participants responded positively. It is interesting to note the idea of lecturing and preaching and not wanting to be told what to do by experts has been raised again, yet this was ranked lowest in the barrier task. However, it seemed important particularly when considering diet, likely due to the confusion around what is a good diet and perception that experts can't make up their minds:

> *"I used to look for things in the papers where it says like a glass of red wine a day [is good for you]. I've got four of them, four articles, but my wife's got three that say a glass of wine a day is bad for you. So, you say, well, where the hell are we?"* (Tim, 79yo, Stage 3)

It seemed a relaxed cooking class or garden to plate activity could alleviate some of this tension, providing education in an informal environment and creating social interaction.

Education

As expressed in Section 5.13.2 there was some interest or necessity for education, especially around sedentary time and diet. However, it was suggested this had to be done in the correct way regardless of the topic. It was suggested this could be incorporated into the programme or as an add-on at the end, for example a physical activity session with a point to discuss diet at the end; *"that could be like at the end of a session you talk about dietary recommendations and what would you say is a good food for this"* (Rebecca, Project assistant, Stage 3). In addition, there was acknowledgement of the necessity of education around sedentary time and a potential to incorporate this into the programme. No discussion around education for physical activity was prevalent, however, this is likely because participants were generally active and aware of the benefits of physical activity.

Technology and prompts

Somewhat different to the other activities mentioned, technology and prompts to reduce sedentary time and increase physical activity were also considered by the group. It seemed many in the group used these types of tools to do this already and were keen to emphasise the benefits of these, stating:

> *"So it's exercise that raises my heart beat, standing time and also the number of steps that I've done – so my target's ten thousand, for no reason that I know of."* (Tim, 79yo, Stage 3)

It is interesting to see the point around 10,000 steps made, highlighting perhaps the arbitrary nature of this goal but also the need for education around recommendation and guidelines for physical activity. It was also said that while such devices are not always effective, they do act as a useful prompt: *"it's a reminder, though, it's a reminder [to break up sedentary time]"* (Kathy, Instructor, Stage 3). Although possibly not suited to the remit of the intervention or programme to be developed in this instance, it is important to consider all aspect determined.

5.13.4 Who's running it?

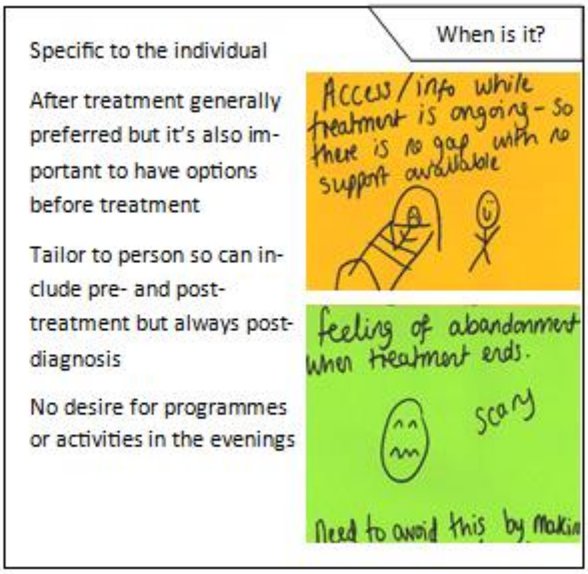
Figure 25: Idea generation overview section-Who's running the intervention?

A further significant component of a future intervention discussed throughout the process was the "who", specifically who might be running the programme (i.e., peer-led vs professionally led). As no definitive answer had been agreed on to the point of Stage 3-workshop this was raised again with the group as whole. However, this decision seemed one of the most difficult to make for the group and ultimately a combination of peer-led and professionally led was preferred, as this would incorporate the benefits of both Figure 25. In addition to this there was a suggestion of a progression type format with a professional at the start to facilitate the programme and cover any necessary bureaucratic issues, with a peer component then being embedded: *"Yeah progression from professional to group"* (Alfie, 71yo, Stage 3). However, others also mentioned the possibility of a buddy, with the *"buddy for this purpose could be about healthy living and it could cover things like diet and positive mental health and exercise"* (James, 67, Stage 3).

Another component considered was the tutors “way of being” (Alfie, 71yo, Stage 3), this was discussed primarily in focus group 2, Stage 2 but is certainly an interesting concept to consider, as it highlights again not only what is required for a successful intervention but how personalities and individuals can affect the success. Participants discussed *“just that way”* (Alfie, 71yo, Stage 2), when describing an interaction and rapport with a tutor or group leader, highlighting it was “difficult to quantify” (Alfie, 71yo, Stage 2) what this meant. However, it was acknowledged that it is *“something you either have or you don't”* (Ted, 68yo, Stage 2).

It is also helpful to note the distinct point made during the idea generation that the person leading the group does not have to be a healthcare professional (Figure 25), which fits well with the notion of a community-based programme, something with which everyone agreed.

5.13.5 When is it?



When is it?

Specific to the individual

After treatment generally preferred but it’s also important to have options before treatment

Tailor to person so can include pre- and post-treatment but always post-diagnosis

No desire for programmes or activities in the evenings

Access/info while treatment is ongoing - So there is no gap with no support available

feeling of abandonment when treatment ends.

scary

Need to avoid this by Makin

Figure 26: Idea generation overview section-When should the intervention run?

As with many of the aspects discussed during the process, timing, in terms of when individuals would prefer to attend an intervention, considering their cancer journey (i.e., before, during or after treatment) was identified as very individual from the outset (Figure 26). However, there was general consensus that after treatment was preferred as is evident below:

> *"Yeah, I think after treatment because you're so concentrated on the treatment that you're going through that you can't think past that until you've actually been through it." (*Shirley, 66yo, Stage 3*).*

> *"And sometimes when you get a diagnosis, if it's devastating, you're maybe not in the place to do it." (*Kathy, Instructor, Stage 3*)*

> *"I think a good three to six months after your treatment…" (*Dave, 68yo, Stage 2*)*

> *"For me, I think it would be after the treatment."* (Ted, 68yo, Stage 2)

There was also a distinct sense of abandonment evident in stage 3 (co-design workshop), which seemed to contribute in a way to the need for provision of an intervention after treatment. Discussion of this centred around the feeling of being left after treatment, with nothing to look forward to and perhaps using or having a future intervention, specifically for older adults living with and beyond cancer.

> *"But, I mean, a lot of research shows that people do feel quite abandoned after they've had their treatment, you know, they're kind of left with…"*
> *"Funny, I felt like that. I had had these operations, the chemo, the radiotherapy…and then all of a sudden you wake up one day and you think, oh, that's it."*
> (Group discussion, Stage 3)

Although most of the discussion was around post treatment programmes, there was also discussion of appropriate information provision regarding such programmes before/during treatment, as well as discussion regarding the benefits of prehab and the potential of providing this as an option for those who feel it suits their circumstances. This notion of prehab was put forward by an individual from Group 2 (Professionals/Volunteers):

> *"There's a big shift towards being the best you can be, in the best health you can be before you go through any treatment. So, to build up strength and fitness before you were going through anything is really beneficial afterwards; I've not had cancer so I can't say personally."*
> (Kathy, Instructor, Stage 2)

However, it was acknowledged this was "different for everyone" (Kathy, Instructor, Stage 2) and therefore, it was agreed after treatment was generally preferable but that "if you wanted to come before you could" (Rebecca, Project assistant, Stage 3).

A further concern regarding timing discussed was time of day, it was agreed during the day was the most preferred time for provision of a future intervention for the target population, older adults living with and beyond cancer were said to feel "better in the mornings" (001, interview). Individuals also noted that they:

> *"think evenings are out because I always find that by the time the evening comes and you've had your dinner you just want to sit and relax anyway."*
> (Shirley, 66yo, Stage 3)

5.13.6 Where is it?

Figure 27: Idea generation overview section-Where should the intervention take place?

It was clear preferred locations for future interventions were points of existing social interaction. This is effectively conveyed in the idea generation as 'A point of social contact-A place' (Figure 27). Such focus on a point of social contact is an important finding, as the importance of social interaction and contact was deemed as most important regarding any future intervention. Discussion centred on the potential of church halls, libraries, community centres, garden centres, allotments and leisure centres. These are all places where individuals can and usually do currently meet, especially among this age group, which connects back to the idea of social contact and potential for group activities. The potential of garden centres as a location for any future programme was brought to light as a means for us to go to the target population, rather than require them to come to us;

> *"Yeah, because like [Local garden centre]…Yes, definitely. So like that's a bit of a…not hotspot, but there's something that attracts people to those places."* (Calum, Volunteer, Stage 3)

Another location and/or activity suggested for a future intervention was the potential to maintain local plots and planters in the community, once again linking to the element of gardening but also social interaction. Regardless of location, the importance of a sense of community and enabling interaction was apparent throughout. Individuals also indicated that the programme would not have to take place in a pre-defined community centre or health care setting and were keen to consider other community-based locations that would meet the necessary requirements to facilitate such a programme. The ability to travel to the programme location with ease and/or ensure the programme is available locally to those who need it, as well as ensure necessary facilities are available was also emphasised here, reaffirming the barrier ranking results (Figure 23).

5.13.7 How do people find out about it?

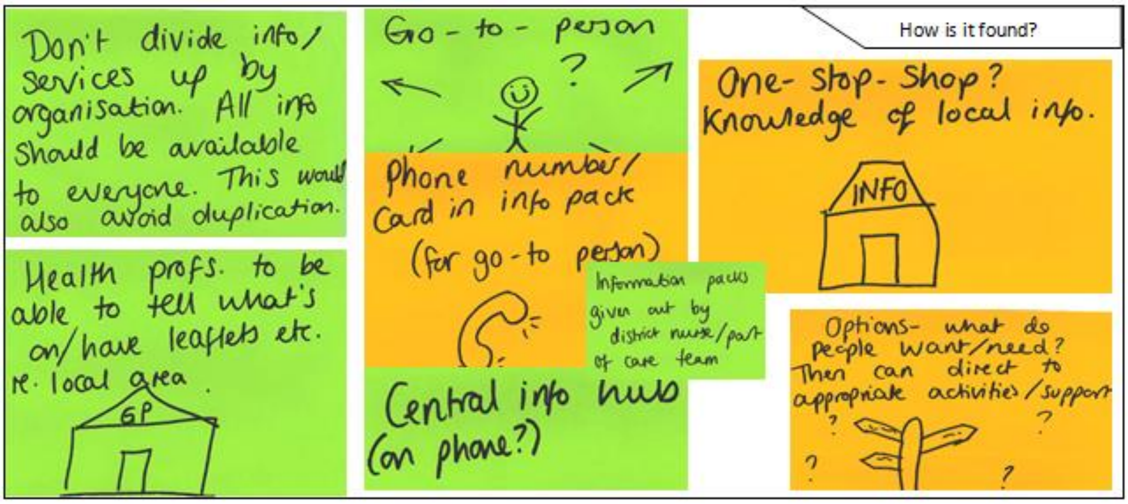


Figure 28: Idea generation overview section-How should people find out about the intervention?

Determining a suitable means for people to find out about an intervention was discussed at length throughout the process but primarily during the final co-design workshop (Figure 28). Before this point the "how" had predominantly been raised as a barrier to participation. It was therefore necessary to explore how to overcome this barrier. A lack of signposting/referral or information sharing was evident, as those who were interested in the programmes or the target group for intervention were not aware of many of the services and programmes available to them. More interestingly, the professionals involved were also unaware of many services and programmes outwith their own organisation. Ultimately a combination of ways of information sharing is likely the most successful, including a go to person, one stop shop, and referral, particularly where this involves considering which best suit the individual. These potential options for information sharing raised throughout the process are described below.

Go to person/one stop shop/referral

To alleviate the issue around how people find out about programmes and activities a one stop shop or go to person was recommended:

> *"Wouldn't it be great if there were people, volunteers maybe, that could go and visit and say, well, this is what we do, what do you think, is there anything here that you think might be interesting."* (Dave, 68. Stage 3)

Participants thought such a service could (or indeed should) be used to refer on to services and facilities appropriate and needed by those living with and beyond cancer, including interventions. Such a service would, therefore, ensure all individuals find out about all the services available to them, including specific interventions. However, there was some discussion and concern about the feasibility of a 'Go to person', particularly for those who may be more isolated. Therefore, requiring this "go to person" to go to them, rather than being part of a one stop shop and how this could be practically managed and facilitated, as evident in the discussion below:

> *"So based on what you were saying…we've got this Go-To person; would it be quite important for them to come to you first and then you know who they are and you can contact them?"*
> *"That would be a physical impossibility."*
> *"Yes, the numbers. That would be ideal but would that be…?"*
> *"I think it would be a huge amount of…that's thousands and thousands of people…And I think…would you not need to employ somebody to do that. You'd actually physically have to employ someone to do that; you couldn't expect somebody to do that voluntary"* (Group discussion, Stage 3)

Due to potential barriers associated with the idea of a "Go to person", a telephone service was also suggested to enable people to find out what is available in their local area: *"like I say* [having someone] *at the other end of the phone"* (Shirley, 66yo, Stage 3). There was also some interest in development and use of a tool, similar to a holistic needs assessment, whereby the potential participant or individual living with and beyond cancer ticked options on a list provided to them. This would then be used to signpost the individual to appropriate services, including interventions. Involvement of aa buddy in this process was also considered to be a key component of its potential success:

> *"I need company during the day and I'd maybe like to go shopping or I'd like to go to a walking club, and he might be able to tick a few boxes and maybe have*

> *even a few contact numbers, maybe a type of buddy thing as well to build up…they don't need a lot."* (Tim, 79yo, Stage 3)

Further results regarding the necessity of ensuring people can find out about the programme and how to facilitate this was derived from the discussion centred on the personas, particularly persona 2 (i.e., not motivated). Initial discussion emphasised that this person was very negative but lived in a city, where it was said *"they've got everything on their doorstep basically"* (Alfie, 71yo, Stage 3). However, it was later agreed a city could be a lonely place and in turn conversation moved to how to actively reach this individual and encourage them to participate as it was *"these kind of people that are reticent to do it, once they get there it opens up a whole new world for them"* (Kathy, Instructor, Stage 3). It was acknowledged that this person would not consider more passive advertisements, e.g., leaflets, and instead needed someone to actively approach them to encourage participation. Such consideration links to the idea of a 'Go to person' as mentioned above. However, this takes this to an extra level with the acknowledgement that some would not actively seek out a 'Go to person' and instead someone would have to work to engage with them;

> *"A person like this would probably just put a leaflet in the bin."* (Rebecca, Project assistant, Stage 3)
>
> *"I think it would need to be the specialist nurse or within your GP practice someone actually approaching them and saying, you know, now that your treatment's over…come on, there's things you can do and there's lots of things available."* (Shirley, 66yo, Stage 3)

This adds an additional layer to the discussion around getting the word out, as it emphasises not everyone would use the channels available to them and instead might need additional support with direct health care services possibly being the first point of contact for this and then referring to other services in a way akin to social prescribing.

5.13.8 How do we get people through the door?

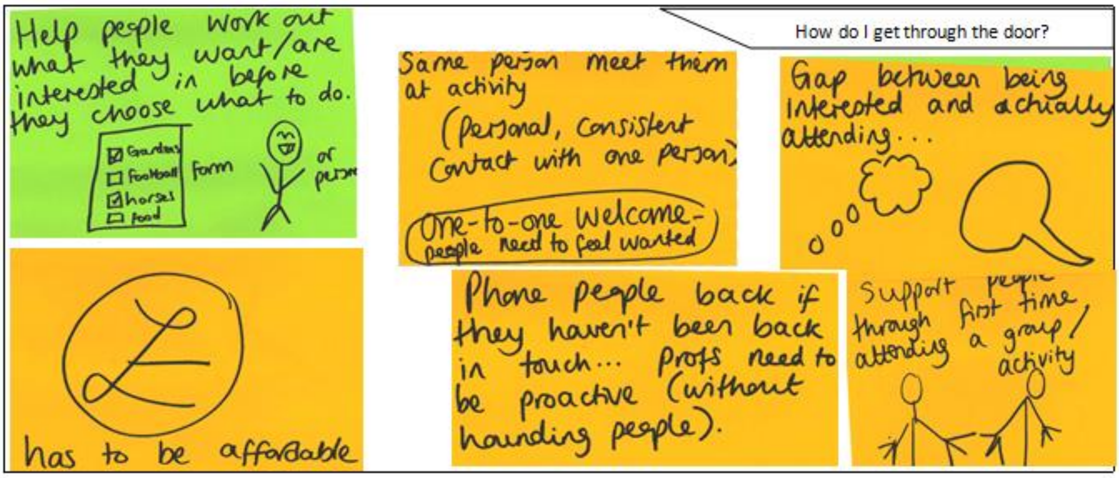


Figure 29: Idea generation overview section-How do we get people through the door?

Throughout the process it became clear that due to the barriers identified people may have the intention to attend a programme but when it actually comes to attending may find it difficult. Therefore, it was necessary to discuss this openly and consider how exactly people could be helped to access programmes and interventions (Figure 29). Participants emphasised in the workshop that: *"the biggest problem is getting people through the door"* (Rebecca, Project assistant, Stage 3). It was also acknowledged during discussion at this stage that for some it:

> *"is an issue, if you're fed up and you're feeling quite isolated and you're dealing with a medical condition and not feeling a hundred percent, you know. It does take quite a leap to say I think I'll just go along and see what this is like."* (Dave, 69yo, Stage 3)

This sentiment further highlights the need to focus on this aspect of accessibility. Participants generally considered their own experience when thinking about this issue. Examples of strategies that have worked in the past, included having a sole point of contact, a personal touch, particularly on the first day when it was recommended as good practice to meet people in person before or as they attended their first session of the programme or intervention. Some examples of how this is done in practice were described by participants:

> *"That's what basically I do; I meet them at X and take them along personally and the first time I'm with them all the time."* (Calum, Volunteer, Stage 3)

> *"I always phone them because I like to know…I like them to know there's a person. They're going to look for me when they come in, where I'll be and then I can show them things and then, you know… And I walk with them the first time too; I always do that."* (Kathy, Instructor, Stage3)

> *"What I tend to do is if I speak to someone on the phone and they're like, mm, then I'll send them the timetable, a little bit more information, descriptions and stuff and say have a wee look, if there's anything that takes your fancy let me know and get back in touch, blah, blah, blah, ask me any questions. So, I send them that as an email. And then if they've not got back in touch with me then I'll go, I never heard back I'm just wondering… I don't want to hound them too much…"* (Rebecca, Project assistant, Stage 3)

Although there was a focus on ways to help people 'get through the door' there was also the acknowledgement that over-encouragement of participation can be off-putting, as well as the fact that people often have competing and shifting priorities over time. This highlights the fine line between encouraging and motivation and too much pressure, which could, in turn, lead to non-participation and demotivation.

A further concept considered with regards to accessibility was cost. Cost had previously been identified as a high-ranking barrier in Stage 2-Focus groups and was again highlighted throughout the idea generation and prioritisation process. Participants suggested that the programme should be free or affordable. However, queries were raised around who might fund this, again linking to the practical concerns raised by professionals.

5.14 Chapter summary

Chapter 5 has described the methods of Part B-Codesigning. Each of the three stages were explored in turn, emphasising the iterative nature of the process and describing how each stage informed the next. Then the findings were discussed in respect to each of the objectives of the research, detailing recommendations, and potential elements of a future intervention. The next chapter will describe the methods and findings of Part C-Evaluating.

Chapter 6. Part C: Evaluating

6.1 Chapter overview

In Chapter 6 I explore Part C-Evaluating. This is an evaluation of the co-design process from the perspective of the participants and my own perspective, designed to understand the extent to which the process itself was acceptable. I first discuss the rationale and aims of this Part, drawing on the fact that process evaluation is often overlooked in this type of work but recommended in EBCD. I then discuss how this evaluation was implemented, detailing the surveys and reflections considered to draw conclusions. Next the results from these are described, detailing the 4 themes identified, 1. *Learning & doing*, 2. *Spaces & places*, 3. *Relationships & roles*, and finally the overarching theme of *'Putting the co into co-design'*. After exploring these themes and my own reflection regarding the process I then briefly discuss recruitment and retention, as relevant factors contributing to overall picture of the acceptability of the work.

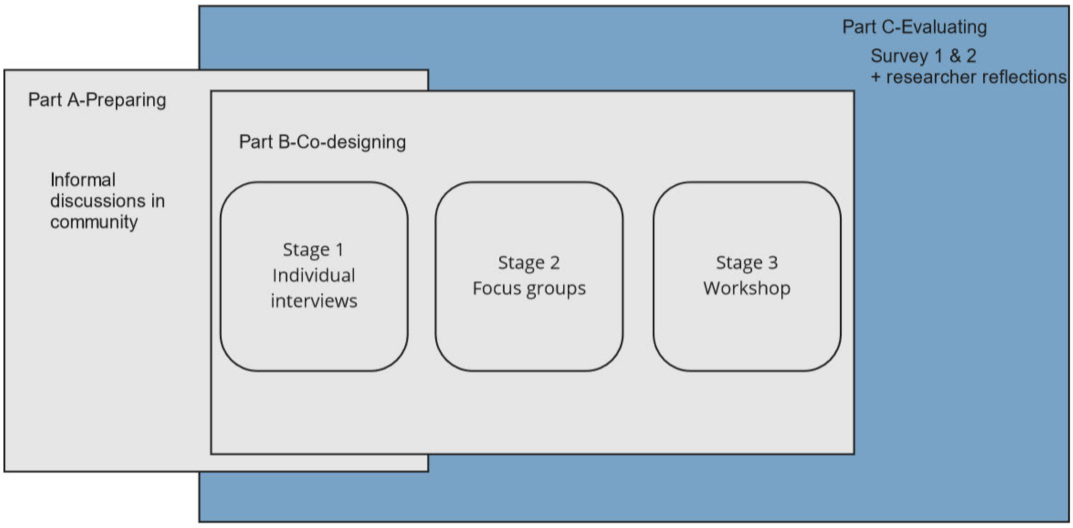


Figure 30: Research process highlighting Part C-Evaluating

6.2 Rationale and aims

A process evaluation was embedded throughout Part B of the research i.e., Co-designing Figure 30, namely Part C-Evaluating. It was critical to understand what worked throughout the process to inform future co-design and/or other collaborative research. This evaluation was conducted specifically to explore objective 4 of the research:

> Objective 4: To evaluate the experience of using co-design from the perspective of both the participants and researcher

This evaluation component was deemed necessary, as common issues with group work can be due to the power dynamics evident. Therefore, it was decided to give participants a safe space to speak out should they feel not able in the group, but this would also allow us to tackle any issues with power evident. The evaluation also captured a snapshot of the experience for participants to inform practice for future similar processes. In all the evaluation ascertained the inclusivity, acceptability and feasibility of participating in the process. Although co-design is currently implemented broadly it is rare for the process itself to be evaluated and even rarer for the position of the researcher to be considered (Bowen et al., 2013; Palmer et al., 2019; Slattery et al., 2020; Yadav et al., 2021). Instead, the focus is often on evaluation of the product/service/intervention developed. However, I wanted to acknowledge myself as a part of the process and explore the acceptability of this from both the perspective of the participants and myself. Evaluating the process is also recommended in EBCD (The Point of Care Foundation, 2022a) It is expected this will help others considering similar processes in the future, particularly those who may be new to co-design methods.

6.3 Design

An evaluation component was embedded within the co-design process. Evaluation is an important part of EBCD (The Point of Care Foundation, 2022a), however, in this instance we are discussing the evaluation of the process, as opposed to the evaluation of the outcomes. This evaluation was intended to assess participant's perspectives of the process, to ensure they felt involved, considered, and heard in the process but also to ensure they agreed with the decisions being made. Previous research has evaluated such processes using interviews (Bowen et al., 2013), however, it was agreed with the team that this not feasible for this project, due to the resources available and time constraints. Instead surveys and fieldwork notes/reflections were considered, both of which have also been used before in combination with other methods for such evaluation (Hyett et al., 2020). This Part of the work comprised of 2 surveys, drawing very loosely on the theoretical framework of acceptability, to ensure components of acceptability including, willingness, inclusion and attitude (Sekhon et al., 2017) were considered. Both surveys included questions expected to elicit quantitative and qualitative data, with an aim of reducing burden on the participants. Survey 1 was conducted during Stage 2-Focus groups and Survey 2-during Stage 3-workshops. In addition to the surveys my own reflections and field notes were considered, as well as recruitment and retention rates of the process.

6.4 Participants

All participants who attended the focus groups (Stage 2) and/or final co-design session (Stage 3) were asked to complete the evaluation surveys. 100% of those involved in these stages completed the surveys (n=11 Stage 2 & n=7 Stage 3). Details of participants involved in each of these stages can be found in Section 5.3.

6.5 Materials

The evaluation comprised of survey components, incorporating both Likert scale and open-ended questions to ensure both succinct measurable information and rich, detailed information were obtained. Two surveys were developed, one used throughout the process, and one used at the end of the process (Appendix 28 & 29).

6.5.1 Survey 1

Survey 1 used throughout the process, specifically at the end of the focus groups (Stage 2) and comprised of 5 statements, as below:

1. I am happy with the way the process is going
2. I agree with the priorities set out
3. My views and opinions are taken into account
4. I have the opportunity to voice my views and opinions
5. The group hasn’t taken my ideas on board

Questions were kept to a minimum to reduce the burden on participants. Each of the questions were expected to reflect the anticipated outcomes of the process, in terms of acceptability of the process itself. A negatively worded question was included to ensure participants understood negative comments were accepted, as I aware there was a possibility that the method could result in a positive bias due to the setting it was carried out in. This benefit was expected to outweigh the often cited issues of using negatively worded questions (i.e. confusion, fatigue and inconsistencies (Colosi, 2005), especially as only one was used.

Participants were asked to rate their agreement to each question on a one-to-five-point Likert scale, where one is strongly disagree, and is five is strongly agree. A box for additional comments regarding participants' responses to the statements was available.

6.5.2 Survey 2

Survey 2 used as a broad means of evaluation of the entire process was issued at the end of the workshop (Stage 3, i.e., the end of the process).

Again, this focussed on participants experiences within the process with a particular focus on the acceptability of the process, not just of taking part but also of practical elements that may influence taking part i.e., location. This survey consisted of 8 statements, as below:

1. I was comfortable throughout the process
2. I would be happy to participate in a similar process again
3. I felt like I was contributing to something worthwhile
4. I enjoyed the tasks and activities we completed
5. I found it difficult to engage with the process
6. I felt part of the group throughout the process
7. The timing of the sessions suited me
8. The location of the sessions suited me

As with Survey 1, participants were asked to rate their agreement to each statement using a five-point Likert scale, from 1 strongly disagree to 5 strongly agree. A further four questions were also included, these were open ended questions, intended to ascertain rich data regarding participants' perspectives of the process, specifically what worked well and what did not. These were as follows:

1. Please use the box below to tell me how you thought the process went
2. Please use the box below to mention anything you have gained or learned from the process
3. Please use the box below to let me know what you thought was good about the process
4. Please use the box below to tell me what you think could've/should've been done differently about the process

6.6 Procedure

Participants from both groups (Group 1-older adults living with and beyond cancer and Group 2-Professionals/Volunteers) who attended the focus groups (Stage 2) were asked to complete Survey 1, after the focus group had ended, to gain their perspective of the sessions and their perceived involvement and ability to contribute. All participants who attended agreed to complete the survey. Participants completed the survey by hand and were given the opportunity to ask questions regarding the content if necessary. Participants were asked to complete the survey individually to ensure a sense of confidentiality and enable participants to be truthful in their answers, as much as possible in the situation.

Participants who attended the workshop (Stage 3) were asked to complete Survey 2, to gain their perspective of the process as a whole and identify aspects they enjoyed and aspects they felt could be improved. Survey 2 also assessed the appropriateness of the timing and location of the sessions, determining the acceptability of the practicalities of the process more broadly. All participants who attended the workshop (Stage 3) agreed to complete Survey 2. As with Survey 1 participants completed the survey by hand and were given the opportunity to ask questions regarding the content if necessary but were asked to complete the survey individually to ensure a sense of confidentiality and enable participants to be truthful in their answers.

Throughout the process the researcher reflected on the data generated and the interaction with the participants. This reflection was also deemed important in ascertaining the acceptability of the process but from the perspective of the researcher, particularly as this was a partnership/collaboration. Therefore, fieldwork notes regarding the acceptability of the process from the researcher’s perspective were also consulted throughout the process, to ensure the workings of the process but also when evaluating the acceptability of the process. Consent for the co-design process as a whole also covered the evaluation phase of the study, as this was embedded within the wider co-design process.

6.7 Analysis

Quantitative data collected was collated and entered into Microsoft Office Excel v16 (Microsoft, 2019a). Descriptive statistics (i.e. ratios and frequencies) were calculated to ascertain the level of agreement with each statement.

Qualitative data was collated and typed up using Microsoft Office Word v16 (Microsoft, 2019b). Thematic analysis using Braun and Clarkes 6 stages of thematic analysis was conducted by hand (Braun & Clarke, 2006) Each of the 6 stages were followed as suggested, using an inductive and deductive approach, drawing on answers to the quantitative data and the necessity to evaluate the feasibility and acceptability of the process but also learning from the qualitative data. Initial codes were highlighted by hand and as the process of analysis progressed, these were gradually developed into themes. Each key theme conveyed a key aspect associated with acceptability and feasibility of participation in the process, ensuring the key aim of the evaluation was met.

Fieldwork notes were also consulted during this analysis to incorporate the perspective the researcher throughout. These fieldwork notes were generally used to facilitate the thematic analysis but also to complement and evidence the themes developed where appropriate. Reflection is an important tool in research and in particular when considering such processes, as it points the lens back at us as researchers and enables self-awareness (Dahlberg, 2002), which could and should lead to valuable insights. This reflection was weaved into the analysis and write up where possible.

6.8 Key insights from Part C-Evaluating

The results of the surveys to evaluate the co-design process from the perspective of the participants are now presented. Evaluation based on my personal reflections captured through fieldwork notes are also discussed in line with the results of the surveys, ensuring both the participants and researcher's voices are heard in the evaluation. First survey results are briefly explored before the 3 key themes and 1 overarching theme are considered in detail, drawing on all data sources available.

Results from the evaluation survey completed after Stage 2 (Focus groups), indicated participants from both Group 1 (Older adults living with and beyond cancer) and Group 2 (Professionals/Volunteers) found the process to be acceptable, meaningful, inclusive and agreed with the priorities. Similarly, to the evaluation carried out at the end of stage 2 (focus groups), the evaluation at the end of stage 3 (co-design workshop) was also positive and indicated the process as a whole was positive and acceptable to both those from Group 1 and Group 2. The results from the evaluation survey completed by those involved in Stage 3 (workshop), indicated the process as a whole was enjoyable. This was expanded further in the qualitative analysis below, throughout which the quantitative survey responses, from Survey 1 and Survey 2 are embedded to create a full picture of the themes identified and perspective of the process.

Qualitative data collected regarding participants perceptions of the process also indicated it had been successful and acceptable to those involved. Results of the evaluation after both Stage 2 (focus groups) and Stage 3 (co-design workshop), as well as the researcher's reflections on the process, identified three themes, being 1. Learning & doing, 2. Spaces & places and 3. Relationships & roles. Encompassing these three themes was a further overarching theme namely 'Putting the co into co-design' (Figure 31).

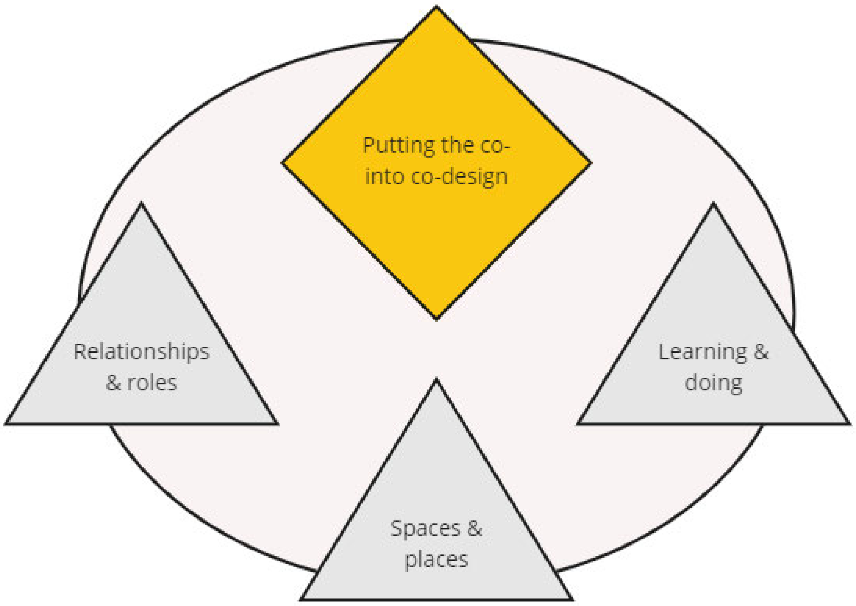


Figure 31: Overview of themes from Part C-Evaluating

6.8.1 Theme 1: Learning & doing

Participants indicated a sense of shared learning through the process, evident in both the evaluation from Stage 2 (focus groups) and Stage 3 (workshop). Participants relayed this sense of shared learning through the process in Stage 2 (focus groups), for example stating:

> *"This is a learning curve so all opinions are important."* (Dave, 68yo)
>
> *"A fair discussion. Covering lots of views."* (Harry, 69yo)
>
> *"Interesting discussion and quite similar views across programmes."* (Rebecca, Project assistant)

This sense of shared learning was further evidenced throughout the evaluation of the overall process, conducted at the end of Stage 3 (co-design workshop). In participant's answers to the four open ended questions of Survey 2, evidence of shared learning was apparent. Participants from both Group 1 and 2 consistently quoted learning and information sharing throughout these questions:

> *"Great information sharing."* (Rebecca, Project assistant)

> *"It was interesting listening to other people's viewpoint."* (Shirley, 66yo)

This sense of sharing views and opinions was reflected in the quantitative data collected too, with nine of eleven participants indicating they agreed/strongly agreed that their views and opinions had been taken into account, while all participants disagreed with the statement that their ideas hadn't been taken on board by the group (Survey 1). This emphasised a sense of being valued and able to contribute, encapsulated in this idea of doing and working together. Data from Survey 2 also emphasised this point with all participants stating they felt the process had been worthwhile.

Participants also indicated shared learning in the development *"Many good ideas came out during the process*" (Calum, Volunteer). Also, learning with regards to existing programmes, e.g., "*Info regarding Prostate Scotland and walking group"* (Rebecca, Project assistant) and *"I learned a lot about other programmes"* (Kathy, Instructor). A further point to consider within this theme is the acknowledgement that *"everyone is an individual and should not be compartmentalised"* (Calum, Volunteer). Such a point emphasises one of the key outcomes of the shared learning enabled throughout the process.

Moreover, this sense of shared learning was a key point in the evaluation and determination of the acceptability of the process from my perspective, regarding learning from both within the process and about the process. Having not used co-design before and having little experience in qualitative methods, conducting this process was a great learning experience. I learned to value the importance of building relationships with others to ensure the success of the research but also to value their input. I also gained a wealth of practical experience in conducting a variety of different activities and developed my understanding of the necessity to adapt to circumstances. For example, when first asking participants to input into the persona task, I could see they were apprehensive. I then reduced the burden of this by giving them the opportunity to opt out or quickly complete the form with little discussion. This worked well and only one participant opted out. Similarly, when I asked participants to rank priorities, I first used stickers as this was something I had done in training. However, it became evident quickly that some were struggling with the stickers due to dexterity issues and so I chose not to use them again. These are a couple of limited examples of both research focussed and practical focussed learnings from my perspective. In all, learning and doing was key throughout the process and a major driver within the process.

6.8.2 Theme 2: Spaces & places

A further theme evident from the qualitative data collected at both the end of Stage 2 (focus groups), Stage 3 (co-design workshop) and evident within the researcher's reflections was the role of Spaces and Places, in particular the need and success in creating a safe discussion place, as well as the influence of physical places on the process. This development of a safe discussion space was vital with regards to the success of the co-design process, as well as a key facet in ensuring the process was acceptable to all involved. All participants expressed they felt they had the opportunity to express their opinion and 6 of 7 felt it was easy to engage with the process (Survey 2). Participants commented on their ability to discuss difficult topics, reflect on their experience and air complaints that they may not have otherwise been able to raise, as is evidenced below:

> *"A very difficult discussion but the process will work through the discussion."* (Tim, 79yo,)

> *"Talking about my experience will hopefully help someone*." (Shirley, 66yo)

> *"The process went very well and although it was a very difficult subject, as we went through the stages it developed into a great subject."* (Tim, 79yo)

> *"Made me think about the provision of physical activity and diet for people with cancer and to reflect on how lucky I have been and also how much the prostate cancer support group helped me"* (James, 67yo)

The ability to do so reflects the safe discussion space developed throughout the process, as participants clearly felt comfortable and relaxed in the environment and discussed topics which they felt were *"difficult"* (Alfie, 79yo). This sense of a "difficult subject" is interesting in itself and refers to the discussions focussing on the cancer experience. Although, the actual cancer experience was not a focus of this research, it was important to acknowledge this and allow people to explore this where necessary. This room for a safe space for discussion also helped build rapport with and between the group, as well as enabled the progression and maintained engagement with the process. However, as is evident the participant indicated this eased throughout the process and evolved into something "great". This evolution is perhaps due to the narrowing focus throughout the process, moving from initially discussing the cancer experience more broadly to discussing key aspects and the development/requirements of a future intervention. Thus, the process was acceptable, and it is evident participants perceived an effective progression throughout the process, in a safe and comfortable environment, emphasising the importance of Spaces & Places.

The ability for individuals to feel comfortable in airing *"complaints about after cancer"* (Shirley, 66yo) also denotes the development of a safe discussion space. However, this idea of raising complaints also links to a broader influence on the process and likely attributed to the acceptability of the process, in that all participants came to the table with their own agenda and were at some point or other given the opportunity to discuss this, be it complaints or otherwise. This open floor in a safe discussion space certainly contributed to the acceptability and engagement within the process.

Moreover, steps were taken from the perspective of the researcher to ensure the discussion space developed was safe for all involved and provided a platform for a variety of discussions. To do so tools such as ice breakers were used to allow participants to get to know one another and/or why they were involved in the study. Also, participants came to the larger co-design workshop (Stage 3) already knowing individuals from Stage 2. Thus, rather than it being a case of a large group of individuals coming together it was three small groups of individuals, ensuring those involved were comfortable and had common experiences with others. Those recruited to Group 1 (Older adults living with and beyond cancer) in particular and in some cases

Group 2 (Professionals/Volunteers) represented a homogenous group, in that participants had attended or delivered similar or the same programmes. Those from Group 2 represented in some instances the same organisations and/or services and therefore, had similar views, opinions and training. This sense of homogeneity attributed to the acceptability of the process, in that it was evident such homogeneity and familiarity contributed to the development of a safe discussion space and in turn the acceptability of the process.

Further contributing to the development of a safe discussion space is the effort to develop a comfortable environment in a location suited to all involved. The researcher sought out and ensured where possible the spaces used for all 3 stages of the process were suited to the needs and tasks of that stage, as well as to those who were participating. Participants indicated in Survey 2 they were comfortable throughout the process, with all strongly agreeing with this statement. However, the researcher reflected this may not portray the issues evident with some of the spaces used. For example, one interview (Dave, 68yo) was conducted in a local library, and although the space was comfortable and a suitable environment to have confidential discussions, there was a great deal of background noise from traffic outside that interfered heavily with the recording. However, this is a practical issue, and it is evident that although background noise interfered with the recording the space itself was welcoming and suitable for the interview, and most importantly was a space the participant felt comfortable in.

Similarly, I sought out a comfortable place for the focus groups, identifying a space in a local café. This café was also selected to remove any likely influence or association with organisation and was an attempt to level any power imbalance associated with for example, asking participants to meet at the university, where I might feel comfortable, but they might not. However, due to the time of year the initial place was very cold, thus, the next group was held in a different room at the same location. Yet, in this instance participants commented on the difficulty in finding the venue. Therefore, the decision was made to move the final focus group (Stage 2) and workshop (Stage 3) to a place within the university. Participants were happy with this move and comfortable in the new place at the university, likely because by this point, they were comfortable with each other, as they had previously met. Thus, the place itself certainly contributed to the acceptability of the process and the researcher ensured all spaces used throughout were conducive to the development of safe discussion safe, which was successful as is evidenced above. This thought and consideration was reflected in the overall evaluation with all participants indicating they were happy with the location and timing of the sessions.

As previously mentioned, social aspects were embedded within the process, for example allowing the participant to veer off topic during the interview, a coffee and a chat before the focus groups and lunch and chat after the focus groups (Stage 2), with a similar set up for Stage 3 (Workshop). From my perspective these social events were key in ensuring engagement throughout the process and ensuring the acceptability of the process itself. Participants pointed out the "social atmosphere", the enjoyment in talking to others and relaxed environment, all of which contribute to the social space and the acceptability of the process. This sense of social space was evident as a requirement of any developed programme throughout the co-design process. It is therefore interesting that the social space within the co-design process was a key feature attributing to the acceptability of the process.

6.8.3 Theme 3: Relationships & roles

Participants were generally complimentary with regards to the facilitation of the process, indicating the process had been facilitated in an acceptable manner, consequently contributing to the acceptability of the process, e.g.

> "Lynsey has been unfailingly well organised, friendly and efficient"
> (Arthur, 79yo)
>
> "Lynsey keeps the focus where it should be which is difficult as we tend to go off on tangents personal to each participant." (James, 68yo)

However, the impact of power dynamics may have influenced the perceptions of individual's roles within the process and ultimately impacted the balance of the "co", yet all participants indicated they felt part of the group (Survey 2). Throughout the process I was aware of the potential influence of power dynamics and made attempts to reduce this influence. For example, interviews were conducted in a location convenient to the participants and focus groups were conducted in a local café (Group 1) or the university (Group 2). The university was not recommended as the first site for interaction with the focus groups due to the possible connotation of this (i.e., viewed as an "ivory tower"), which may have negatively impacted the relationship between the researcher and participants. However, issues were identified with the café venue. Although the location was deemed suitable the venue itself was not, therefore, the decision was made to move the workshop (Stage 3) to the university. As this decision was for the most part made in collaboration with the participants, it is unlikely the move to a location associated with power for some influenced the power dynamics of the group, particularly as this was in the latter stages of the process. During Stage 3 of the process where both groups were brought together, measures were also taken to limit the influence or perceived influence of power dynamics. For example, the ice breaker focussed on an interesting fact about each of the participants rather than their role within in the study or more broadly, to ensure participants did not feel excluded or unqualified (Forsmars Group, 2017). However, participants naturally told their stories in relation to cancer, as this was the key connecting facet for participants with each other and with the study. As this happened naturally it is important to consider once again the safe space that was developed but also the assertion of participants' stories within the process that they directed themselves at times, i.e., without prompting, emphasising a sense of comfort and equality within the process.

Throughout the process and on reflection of the evaluation comments I became aware of the influence of the power dynamic between the researcher and the participants, rather than between the two groups of participants. Although I endeavoured to reduce the influence of the researcher participant power dynamic it was still in instances evident. For example, Harry (69y/o) referred to the researcher as "the boss" during the focus group stage and is evident the researcher has been referred to as the "tutor" (Alfie, 71y/o) during the evaluation. These phrases emphasise the sense that the researcher was in control of the process throughout. Also, indicating a potential flaw in the process itself, if it was seen as less than collaborative from the perspective of the participants. However, this may also be reflected in the notion that participants were there to help me, as when asked why they were taking part this was often the response, either to help the researcher or help others in a similar situation to themselves, often exhibiting a sense of altruism (fieldwork notes). Therefore, the sense of the researcher controlling the process makes sense as there was a pre-conception of contributing to something bigger but also an acknowledgment that they were helping me with my studies.

Moreover, as I facilitated the process and the activities, this sense of a “tutor” is fitting and perhaps does not relay anything untoward, especially as comments were generally positive about the facilitation and without the facilitation the process would not have progressed. Therefore, it is evident a facilitator of sorts is required particularly when goals have already been established before the outset of the process. However, that is not to say this is the best or only means of facilitating such a process but merely that in this instance the facilitation implemented was acceptable. Other means of facilitation will be discussed later in the thesis in light of future recommendations.

Although I was aware of this power dynamic and potential imbalance, I was also aware of the positive impact of the process and relationships developed, mirroring the results and feedback of the participants. The build-up of the process really enabled the development of relationships between me and the participants, and eventually among the participants themselves. I felt participants had to initially trust me to some extent to allow me into their home or meet me in a public space. I spent a great deal of time in these first meetings and beforehand working to create that trust and rapport. It could be simple things, for example one of the participants was from the same local area as me, we discussed walks in the area and usual barriers-I knew all too well how bad the busses could be. This really helped put both me and the participant at ease. I am aware this won’t be possible for all interviews but finding that common ground early on was useful and seemed to encourage participants to open up. In addition, I took the time to listen to participants story and experience of cancer, the highs and lows and gave room for discussion they felt were important. I was aware, as were they, that there was a focus on the behaviours but it felt necessary to start from the beginning and understand their perspective. Some might say this was unethical as the data was not carried forward to a great extent, however, I would suggest it really was necessary to enable the process and most importantly build the relationships necessary to ensure engagement and success.

In addition to this I was also aware of the relationships built between participants. I worked to enable this as much as possible. For example, I set out seating plans, perhaps a little paternalistic but I felt it necessary as I was aware some people knew each other from other groups and organisations. This knowledge was only possible due to my decision to embed myself to an extent within the wider cancer community in the area and actively participate in groups and organisations instead of following the recommendations of EBCD and conducting non-participant observation. This work to build relationships between groups and individuals throughout the process was very useful. It created a wealth of discussion, ensured there were no cliques, with everyone's voice being equal as reflected in the participant evaluation but most importantly it seemed to enable the development of lasting relationships, with individuals sharing telephone numbers with each other and discussing groups/events at the celebration event. This was so great for me to see as a researcher and the facilitator of the process. It felt like there had been a direct benefit for those involved, particularly as social interaction was one of the key needs identified.

In all I could feel that people trusted me but also trusted the process and others involved, often requesting and offering support to one another. This was also reflected in the evaluation surveys, in that individuals felt heard throughout the process and had their views taken on board. A group without such positive relationships or that had not taken the time to develop these relationships may not have been so successful. This highlights the importance of relationships within such processes. It is worthy to note that following the EBCD process moving from individual to group settings has likely attributed to this and can be identified as a key strength of the process.

6.8.4 Overarching theme: Putting the co into co-design

In all participants were happy with the process, willing to participate in a similar process in the future and had enjoyed the process, all of which is likely due to the collaborative nature of the process, emphasising the key overarching theme 'Putting the co into co-design’. This overarching theme is evident in each of the sub themes already described.

Putting the “co into co-design” is evident within this sub theme of developing a safe discussion space. As is evident work and steps were taken to ensure the development of this safe discussion space. The majority of which was conducted in a collaborative and inclusive manner, for example participants were given the opportunity to dictate where their interview would be conducted and had the opportunity to discuss the spaces for the focus groups/co-design workshops. The comfort and openness of the participants is reflected in the development of a collaborative and inclusive approach between all involved including the researcher and co-facilitators (in the instance of stages 2 and 3). Such collaboration and inclusiveness exemplifies the “co” in co-design and determines co-design as acceptable to both the participants and researcher, due to the main facets of co-design itself and the ability to work together. This space ensured participants could enjoy and feel comfortable in discussing a variety of topics with those involved but also created a sense of cohesion and friendliness within the group, particularly during the embedded social events (i.e., lunch, coffees and the celebration event). Evidence of this social space was available as follows:

Also, embedded within the overarching theme of ‘Putting the co into co-design’ is the subtheme of *Shared learning and doing*. It is clear from both the perspective of the participants and the researcher that this shared learning was possible due to the inclusiveness of the group but also the collaboration enabled and facilitated within the group, i.e., ‘Putting the co into co-design’. Thus, key aspects ensuring the acceptability of the process was not only the enablement of shared learning but also the way this shared learning was enabled within a co-design process, i.e., within an inclusive and collaborative setting.

This sense of a social space also contributes to the overarching theme of ‘Putting the co into co-design’ in that it is evident not only collaboration has occurred but more that those involved developed and built on relationships throughout the process, with each other and with the researcher. Thus, the ‘Co’ of co-design was evident and influential with regards to the acceptability of the process, incorporating relationships and roles. For the most part the researcher would describe those involved as collective “we” rather than a group of individuals, a term certainly attributing to the acceptability of the process but also attributing to the development of a co-design process embedded within the philosophy of co-design rather than being tokenistic in nature. It is unclear when this decision was made, however, it fed into the sense of togetherness created in the group. For that year we were a “we” and worked together to learn and create, exemplified by the relationships and roles developed and embraced.

Relationships were key to the process and defined, in a way, the ‘Co’ of co-design. Since reflecting in the viva exam, I have become aware that my perspective of co-design centres on relationships, without these and trust I believe the process would be unsuccessful. As a researcher I placed myself in a community in which I did not belong. Therefore, I had to work to build relationships and trust with those who could enable access and then those who were interested in the process. Throughout, I was aware individuals were taking part to help others in a similar position to them, and at times I found this a burden, as I was not sure the outcome could ever live up to their expectations. However, now in hindsight I am aware the process was useful to those involved and has led to key recommendations for future services and provision. Relationships and trust, with an understanding of the necessity to adapt enabled a process where we successfully put the co- into co-design.

Yet, from my perspective several key issues in running the process were encountered, all of which influenced this sense of 'Putting the co into co-design’. For example, the necessity to run, facilitate and progress the process on my own. Running the process as a sole researcher was difficult and the decision was made to involve secondary facilitators/note takers throughout Stages 2 and 3, to enable the tasks and address any missed discussion points. The use of secondary facilitators ensured the process was acceptable from the researcher’s perspective with regards to the running of the groups and implementation of the tasks throughout them. Working as part of team like this can also be reflected in the theme *‘Putting the co into co-design’,* emphasising it takes more than just those actively involved in the process to make it work. Running the process and determining which aspects to carry forward to the next stage of the process as a sole researcher was also difficult and certainly impacted the acceptability of the process from my perspective. This burden was alleviated via discussions with my supervisors.

An example of the input from discussions with supervisors regarding tasks and information to be carried forward can be evidenced through the prioritisation of key concepts tasks and the manner in which this was ultimately used. Initially I had planned to discuss each of the key concepts included in the maps for prioritisation (Section 5.6.2.3). However, on looking at the maps my supervisors suggested simply showing participants the maps with no explanation to allow them to make their own assumptions about the concepts included and ensure I didn't influence their priorities. Ultimately this worked well and led to some interesting conversations around some of the concepts. Another instance wherein my discussions with supervisors influenced the process and tasks developed was around the development of personas. Initially I had anticipated developing personas similar to those used in marketing research, including a detailed description of the individual, name, gender, age etc. However, on reflection it became clear gender was a key point often raised by certain participants and a point which I felt might dominate the persona discussion should the personas be named etc. After discussion with my supervisors, we agreed to get the most from this task it would be best to have only the points relating to the intervention as described in the persona. Consequently, meaning the personas were gender neutral.

As an inexperienced researcher, it was often difficult to make decisions and this at times influenced the perceived acceptability of the process, as well as the acceptability of conducting such a process as part of a PhD. This inexperience was also beneficial in some ways, the need to learn how to navigate the process and identify and implement the activities possibly attributed to some of the success, i.e., the prolonged engagement and relationships developed, and as such are reflected in the overarching theme 'Putting the co into co-design'. It may also have attributed negatively to the outcomes of the process. Had I been more experienced I may have been more forthright in what I needed from the process.   However, in many ways this feels like it is the opposite of the point of the process. I managed to engage the population, get and keep them involved in the process and understand their needs beyond the behaviours. In some ways I feel it is a limitation I never actually got to an intervention but in others I have learned so much about the methods and can use these skills in the future, taking a step back to really understand the issues we need to explore before beginning to consider solutions. Thus, the insights and learning gained from the progression of the process, as well as working with the second facilitators and supervisors ensured the process was acceptable and feasible from the perspective of the researcher, even though it was incredibly difficult to maintain and progress.

6.9 Recruitment and retention

To further explore the acceptability of the process, recruitment and retention figures were consulted. Owing to the use of process consent and the restraints and changing circumstances of participants, participant numbers at each stage varied. All of those recruited to both groups took part in Stage 1, while 73% (n=8) of Group 1 and 34% (n=3) of Group 2 took part in Stage 2 respectively and finally 36% (n=4) of Group 1 and 33% (n=3) of Group 2 participated in Stage 3 (Figure 32). The predominant reason for non-participation in Group 1 at Stage 2 was a lack of time (n=2), while one participant was not contactable after the interview. At Stage 3 the predominant reason for non-participation in Group 1 was deteriorating health and/or hospital stays (n=5), while one could not make the time and dates set out. For Group 2 the majority cited a lack of time as the reason for non-participation, at both Stages 2 and 3. However, two participants in this group did not respond to further correspondence after the interview. These figures are broadly in line with those expected in EBCD studies, where previous research has cited an expected drop rate of 50% at each data generation point, i.e. the three stages in this instance (Donetto et al., 2014).

Along with the retention data it is important to consider recruitment. The main means of successful recruitment for Group 1 was gate keeper assisted methods, while for Group 2 it was generally snowballing/word of mouth (Table 24 and Table 25). Both these methods rely on trust in sources for recruitment, emphasising the importance of trust from the outset and throughout the process, a phenomenon that can again be seen in the overarching theme of ‘Putting the co into co-design’.

When setting out to do this work I had expected that it would be most difficult to recruit to Group 1 (Older adults living with and beyond cancer), however, the links I made with the community really helped with this and this aspect of recruitment was much easier than anticipated. The same cannot be said for Group 2 (Professionals/Volunteers). Recruiting to this group was fairly difficult as many were happy to distribute information and share with service users/colleagues but did not have the time to commit to the process. To facilitate recruitment, it was important to stress that it was not necessary to take part in each stage, although these were set out in the initial interview. However, as is expected this also had its drawbacks in that few actually participated in every stage. This is a reflection of the adaptive and pragmatic nature of the process, having both pros and cons. Yet, for the most part the pros certainly outweighed the cons and contributed significantly to the success of the work.

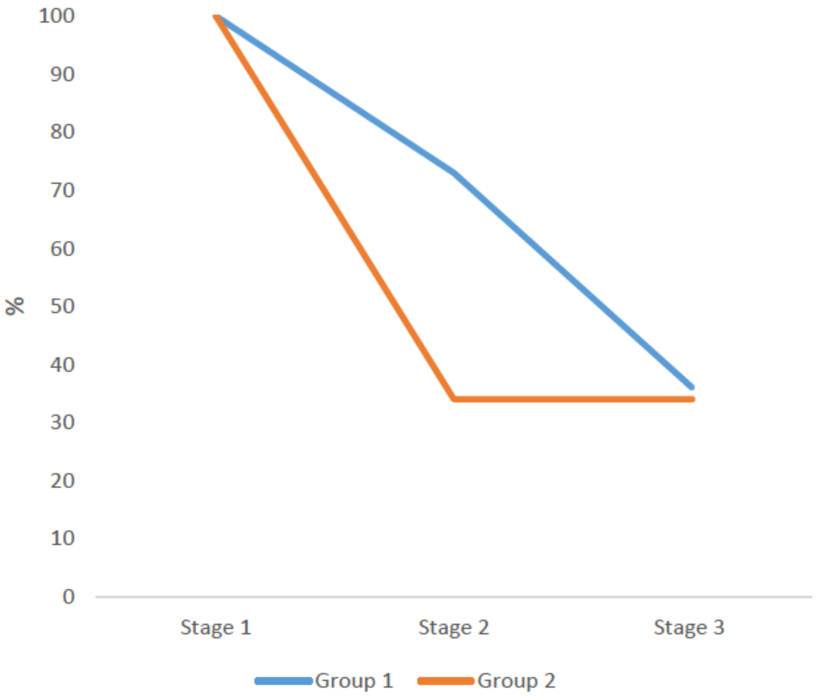


Figure 32: Participant % at each stage by group

Table 24: Methods and services for recruitment, Group 1

Participant no	Service Recruited via	Recruitment method
001	Chronic illness physical activity programme	Gate keeper distributed info
002	Chronic illness physical activity programme	Gate keeper distributed info
003	Chronic illness physical activity programme	Gate keeper distributed info
004	Cancer specific walking group	Gate keeper direct discussion
005	Cancer specific walking group	Gate keeper direct discussion
006	Cancer support group	Gate keeper distributed info
007	Cancer support group	Gate keeper distributed info
008	Cancer support group	Gate keeper distributed info
009	Cancer support group	Gate keeper distributed info
010	Cancer specific 3rd sector organisation	Word of mouth
011	Cancer support group	Presentation at group

Table 25: Methods and services for recruitment, Group 2

Participant no	Service Recruited via	Recruitment method
101	Cancer specific organisation	Snowballing
102	Cancer specific organisation	Snowballing
103	General support organisation	Snowballing
104	Food and diet organisation	Direct contact
105	Cancer specific organisation	Direct contact
106	Cancer & physical activity programme	Snowballing
107	Cancer & physical activity programme	Snowballing
108	Cancer & physical activity programme	Gate keeper
109	Cancer & physical activity programme	Gate keeper

6.10 Chapter summary

Chapter 6 has explored Part C-Evaluating. Throughout this chapter I have discussed the evaluation components embedded within the broader co-design process. I used these to determine key themes which represented and described the acceptability from the perspective of both the participants and included some of my own reflections to create an understanding from my perspective too. This chapter has provided evidence for each of the themes identified, and briefly discussed recruitment and retention rates in support of the conclusion that the process was acceptable to those involved. After the process had ended, I revisited it and the data collected to determine any key insights with regards to the overall aim of the work. I will now explore this analysis and the findings from it in the following chapter.

Chapter 7. Reflection and recommendations

7.1 Chapter overview

Chapter 7 explores my reflections and additional analysis looking back through the process after it was completed, to generate any further insights and bring all the findings together to determine key recommendations for future intervention design. This analysis has identified three key themes to consider when developing future interventions based on the information derived from Part A-Preparing and Part B-Co-designing. These themes are ***Considering the individual***, ***Enabling access***, and ***Social is key***. As well as this, recommendations regarding theoretical underpinnings are explored based on my reflections and additional analysis of the co-design process. Each of these themes will be considered in turn in this chapter. And finally, a unique outcome of the work is explored in that it seemed evident that the process was in many ways emulating the desired intervention.

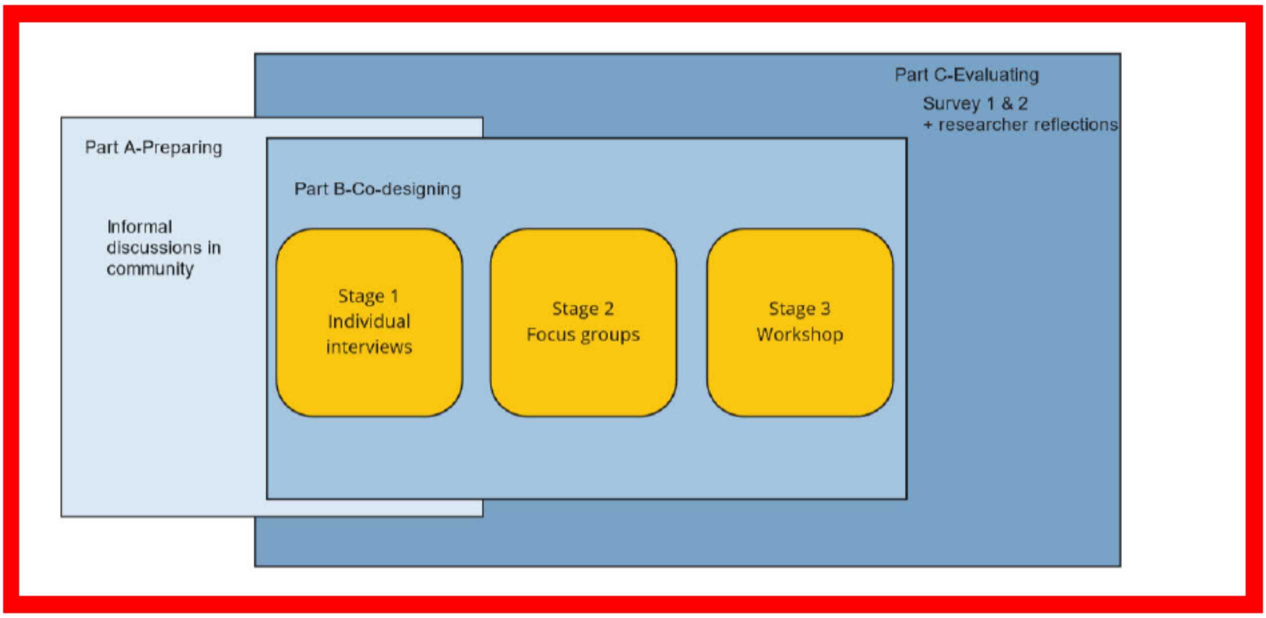


Figure 33: Research Process, highlighting focus on full process

7.2 Rationale & aims

From the outset of the project I was aware the analysis was going to have to be conducted quickly to enable progression through the process at a suitable rate. However, I also felt it would be necessary to reflect and re-consider the data as a whole after the process was complete to ensure the overarching aim of the work was effectively considered Figure 33. Therefore, I chose to use Braun & Clarke's (2006) thematic analysis as this facilitates a reflexive approach and enabled the incorporation of my experience. Moreover, the stepwise approach of this, allowed for quick coding in the initial analysis and then a revisit of this to condense and build themes after completion of the process, effectively building layers of analysis.

7.3 Analysis

Although the overarching aim has already been considered in previous chapters, it was decided the evidence and data should be reconsidered at the end of the process to develop specific recommendations for moving forward. This was deemed to be particularly useful as instead of one set intervention a number of ideas and concepts for future interventions were developed within the process. Therefore, it was necessary to consider what connects these ideas and concepts. Moreover, it had always been the intention to revisit the data and complete the remaining steps of the thematic analysis process as described by Braun & Clarke (2006). At this point the focus of the analysis was primarily on steps 3-6, however, further familiarisation with all data was carried out before proceeding with these steps to condense down codes.

1. Familiarising yourself with your data.
2. Generating initial codes.
3. Searching for themes.
4. Reviewing themes.
5. Defining and naming themes.
6. Producing the report.

This analysis involved a detailed process using NVivo 12 (QSR International Pty Ltd, 2020), wherein the data from each stage of Part B-Co-designing was re-analysed. The original analysis was explored in detail to identify key elements that frequently presented. NVivo was used to facilitate this, as the data and previous analysis conducted was lengthy, and NVivo provided a suitable platform to organise and consider this. From writing the thesis and being an active part in the process I was also aware key considerations were already prevalent in my thinking. I accepted this and worked with it, to ensure I continued as an active part of the process, which was facilitated by the analysis technique selected, as this actively encourages and incorporates the perspective of the researcher (Clarke & Braun, 2016; Delve. Ho &

Limpaecher, 2022). All data from all Stages and Parts of the process were considered and codes identified as overlapping were collapsed into one node, creating overarching themes prevalent throughout the process. These themes were then condensed further and named in line with Braun & Clarke's (2006) process. These themes were reflective of key intervention recommendations for consideration in future work.

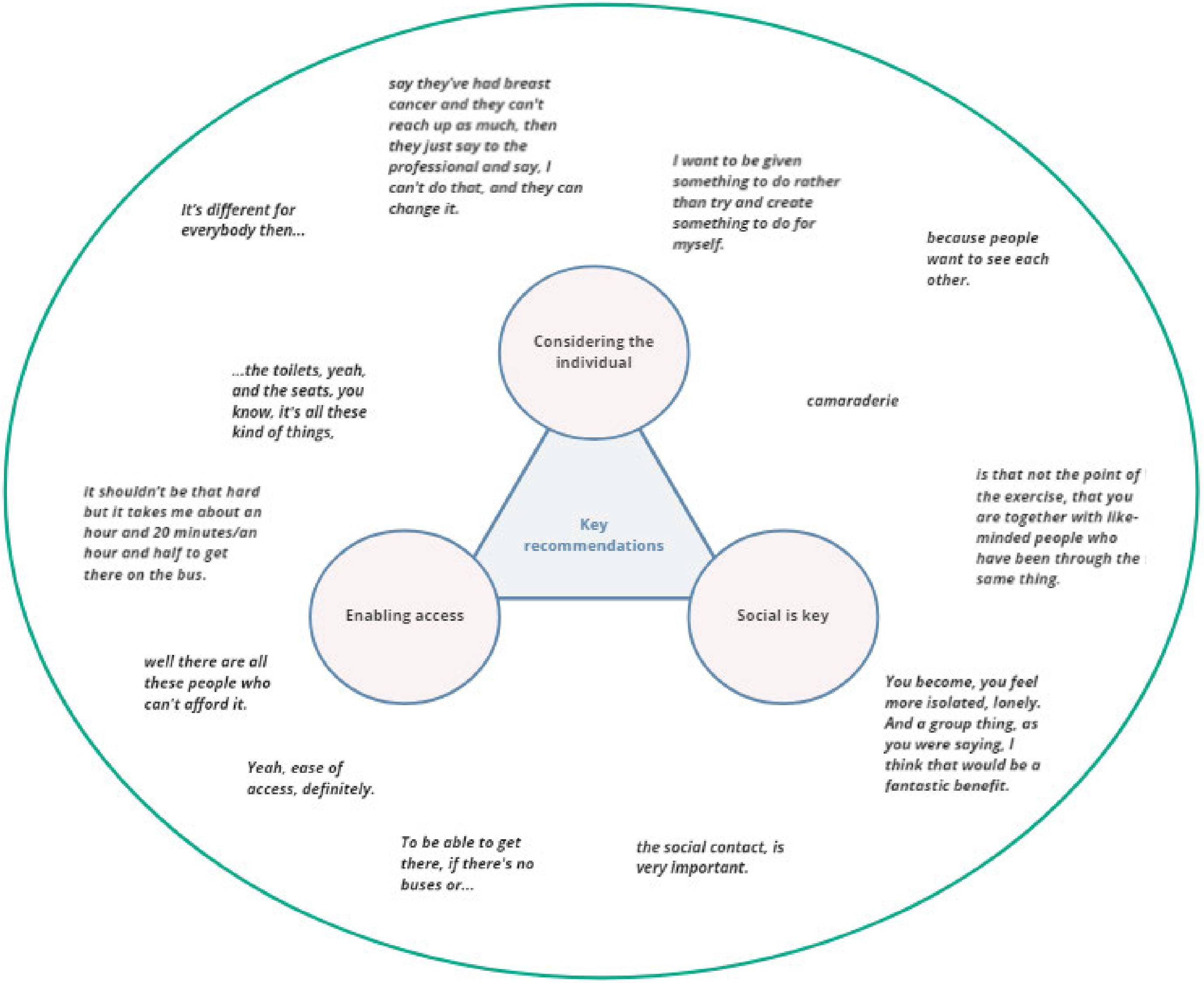
Objective 3 was also considered at this point, as it had been previously decided the theoretical concepts were not suited for explicit consideration within the process, due to previous issues with abstract concepts. For example, participants struggled with the development of the personas, as they found it difficult to think of a hypothetical individual. However, it had be an intention and objective of the research to consider these and therefore, space for reflection was built in after the completion of the process to draw any conclusions or recommendations to be considered regarding theoretical underpinnings of interventions moving forwards. Also, it is important to note the practical considerations of embedding such detailed analysis within the process.

Reflection box 11-The cancer journey or the intervention

At this point it was again important for me to ensure the data focus was on the intervention development and the behaviours, as opposed to the cancer journey more generally. I am aware EBCD focusses on the experience, however, it was important to consider what experience I meant when considering the aims of the research. Giving participants a platform to discuss their cancer experience more generally was important and certainly facilitated the building of trust and rapport evident, yet I also had to ensure the process was moving toward the predefined goal. I discuss my reflections on this and how the process may be facilitated differently for future projects in the Discussion chapter. It is however, important to understand at this stage why the data and analysis focusses on the intervention only.

7.4 Intervention recommendations

From the initial data analysis and additional layer conducted after completion of the process, three key recommendations for future intervention design could be made, these being: (1) Consider the individual; (2) Social is key, and (3) Enable access (Figure 34). Support for each of these key recommendations can be found in each phase of the research. Although not common in thematic analysis, for an idea of how prevalent these themes were throughout the process the overall coding identified each of these referenced in the data as follows: Consider the individual referenced in all interactions with participants and 88 key points referring to this theme identified, Social is key was also mentioned in every interaction, with 118 references and finally Enable access was mentioned in 22 of 24 interactions, 79 times. One interaction is one point of data generation within the process, for example one interview may be classed as one interaction, while one focus group would also be classed as one interaction. These have solely been set out like this to emphasise the prevalence of these themes within the data and throughout the process.



say they've had breast cancer and they can't reach up as much, then they just say to the professional and say, I can't do that, and they can change it.

It's different for everybody then...

I want to be given something to do rather than try and create something to do for myself.

because people want to see each other.

...the toilets, yeah, and the seats, you know, it's all these kind of things,

camaraderie

It shouldn't be that hard but it takes me about an hour and 20 minutes/an hour and half to get there on the bus.

is that not the point of the exercise, that you are together with like-minded people who have been through the same thing.

well there are all these people who can't afford it.

You become, you feel more isolated, lonely. And a group thing, as you were saying, I think that would be a fantastic benefit.

Yeah, ease of access, definitely.

To be able to get there, if there's no buses or...

the social contact, is very important.

Figure 34: Illustration of themes and associated evidence

7.4.1 Considering the individual

A key theme throughout the process and confirmed in the reflexive analysis was considering the individual. At each point in the process, it was clear all aspects were required to be tailored to some degree or to at least acknowledge that everyone is different within the realms of what is practical to provide:

> *"I think it's up to the individual how they're feeling to start with and how much help they would get out of things like this."* (Calum, Volunteer, Stage 3)

This sense of everyone being different was also acknowledged within the realms of cancer and treatment with participants stating: "I think at the end of the day, cancer is a personal thing and how you cope with it is a personal…It is an individual thing" (Arthur, 79yo, Stage 2) and so acknowledging that after care should also be individual as well, especially as it "depends what other health problems you have as well" (Shirley, 66yo, Stage 2) (where after care in this instance would be an intervention).

This individualised impact of cancer was evidenced in light of activities provided too, with a need to be able to tailor activities to individuals' abilities. This tailoring could be as minor as:

> *"if they can't do something for whatever reason, say they've had breast cancer and they can't reach up as much, then they just say to the professional and say, I can't do that, and they can change it."* (Rebecca, Project assistant, Stage 2)

Yet, although minor it was acknowledged this can make a big difference, creating a sense of inclusion and a comfortable environment to express needs. On reflection it is possible this also links to the often-mentioned necessity of a certain type of person leading the programme, someone empathetic and understanding or just having "that way" (Alfie, 71yo, Stage 2).

In addition to these points there was clear focus on the negative impact preaching and lecturing can have. Although ranked further down the barrier ranking tool, the impact of preaching and lecturing kept being raised, indicating it may have more of an impact than the ranking tool would suggest. This again supports the need to consider the individual and ensure communication regarding the behaviours in particular are suited to the person. If this is not successful it is likely based on these results that attrition will be high and attendance poor, leading to an unsuccessful intervention, regardless of whether other aspects are incorporated e.g., social interaction. Thus, it is clear on many considering the induvial is important and wide reaching across the other elements discussed and identified in this process, i.e., focus, format, timing, activities, barriers etc.

7.4.2 Social is key

From the outset (Part A-Preparing), and even before that in conducting the systematic review, it was suggested a social element would likely be required in any future intervention, with this being a key feature of previous programmes that were said to work (Section TT). The social aspect seemed key throughout the process, being mentioned at every stage with regards to past programmes, future programmes, peer support and cancer specific support. This need for a social aspect was also reflected in the activities suggested and desired format of the intervention (i.e., face-to-face group activity). In all it was highlighted that:

> *“the group activity, the social contact is very important”* (Ted, 68yo, Stage 2)

A sense of camaraderie in previous groups and the notion that people make friends within groups was also highlighted, all of which was expected to reduce isolation. Through this social interaction a sense of belonging was also facilitated:

> “it just means that they feel that they're wanted within the group, you know, so they're part of something.” (Kathy, Instructor, Stage 2)

Although referring to another group already running, I felt recreating this sense of belonging in any future group or intervention would be key, particularly for those who may be more isolated and therefore those who may benefit most.

This sense of camaraderie was also highlighted in terms of cancer specific groups, with an emphasis on the need for cancer specific programmes and the social support such programmes can give regardless of the behaviours targeted, as evidenced when discussing attendance at a support group in particular:

> *"No, I tell you why they come along, they come along for the camaraderie. They come along because they want to be with people who are in the same boat as them."* (James, 67yo, Stage 1)

As well as these points it was clear a social space was required when discussing a future intervention. In fact, it was stated the space that said intervention would be held had to be a social space (Idea generation overview, Figure 27). This again, emphasises that this sense of a need and focus on the social interaction was key throughout and generally the primary aim of any future intervention with the activities associated with the behaviours being used to facilitate this, (e.g., walk and talk). These social aspects were said to be very important for people who had experienced cancer.

7.4.3 Enabling access

A third recommendation to consider was around access to the intervention, be it ensuring public transport links, providing services locally but also spanning advertisement and signposting, as well as means to ensure people actually attend services to ensure those who may benefit have the opportunity to do so. Essentially this recommendation combines the findings regarding practical barriers, how to get the word out about the intervention and how to actually get people through the door, all of which culminates in an overarching need to enable access. However, participants considered the practical considerations associated with some of the ideas generated regarding these points. In particular, issues related to funding, staffing and training were referenced generally and specifically when considering how people find out about the programme. For example, when considering a telephone line for people to call to find out about activities it was deemed to be likely impractical due to the cost associated with paying someone and the burden such a task would be for a volunteer:

> *"But even if they could phone someone who takes your name and your number and will come back to you because that way they could then go to someone else, but if you're talking about a volunteer who is going to have to do this that's a huge amount of work for one person."*

> *"Absolutely."*
> *"It's an impossible task for an unpaid person really. You're talking about them not having any life; they're going to work forty hours a week, you know what I mean"* (Group discussion, Stage 3)

This issue regarding burden and costs was also highlighted when considering the "go-to person", with participants stating a "go-to person" who may be a drop in or a home visit as:

> *"not feasible at all, but wouldn't it be great if there were people, volunteers maybe, that could go and visit and say, well, this is what we do, what do you think, is there anything here that you think might be interesting".* (Alfie, 71yo, Stage 3)

Other points regarding the necessity to focus on access were also raised, including the requirement for transport to the programme, costs of attending the programme and creating effective means to raise awareness of the programme, as explored in Chapter 5. Although most of these points have been raised individually already within the thesis, it seemed important to acknowledge the impact and necessity to enable access, as an overarching recommendation, through a culmination of all aspects that refer to this theme.

7.5 Theoretical considerations

Within the research process I had initially planned to consult participants regarding theories, but it became clear this would be too abstract for them (from my perspective at least) and instead the focus should remain on their needs. Therefore, in addition to the completion of the thematic analysis, the data collected throughout the process was considered with reflection on potential theoretical underpinnings. Reflection is an important tool in research (Dahlberg, 2002) and allowed for consideration of myself and my role within the research as discussed in Chapter 6, but also consideration of key aspects and results of the work. I reflected on the use of theories and how/if these fit within this process. The reflections were solely from my perspective as an active member of the co-design process. These are considered later in Chapter 8 and Chapter 9 in light of the literature and evidence to make informed recommendations for future work.

As suggested within the co-design process it was key to acknowledge that I, as the researcher, was a part of the process and this reflection enabled that, whilst also facilitating consideration of an objective that may have otherwise been overlooked (Objective 3). Having this perspective from the outset, through the incorporation of the Adaptive Theory Approach (Layder, 1998) was important, as my knowledge built through the process, working with individuals to emphasise their views.

Some professional and volunteer participants working in dietary and physical activity programmes often mentioned the Transtheoretical Model (TTM), a theory that was also used often in the interventions identified through the systematic review (Chapter 2). Consideration of this model was also evident in the barriers raised by professionals with stage of change as a potential barrier to participation, described as readiness to change. Therefore, stage of change was considered when finalising the personas to be used in Part B-Stage 3, as discussed in Chapter 5. However, that is not to say the TTM is the most suited theory when considering the development of interventions such as that discussed in this thesis. In fact, this theory of change is often heavily criticised, as the stages likely do not reflect behaviour or behaviour change and the process of change is oversimplified in this model (Adams & White, 2005). Such criticism is, in part reason for the selection of an adaptive approach to theory and to ensure any theoretical recommendations effectively reflect the outcomes of the process. This approach has allowed me to consider theoretical underpinnings throughout the process without the necessity to ascribe to one set theory from the outset. Such an approach is suited to the exploratory and pragmatic nature of the research and is expected to lead to an insightful contribution regarding the place for theory in intervention development.

Based on my exploration of the literature and in some ways my experience in research, I had determined the aim of the research as:

> To use co-design to develop intervention recommendations with and for older adults living with and beyond cancer to improve the behaviours diet, physical activity and sedentary time.

Initially this seemed reasonably well received with recruitment to the research going well, and a sense of potential benefit in designing such a programme expressed by participants. However, early on it became clear participants were less interested in the behaviours than I first anticipated. Instead, participants wanted to explore their own issues in some cases but more predominantly explore the development of an intervention that enables social interaction. Thus, I began to wrestle with the sense that I was imposing the behaviours on the participants and the process when in fact other outcomes may have been more relevant to their needs. However, as the study progressed, I stuck with the premise of exploring physical activity, diet and sedentary time to some extent as this had been the original aim and in doing so it became clear activities relevant to these behaviours could be catalysts for the goals perhaps more relevant to the participants, (i.e., possibly not interested in becoming more physical active but interested in walk and talk due to the social component). This has led me to consider the divide between our goals as researchers and the goals of participants in participatory research. However, it is first necessary to acknowledge and reflect on the behaviour change theories considered and integrated throughout the co-design process.

The Medical Research Council framework for the development of complex interventions indicates these should be theoretically based (Medical Research Council, 2006). However, being an active part of this co-design process has led me to consider the role of theories, particularly behaviour change theories, especially their seemingly contrasting nature with participatory research. This has led me to the question how we select appropriate theories.

Results from the systematic review (Chapter 2) found similar issues across interventions that were theoretically informed and those that were not, where eight of 15 were not theoretically informed. This accompanied with the limited use of a theoretical basis for seemingly successful programmes and services I observed in Part A-Preparing, as well as the clear focus on social and personal factors (as opposed to the behaviours themselves) in Part B-Co-designing, led me to reconsider the role of the top down or positivist approach of behaviour change theories in such processes. I noticed a contention of sorts between this open, flexible, person-focussed process that is co-design and the implementation of structured, research-focussed theories. I began to recognise, on reflection, that theories are by their very nature simplifications of complexity, yet the process conducted, and findings presented reflect complexity and work to truly understand the needs of the participants. I, therefore, found it difficult to discern a conclusion regarding the use of theories of change in this context. I am aware of the benefits of theories, but I propose that we must consider their role in processes such as this and be open to consider theories beyond our usual field. Below I discuss how I came to this conclusion and explore theories from other fields that may be more suited.

From the systematic review two behaviour change theories were identified as having been used in previous interventions, these were considered throughout the process and in some instances drawn upon to inform tools and discussion. These were the Transtheoretical model (Prochaska & DiClemente, 1983) and social cognitive theory (Bandura, 2002). In addition to these, other common behaviour change theories were considered and drawn upon in some way within the process due to my thinking and understanding or discussions had with the groups. A description of how these theories were considered throughout the process and with regards to the findings can be found in Table 26.

Table 26: Overview of behaviour change theories considered

Theory	Overview	Common criticisms	Informed or incorporated into the process	Considering the process findings
Transtheoretical model of change (Prochaska & DiClemente, 1983)	A stages of change model moving from pre-contemplation to maintenance of behaviours, enables tailoring of interventions based on point in theory.	Stages may not actually exist. Doesn't consider other relevant influential factors which contribute to intention-behaviour gap. Too linear-do	Raised in systematic review-considered at this time. Used to facilitate development of personas to create discussion. Considered and mention by Group 2 as useful tool when working	The results mentioned this theory in some instances-for example stage of change was seen as a barrier by Group 2, but this is likely more so a useful tool for practitioners. It did not fit with the participants circumstances or support the main overarching

		people really behave and think like this.	with individuals. But seemed too simplistic when considering the circumstances of participants, their needs, barriers and goals.	findings, as it generally omits these type of concepts and considerations.
Social cognitive theory (Bandura, 2002)	Flow explaining progression to behaviour participation, with influence of barriers, facilitators, goals and self-efficacy.	For this study it seemed goals should be the end point not behaviour. Also, intention behaviour gap evident in this theory.	Not included in the process, instead informed some facilitation of the tools of the process, i.e. need to prioritise barriers and facilitators to understand impact on behaviour. Self-efficacy and confidence key components in this prioritisation	Useful theory throughout, as has a focus on barriers and facilitators and how these impact behaviour. Considered more broadly as moving through the process and informed inclusion/prioritisation of barriers and facilitators. Inclusion of self-efficacy.
Nudge theory (Thaler & Sunstein, 2009)	Manipulating the environment to result in behaviour change	Takes decisions away from individuals- opposite of the purpose of this work	Not included in process but nudge was a point included in priority maps, however, this had a slightly different meaning to that of the theory.	Considered as some interviews with professionals mentioned gently nudging individuals to change behaviour. However, this is not the same as nudge theory, which I learned when researching this theory.
COM-B (Michie et al., 2011)	Capability, opportunity, motivation=behaviour	Reductionist	Not included in work, although motivation was a big part and this was discussed in different ways that people could engage with	It is possible that the barriers could have been embedded in this model as is common, however, the barriers were often referring to something more than behaviour

				participation and so I decided conducting this would be reductionist and eliminate some of the richness of the data and nuances of the barriers identified. I did however, consider the components as mapped to the TIDIER framework in light of this theory to add another level to this aspect of the work, see Chapter 8.
Self determination theory (Deci & Ryan, 2012)	Impact of motivation type on behaviours. Intrinsic vs extrinsic.	Complexity and stage type process, where it is unlikely participants naturally progress but instead experience more than one type of motivation at a time	Motivation was considered throughout, with a clear lean towards intrinsic motivation- need for fun enjoyment. But also an acknowledgement of the important of external goals.	Discussed motivation throughout but not the theory. I was however, aware of the theory throughout and used this to facilitate conversations around different types of motivations. I expected professionals to understand the difference between extrinsic and intrinsic motivation. However, that was not the case.
Theory of planned behaviour (Ajzen, 2011)	Attitude, norms and motivation=behaviour.	Intention behaviour gap. Reductionist, need to move away from behaviour as end point.	Again, motivation considered but more from the perspective of SDT.	I did not consider this theory much. At one point attitude was briefly raised in a group, which made me think of this theory, but it was not best suited to this process.

Illness perception model (Leventhal et al., 2016)	Detailing the impact of illness perceptions on intended behaviour.	Focus on a small component that may impact behaviours.	NA	Considered this theory as potentially at the outset of the PhD due to the incorporation of illness perceptions. However, these were not considered further throughout, as the focus moved quickly to the behaviours and intervention design.
Health belief model (Rosenstock, 1974)	Benefits motivation and understanding of perceived severity, leading to impact of behaviour regarding disease prevention	No consideration of habitual behaviours or other external influences e.g., social norms.	NA	Initially I had this may be useful due to the emphasis on health, however, I did not go on to consider this further throughout the process.

From this reflective process on behaviour change theories, it became clear that perhaps behaviour change theories, although informative and drawn on throughout the process, did not reflect the experiences and needs of the participants. This emphasised the tension between participatory methods such as EBCD and often reductionist behaviour change theories. However, it was not appropriate to simply discard these theories and instead they will be considered when reflecting on intervention components as mapped to the TIDIER framework in the Discussion chapter. This adaptive approach has also enabled further reflection beyond the field of health psychology and behaviour change theories.

Reflection box 12-Building on discussion from my Viva

Before my Viva exam I had been considering the role of theories and moved beyond behaviour change theories to theories focussing on person centredness. However, I felt at the time that these still didn't quite reflect the findings of the process. Such theories did, however, reflect the process itself reasonably well. I felt it was important to reflect that the behaviours should not be the end point of a theoretical process and instead be a means to flourishing as described in person-centred theories. In the Viva I briefly discussed relationship focussed theories, this led me to consider these more after my Viva and ultimately led to my discovery of a model I felt supported my results. This model and the means through which I identified it as appropriate in supporting the study results and process will be discussed further in the proceeding pages.

The model identified was the flourishing through leisure model (Anderson & Heyne, 2012). This model also created space for further reflection on what is important to older adults and how this should be considered and conveyed in programmes and services. I will explore this model further in the writing below.

7.5.1 Model of person-centred practice

First, I considered the model of person centred practice (McCance & McCormack, 2016). An overview of this model can be found in Figure 35. The emphasis on flourishing suited my perspective and was reflective of the findings from the process. However, this model seemed overly complex, in that it was difficult to understand and apply to the current research. In addition, the components seem purposefully abstract and not applicable to everyday situations or embedded in everyday language. Moreover, the focus on healthcare meant many of the components did not fit well with the exploration and development of an intervention or service focussing on health promotion, as was the case here. This critique is not in support of more reductionist or simplistic model but more that models and theories should be accessible and understandable, especially when working with and for individuals in the community. It is clear that a person-centred way of working is key in co-design and so in that respect this model is useful. However, the complexity of it does not lend itself well to the process or findings.

A further criticism relevant to the current study and regarding the model of person-centred care by McCormack and McCance is the emphasis on the environment. Although, there is a focus on person centredness, there is a distinct focus on care settings with the model primarily aimed at the nursing profession. This is not a negative but means some components of the model are not only complex but are also irrelevant due to the focus on community services, that can be peer led in this instance.

[redacted]

Figure 35: Model of person centred practice (McCormack & McCance, 2006)

Other fields have also coined person centredness which may be more appropriate. For example, Carl Rogers developed person centred therapy in the 1950's. Again, this puts the individual at the core with the premise of progressing and developing as a person. The relationship with the therapist is key in this process, creating a sense of positive regard and empathy, regardless of the situation. This is founded in humanistic philosophy. Thus, it is clear elements of this are similar to that of the work of McCormack and McCance, it could be said that the therapeutic relationship should lead to flourishing. However, most important is placing the individual at the centre. In this sense this ideal of person centeredness was recommended throughout the PhD findings and within the process itself. However, the goals of these theories were to improve the self or care received, which did not sit with the findings of this work. Instead, a focus on social interaction for fun, enjoyment and to achieve personal goals was key. Therefore, I continued reading into theories where relationships were at the centre.

7.5.2 Flourishing through leisure model

Therapeutic recreation is a model and practice centred on relationships, generally used to support individuals with disabilities, chronic illnesses and the elderly (Kim et al., 2020; Yang et al., 2022). The American Therapeutic Recreation Association (2019) defines therapeutic recreation as the use of recreation and leisure activities to address the needs and improve the well-being (physical, social and psychological) of individuals who have experienced illness or disability. This premise moves beyond behaviour change and instead focusses on leisure and well-being, this is fitting considering the results of this PhD. Thus, it is necessary to consider therapeutic recreation as a potential influence or theoretical underpinning for future services and intervention for older adults living with and beyond cancer.

An offshoot of therapeutic recreation is the flourishing through leisure model developed by Anderson and Heyne (2012). An overview of this model can be found in Figure 36. The flourishing through leisure model focusses on leisure as means to achieve well-being, as is the premise of therapeutic recreation. However, this model expands on this premise emphasising core needs and resources to achieve, and separating well-being into the different components, leisure well-being, social well-being, physical well-being, cognitive well-being, psychological and emotional well-being, spiritual well-being (Anderson & Heyne, 2012). Differentiating between these well-being types is useful when considering intervention and service design for older adults living with and beyond cancer. This PhD found a need for example for social interaction, highlighting the necessary emphasis on social well-being, which is effectively facilitated through this model. This enables a new perspective on interventions and services for older adults moving the focus to their needs and well-being, creating a sense of person centredness as is recommended above.

Furthermore, the reframing of the behaviours as leisure or recreation is helpful and supports the findings of this thesis. Leisure and recreation are more akin to the activities suggested by participants (i.e., Walk and Talk, and Garden to Plate), as these focus on fun and social elements, instead of purposefully improving behaviour participation in physical activity for example. This reframing of the behaviours as leisure activities, also emphasises the role of the leisure activities as a catalyst for the greater needs and goals of the individuals for example social interaction and well-being. In essence this puts the goals and needs of the individuals at the fore, instead of the behaviours, as is the case in behaviour change models. This is a useful perspective when considering the future of interventions and services for older adults living with and beyond cancer. This perspective would still enable increased behaviour participation but the reframing to leisure and well-being could be key in the success of future services and interventions.

Regardless this model is not without its issues, the main one being that a professional is expected to facilitate the activities and ensure resources are available. This in many ways opposes the findings of this thesis in that empowerment and peer support/provision were key. Yet, the need to provide resources, particularly the described facilitation of physical resources (e.g. a safe environment, affordability and community resources (Anderson & Heyne, 2012) to enable participation effectively portrays and supports the key theme Enabling Access. Furthermore, the reframing to leisure and focus on well-being are useful and provide greater insight into the potential of the findings of this work and the necessities for future interventions or services for older adults living with cancer.

Finally, this idea of flourishing has become more evident throughout my exploration of theories. First identified when learning about person centred models, this idea is reflected again in this model. This sense of flourishing suits the outcome of this thesis well, in that the three key themes 1. Social is key, 2. Considering the individual and 3. Enabling access all work together to enable flourishing.

[redacted]

Figure 36: ***Flourishing through leisure model*** *(Anderson & Heyne, 2012)*

7.6 Emulating the desired intervention with the process

A final reflection to be considered at this point, is the sense I got that the co-design process in many ways emulated the preferred service described by participants. Throughout the process and in particular during Part B-Stage 2 (Focus group 2 only) and Part B-Stage 3 (Workshop) I felt the process itself was beginning to emulate the desired intervention. At points in this workshop, I felt like a counsellor or like I was a facilitating a peer support group. This in itself was interesting, participants were learning and encouraging each other, as well as sharing information in a safe comfortable environment (Chapter 6). Essentially, for some, particularly those who had expressed a sense of abandonment, this felt like an opportunity for them to receive some sort of support. This did not detract from the process; in fact, I think it gave a sense of realism to the discussion and suggestions considered. For example, when discussing a possible gardening programme, a participant expressed an interest in gardening but didn't know where to start. This led to conversations around local gardening centres which influenced and were drawn on as potential components for a future intervention but were also discussed in relation to the participants query to provide support.

In Part B-Stage 3 I could see certain members of the group were learning about resources from not only the professionals and volunteers, but also other members of the group based on their own experience. Again, in some ways I felt this reflected the desired intervention as there was an element of professional and peer support. Moreover, this also in many ways emulated the need for a "go-to person" to facilitate discussion around available services and provide support in accessing these services. For example, I noticed one of the professionals shared their phone number with one of the older adults to explore possible participation in classes. These classes had been thought by the older adult to be too difficult to access due to their location, however, it was determined this was unlikely and that many locations were available. This highlights the benefits such discussion and interaction can have, and also emphasises the necessity of specific routes to get information to those who can benefit from it most.

I observed other examples like this in Part B-Stage 2 (Focus groups). In this instance participants often shared cancer related stories and difficulties. It was great to see they felt comfortable doing this, and emphasised the positive nature of the process, environment and relationships developed but also added again an extra layer to the discussions regarding the intervention development and highlighted the need to focus on what is important to participants instead of forcing people down a path of behaviour change that is perhaps not suited to them. Instead, I would suggest that this highlights the need to pare back the process to understand what people want first and what their issues may be to ensure services, products or, in this case, interventions are acceptable and effective.

7.7 Chapter summary

Chapter 7 has taken a step back and looked through the entirety of the process to present key recommendations for future intervention development and delivery. These recommendations were derived from additional analysis of the data generated throughout the process. The analysis procedure and subsequent findings were described. These were 1. Social is key, 2. Considering the individual and 3. Enabling access. After which, I then explored my own reflections as an active member of the process on theoretical understandings and potential underpinnings for future interventions. Finally, I went on to discuss an interesting insight observed, in that the process appeared to emulate in some ways the intervention desired by those involved. Next, I will bring all the findings from the process together with existing literature. I will then discuss the strengths and limitations of this work, before exploring future recommendations.

Chapter 8. Discussion

8.1 Chapter overview

This chapter explores the findings of this research in light of current literature. First the overarching aim is discussed and the means through which this has been achieved are presented. Next, each of the three key recommendations: 1. Social is key, 2. Considering the individual, and 3. Enabling access are discussed. Other potential elements of a future intervention are embedded within these recommendations, as are the barriers, facilitators and key concepts identified, creating an overview of the findings and linking these to other evidence. Finally, the discussion reflects on the preparation and evaluation processes, before theoretical considerations and then strengths and limitations are described.

8.2 Considering the literature and potential implications

This research aimed to use co-design to develop intervention recommendations with and for older adults living with and beyond cancer to improve the behaviours diet, physical activity and sedentary time. To achieve this aim four objectives were set:

1. To engage the community of those who may use and or deliver a future behaviour change intervention for older adults living with and beyond cancer.
2. To understand the needs, requirements, perceived barriers and facilitators of major stakeholders, with regards to behaviour change interventions targeting physical activity, diet, and sedentary time, for older adults living with and beyond cancer.
3. To determine an appropriate theoretical basis for behaviour change intervention design for older adults living with and beyond cancer.
4. To evaluate the experience of using co-design from the perspective of both the participants and researcher.

Both the overarching aim and objectives have been achieved successfully through this research.

The co-design process has successfully engaged with the necessary populations, defined barriers and facilitators to participation in an intervention, explored theoretical bases and evaluated the process. This has led to the development of key recommendations for a future intervention with the potential to improve the behaviours physical activity, diet and sedentary time. The initial focus of the work on improving the behaviours physical activity, diet and sedentary time was maintained throughout. However, the process gradually shifted towards a broader focus of enabling social interaction and regaining functions, whilst using activities that would also improve the target behaviours to do this. Such activities included walk and talk, as well as cooking classes, and garden to plate style programmes. These findings necessitate discussion regarding the focus on the behaviours and the role of recommendations and guidance in this domain. The activities identified may not focus on the behaviours as an outcome or the recommendations/guidance for these behaviours (e.g., 150 minutes of physical activity per week, breaking up sitting time and a healthy varied diet with high levels of fruit and vegetables, Chapter 1) but they could ultimately enable this. However, the primary finding of this research is that recommendations, guidance and research outcomes should not be at the centre of interventions or services, instead it should be a means to enable social interaction for older adults living with and beyond cancer, to gain support and use activities as a catalyst to this. In essence calling for a person centred, community-based approach to enable individuals to flourish as expressed by McCance & McCormack (2016). Human flourishing can be defined simply as doing well (VanderWeele, 2017), which fits well with older adults definitions of health as described in this work where health was seen as doing what they want. This perhaps emphasises a need to move to a more broad definition of health incorporating human flourishing, an example of this would be that of the Ottawa charter where health is defined as a resource to live (WHO, 1986).

In light of this shift in focus and understanding for the need of a person centred, community-based approach to intervention design and delivery, no set intervention was defined, as this would contradict the process and outcomes. Instead, a number of recommendations and potential elements for future intervention design have been identified (including the Focus, Format, Who, What, Where, When and How). The elements identified can generally be embedded in the wider recommendations of 1.

Social is key, 2. Considering the individual and 3. Enabling access. Each of these recommendations overlap as depicted in Figure 34. Each of the three recommendations determined will now be broadly considered in reference to current literature. These three recommendations are also connected, primarily through an overarching need to provide person-centred, community-based interventions, be that for physical activity, or to enable social interaction. Putting the person within their community at the centre is key to ensure social interaction, enable access and consider the individual.

8.2.1 Social is key

This study found participants had a greater interest in the social aspects of a future intervention than in explicitly working to change behaviours. Instead changing behaviours and joining activities were seen as a catalyst to this higher-level goal of socialising. Social connectedness has been identified as the most influential facilitator for participation and adherence to exercise programmes (Farrance et al., 2016). Therefore, it is interesting this seems to have not yet been extrapolated to older adults living with and beyond cancer based on the interventions included in the systematic review (Chapter 2), the majority of which were home based and individual, meaning these were not face to face, with a group or encompassing the level of social interaction seeming required. This is further emphasised through the preference for a face-to-face and group-based intervention, as determined by this work, yet again this was not the case in the home-based and individual interventions included in the systematic review (Chapter 2). That is not to say that face to face interventions do not exist as all involved in Part A-Preparing were provided face to face and were group based. However, this does highlight the evidence identified through the systematic review reflects a different picture to that of current practice, likely due to the current focus of research. For example past research found older adults may prefer to exercise on their own (Wilcox et al., 1999), potentially leading to a number of interventions that are individual based, as was evident in the systematic review. However, this has been challenged with research indicating individuals may prefer group based physical activity, where the group are of a similar age (Beauchamp et al., 2007). Although identified in 2007, this is an important point as evidence from the systematic review conducted for this thesis indicated this is still not being implemented, with many interventions being home based and individual (Chapter 2). This is corroborated by the findings of this work where a specific age group was specified i.e., aged 65+, and a preference for social and group-based activities was evident. Thus, it is recommended future interventions target social interaction, through group-based face to face activities, with the behaviours, especially physical activity as an undercurrent.

At present many interventions targeting physical activity, diet and sedentary time being developed in research now and before the COVID 19 pandemic draw on digital methods (Ammar et al., 2021; Roberts et al., 2017). Yet, a recent study found even with digital interventions there is a desire for a social element (Lloyd et al., 2020). Thus, it is clear the necessity for social interaction as included in future interventions will be key to their success and will likely facilitate improvement in the target behaviours (physical activity, diet, and sedentary time) through the use of these to enable this social interaction.

Two key activities for a future programme or service were suggested, being walk and talk and gardening/garden to plate. Other activities were also briefly mentioned as explored in Section 5.13.3. However, these two were most dominant throughout and seemed to garner most interest. Both also had a heavy emphasis on social interaction or connectedness. This idea of social interaction or connectedness was key throughout as suggested in Chapter 7 and was also evidenced when considering where the programme intervention should take place, with the main outcome being a social space.

Throughout this process it was clear services and organisations, as well as the participants embraced the benefits of social components and activities. Future work should ensure social interaction is at the heart of the intervention, such implementation could lead to a wealth of physical, mental and social benefits, particularly for older adults (Dionigi, 2007; Guida et al., 2020; Huxhold et al., 2014; Seeman et al., 2001). This will build on that already taking place in the community and enable a shift in focus for future research. In addition, individuals may inadvertently meet the guidelines for the behaviours as recommended by the WHO etc. and improve their health. However, it is key to understand this should not be at the fore and instead social interaction should be prioritised based on this research, consequently building on person centred and community-based approaches, to create sustainable change.

It is possible the COVID-19 pandemic will have inhibited the ability to incorporate face to face social interaction in services and interventions, however, this only exemplifies the need for a focus on this more. Moreover, since the COVID 19 pandemic and associated lockdowns, evidence has suggested older adults with pre-existing health conditions experienced loneliness and thus interventions are now needed to ameliorate this (Allen et al., 2022). Such interventions are likely to be beneficial if face to face to help overcome the issues associated with isolation and lockdown (Parlapani et al., 2020; Savage et al., 2021). In addition to this, certain services, for example mental health services have found people prefer face to face appointments in some instances (Vera San Juan et al., 2021). This highlights the need for face-to-face interventions and the benefits of these, specifically for older adults who may be lonely.

In addition, Ireland et al (2019) have previously identified the importance of “shoulder to shoulder” support for women. The results of this study expand the necessity of this phenomena to men, with an emphasis on the need for men in particular to have the opportunity to walk and talk, enabling difficult conversations in a more comfortable environment. All of which also highlights the necessity of social components both to engage with the behaviours and intervention but also to achieve higher level goals, e.g., emotional support or social interaction.

Similar barriers and facilitators to participation have been found in previous research, as were identified in this research. For example it has been suggested physical and practical barriers, as well as social support as a facilitator can impact adherence to a physical activity intervention for older adults diagnosed with cancer (Sun et al., 2020). Other research has identified physical, personal and emotional problems as key barriers to participation in a diet and physical activity intervention, with an awareness of the intervention as a key facilitator, akin to “getting the word out” (Arthur et al., 2016). Thus, the findings of the current work corroborate those of previous work.

8.2.2 Considering the individual

As with social interaction, considering the individual was also seen as key throughout the process, with many discussions supporting this statement (Chapter 7). It was stated explicitly by participants that everyone is different, and choice is necessary. However, it is also prudent to note that participants felt a cancer specific intervention or service was necessary to feel comfortable and have space to explore experiences with the illness. This is a key point as after discussions with community contacts it has become clear that some services are moving toward a chronic illness model due to funding restraints. Therefore, it may be important to consider the cost-benefits of disease specific programmes in the future but with a remit to explore outcomes as defined by participants.

Furthermore, the distinct lack of interest in dietary change evidenced provides further insight into the types of behaviours individuals are willing to explore and the need to develop interventions that can be tailored to individuals' needs. Diet was viewed as very individual and often very personal, which may have influenced the lack of interest in addressing this behaviour. Evidence suggested conflicting advice around diet is often provided, leading to confusion, (Beeken et al., 2016; Hardcastle et al., 2018). Such confusion emphasises a need to understand participants and create tailored plans. Indeed, this may be akin to holistic needs assessment as discussed previously. However, it is possible for some a discussion may be better and on reflection, the "go to person" as described may benefit from being skilled in motivational interviewing to support the tailoring of the referral the appropriate interventions. Motivational interviewing could benefit participants by helping to overcome barriers identified, such as fear, lack of motivation and dislike/personal preferences (Hardcastle et al., 2015). In addition, having conversations throughout will contribute to the social interaction, build rapport, and potentially enhance engagement, acceptability and success of the intervention. Such a process in considering the individual can draw on a person-centred, community- and assets-based approach to create an environment and intervention where older adults living with and beyond cancer can thrive and flourish. This will ensure activities, access and support can all be tailored to suit the individuals needs and preferred outcomes.

Generally, the barriers, facilitators and key concepts identified all point towards the need to consider the individual in intervention design and delivery. Indeed, there must be some overlap to ensure the intervention is feasible but also enables flexibility to ensure it works for those intended to benefit. It is not possible to set up individual interventions, and in fact this would be counterintuitive considering the need for group based, socially focussed activities. However, it is possible to ensure at a lower level these activities can be tailored, and support is provided, possibly through a buddy service for example.

Gender was also a key barrier to participation identified. Throughout the process it was agreed we would consider mixed gender interventions and activities. However, it was clear male only activities were preferable for some, especially those who had been diagnosed with prostate cancer. This effect may be evident as the majority of participants in Group 1 (Older adults living with and beyond cancer) were male. However, previous research often struggles to recruit males, especially in health promotion and disease prevention research (Bracken et al., 2019), emphasising the importance of this finding. These findings regarding gender expand and emphasise the findings of previous work where gender specific interventions have been developed to help overcome this barrier, for example Football Fans in Training (Wyke et al., 2015). However, this research also expands on this, emphasising a need to consider the individual and their preferences, which may in some cases require gender specific interventions for older adults living with cancer. This point also connects with findings regarding Enabling Access, as it was clear throughout the process that those who may not be comfortable in a mixed gender intervention may just need support to participate. Overall, considering the individual is key to ensure success of a future intervention, particularly one that may target physical activity.

It is common to build interventions based on our goals as the researchers or in the case of practice the goals of the organisations, as I have witnessed at times in conversations with services and when conducting the systematic review Chapter 2. However, I suggest we should move away from these organisation-centric models and instead embrace person-centred models of development, implementation and evaluation. Such a move is becoming more common with the Scottish Government among other agencies employing such an approach, through the development and implementation of co-design, i.e., the Scottish Approach to Service Design (Scottish Government, 2019). Although such approaches are becoming more common, with organisations calling for co-designed services and person-centred approaches to services and interventions (i.e., NHS, GMC, Macmillan), it is possible these sometime lean towards the tokenistic end of participation, evidenced in the New Economic Foundation ladder of participation (Figure 7). However, it is necessary to further exemplify the benefits for this approach and truly advocate for it moving forward.

8.2.3 Enabling access

Throughout the process it was evident that work was required to enable access. Thus, “How?” became an important question throughout the process, both with regards to how people find out about available interventions and services, and how we actually get people through the door and taking part. In addition, a key consideration to enabling access are practical considerations.

Those in Group 2 (Professionals/ Volunteers) intimated that there were some great services and programmes available but that these were often hard to find, with organisations essentially competing against each other for funding and therefore not referring between services. This discussion brought to light the idea of a ‘go to person’ as well as a checklist type task, to identify needs and signpost or accompany to services and interventions. Although within the group these were deemed likely unfeasible due to resources required, the literature and current practice would suggest similar methods are currently being trialled. Take the Improving the Cancer Journey programme, for example, this was briefly mentioned in the groups but was only available in Glasgow at the time, this was however, outwith the study area. This service essentially provides a ”go to person”, indicating such services could be possible and further implemented in the future with initial evaluation insights positive (Young et al., 2020).

Within the Improving Cancer Journey programme there is the use of holistic needs assessment, similar to the checklist mentioned by participants. Holistic needs assessment may be a useful tool, as has been suggested in previous research

(Snowden et al., 2018). However, it is likely an informal discussion may be more suited to participants, as this would include a social element from the outset and provide an opportunity to build relationships within the community. It is noteworthy that the holistic needs assessment does not include points regarding social interaction but does include loneliness. Loneliness is, however, an interesting term and one that may have stigma attached to it. Perhaps based on the results of this work future holistic needs assessment should be framed to enable individuals to indicate they may be lonely or seeking social interaction, without explicitly stating this. For example, being able to select an option to meet new people with similar experiences. It is possible community link workers are in a position to do this due to their remit to work with individuals in the community but also connect between primary care services and the community (ALLIANCE, 2022). This link with primary care would also provide a suitable means to identify patients who may benefit from such interventions. In addition to considering how people find out about services and interventions, how we get people through the door was also discussed, emphasising the need to ensure services were tailored, supportive and empowering. Again, drawing on the resources of community link workers may be helpful for this.

A further point to consider regarding access that links to how people find out about it, is ensuring people who are interested actually attend. It was clear motivation could be a barrier and/or facilitator to participation, with readiness to change also briefly mentioned as a barrier. These considerations are key in enabling access, and can be facilitated through considering the individual, via a person-centred approach to intervention design and delivery. Others have also called for such approaches to enable intrinsic motivations, particularly for walking groups, a key activity identified in this work (Frensham et al., 2018).

There is also a need for services and interventions locally, with limited transport requirements. Thus, I propose in practice we must actively consider practical issues for participants and ensure simple barriers such as transport are not putting off those who may benefit, this can be achieved through advertisement which explicitly state transport, cost, facilities available (e.g., toilets). To do this it may be useful to actively engage with the community to assess needs. Previous research has identified practical considerations as barriers to participation, including distance to programme and transport available (Wurz et al., 2015). These barriers were also identified in the systematic review (Chapter 2), with Santa-Mina et al (2013) and Suh et al (2012) identifying transport as a key barrier participation. Moreover, Santa-Mina et al (2013) indicated people felt they were not able, which was also raised in this research with participants indicating the impact of cancer treatment as a potential barrier. Finally, Sajid et al (2016) found people were not interested and sometimes did not like the intervention provided, both barriers which were also raised in this research. Such findings are corroborated and built upon with this work, emphasising a need to enable access through ensuring practical needs are met.

8.2.4 Timing

Throughout the process timing of the intervention delivery became key, both timing in the cancer journey and timing in the day, as explored in Section 5.13.5. Broadly speaking, it was agreed the best time for older adults living with cancer to receive an intervention targeting physical activity and/or diet and sedentary time was after treatment for cancer. This was expected to be most appropriate but also likely to alleviate any possible issues around a sense of abandonment associated with the end of treatment, as evidence in this study and described previously (Ahlstedt Karlsson et al., 2019; Epner et al., 2011; Yi & Syrjala, 2017).

However, there was some discussion about the benefits of finding out about rehabilitation programmes before treatment and for some participating in physical activity to get fit before treatment. Since this work has been conducted this idea of ‘prehab’ has become more common, with a number of studies exploring the benefits (Moore et al., 2021; Shun, 2016; Silver & Baima, 2013; Waterland et al., 2021) and local government funding such work (Scottish Government, 2021). A recent large scale study exploring the benefits of prehab is Safefit (NHS Wessex, 2022). Safefit is online based but provides a large social support element, incorporating some of the key considerations explored in this work. Thus, although the focus was predominantly on aftercare in this work, it is useful to understand the ways in which the results can be extrapolated and implemented in prehab programmes. However, further work would be needed to do this successfully as prehab can lead to a shift of responsibility to the patient at a time when they may not have the resources for this (Giles & Cummins, 2019).

Timing in the day was also discussed, with daytime being preferred by those involved. These factors provide further evidence for the overarching recommendation 'Enabling access'.

8.2.5 Peer-led vs professionally led

Creating an intervention led through a combination of peer and professional support is a novel idea derived from this work and would bring together the benefits of learning from both parties. Professionally-led and peer-led services has been found to have varied benefits, for example it was found professionally led support groups for family care givers had a greater benefit to psychological well-being, while peer-led groups enabled greater social networks (Toseland et al., 1989). Other research has indicated offering both peer and professionally led groups may be more beneficial than offering only one of either type (Pallaveshi et al., 2014). These components were raised in discussions within this work, giving credence to the benefits of both, and instead of offering either, it is recommended both are offered within one intervention. Working in a collaborative way is fitting considering the nature of this work, and it could be said that such an intervention would essentially be co-produced, as defined in Chapter 3.

8.3 Considering theories and models

Objective 3 focussing on evaluation of the process was successfully achieved through the use of an Adaptive Theory approach (Layder, 1998), setting out a flexible platform for theoretical consideration, and removing the need to set a theory from the outset. Significant insight and understanding regarding the role of theories in participatory work, and the development and implementation of future behaviour change interventions has been gained through reflection on the process and results therein. This reflection did not lead to the identification of a set theoretical basis but instead recommendations around the use of an adaptive approach to theory to ensure interventions and services are not wedded to one particular field or theory that is not suited to the service user needs.

8.3.1 Placing the intervention components in current theory and literature

Potential intervention components were generated and prioritised throughout the process (Figure 21). In many ways these are common in past interventions and services but at the same time their focus is somewhat different. For example, the focus of most components is to enable social interaction, build relationships and create a fulfilling environment. The behaviours or activities may also be used to achieve broad goals such as regaining function or a sense of self. These overarching needs can be culminated into the concept of flourishing, and specifically flourishing after cancer. The interventions included in the systematic review (Chapter 2) did not focus on such elements or concepts, and this is perhaps in part why they were for the majority unsuccessful. It was clear from my participation in services and activities that current provision in the community does in fact have an emphasis on such components and on reflection, this was likely a facilitator of their success.

Although too reductionist to be considered as the main means of theory in this instance, as described in section 7.5, some behaviour change theories are useful to consider when exploring the intervention components as described by the participants and embedded within the TIDIER framework. The overarching theme and need for the intervention being social interaction which is evident within in each of the components does not support these models. However, the smaller components do support a variety of behaviour change models including the COM-B (Michie et al., 2011), self-determination theory (Deci & Ryan, 2012) and Transtheoretical model (Prochaska & DiClemente, 1983).

For example, when considering the TIDIER component “Where”, it was suggested that the space had to be local with accessible transport routes, also incorporating the overarching theme Enabling Access. Indeed, this supports the Opportunity component of the COM-B model. As ensuring accessibility equates to ensuring opportunity. However, more importantly the participants indicated a need for a social space, noting the space didn’t matter as long as it was in the community and a social space. This need for a social space is not reflected in the Opportunity component of the COM-B model. Some may suggest it is reflected in the motivation component; however, I would dispute this. Instead, it seemed from being a part of the process that the need for a social space and more so facilitation of social interaction was something greater than the behaviours and therefore, cannot be seen as a motivation to change behaviour. Owing to this reflection I have explored broader theories beyond the scope of behaviour change, see Section 7.5

Motivation, although not considered specifically in the TIDIER idea generation task, was reflected throughout the process. Many indicated motivation as a barrier and facilitator, progressing from having fun or intrinsic motivation to achieving goals and regaining function or extrinsic motivation. This is reflective of the motivation component of the COM-B model but more specifically the motivation hierarchy depicted in the self-determination theory. This is, therefore, an important consideration when developing future interventions and services, however, again it does not reflect the overarching need of social interaction. As mentioned above this may be seen by some as motivation, however, being part of the process enabled me to reflect the findings and needs described, and it was clear the need for social interaction was in fact the end point of the service or intervention and less so a motivation to take part. It was the ‘everything’ of the desired service or intervention. This leads me to the assumption that more focus should be placed on social interaction in future services and interventions, with these likely to achieve unintended or possibly intended change, wherein participation in the behaviours will be a catalyst to achieve the desired wider goal of social interaction. This may, in turn, lead to a variety of health benefits associated with the behaviours and social inclusion.

The “What” described can also be considered with regards to key behaviour change theories. The specific activities identified being Walk and Talk, and Garden to Plate capture behaviour participation and the potential for behaviour change. These activities were suggested as they enabled social interaction and most importantly fun. These components are not common in behaviour change models but could be considered as motives for participation. When considering these components as motives it is useful to once again consider the COM-B model (Michie et al., 2011) and also the behaviour change technique taxonomy (Michie et al., 2013). Fun and socialising may be key motives for participation, although I would propose they are more than motives, they should in fact be the key focus of any future service or intervention for older adults living with and beyond cancer. This leads to consideration of behaviour change techniques, although generally focussing on means to overcome barriers and change behaviours, conducting the research has led me to consider whether fun should be a focus of future research on behaviour change techniques. It is possible this element could add something to services and interventions that is potentially missing, as seen in the systematic review conducted for this PhD. In all I still propose that the focus should be on the three key themes (Social is key, Considering the individual and Enabling access) but these themes and the other findings regarding intervention components could inform future research on behaviour change and intervention design. However, it is necessary to consider all recommendations and needs as a whole rather than compartmentalising these, this will lead to a holistic and person-centred service or intervention.

Mentioned above briefly is the idea of goals. A common behaviour change technique is goal setting (Michie et al., 2013). However, I would not specifically recommend that future services and interventions set goals, as this would lead to something quite formal, when it was clear an informal approach is required. It was evident from the focus and format that an informal, face to face and socially focussed intervention or service was required. Setting specific goals would contrast with this and create a sense of an expert leading the programme or service, which was also ‘frowned upon’ by the participants. Instead, professionals were said to be needed when expert knowledge was required but were less so needed to run the entirety of the service or intervention, with a desire for a combined peer and professionally-led service. A key emphasis was placed on learning from others’ experiences, another potential behaviour change technique. It is, therefore, important to consider the entirety of a service and individual, instead of compartmentalising as is the case for behaviour change theories and techniques. A person-centred approach to enable flourishing is most desirable and reflects broader theories, as explored in Section 7.5 and further discussed in Section 8.3.3.

8.3.2 Acknowledging the tension between behaviour change theories and EBCD

This acknowledgement of a need for a move from behaviour change models and theories to more wider reaching theories for example the flourishing through leisure model is also reflective of the possible tension between reductionist theories such as behaviour change theories and the more inclusive and collaborative approach that is EBCD. EBCD calls for a move to understanding the needs of both service users and providers or, more commonly patients and staff. These individuals are seen as experts of their own experience and are key in facilitating change to improve services. It was this idea that fitted with the current study aims of developing something from the perspective of those who may use and provide it in the future. In contrast to this behaviour change theories and models are often used by researchers or other professionals to change behaviours in a way that is suited to their needs or their perceived needs of the target population. It is clear this contrasts with the goals of EBCD and emphasises potential tension between the incorporation of both.

This tension is also reflective of my experience within the process and in learning, as well as implementing new methods. It is not uncommon to use co-design to develop interventions, and in, fact such participatory methods are recommended now by the new MRC framework (Skivington et al., 2021b). However, at the time of beginning this PhD research there was less emphasis on such methods and the new MRC guidance had not yet been published. Regardless even today there is little, if any literature concerning how we can effectively merge participatory approaches and more traditional reductionist approaches such as behaviour change theories. Yet, many researchers are now doing just that. Owing to this it is important to reflect on these tensions and open a space for further discussion in the future. I had tried to merge my quantitative background in health psychology with a qualitative and participatory approach. Regardless of the tensions the approach was successful. However, being aware of these tensions from the outset in the future will be useful and likely lead to greater insights. Ultimately, it is helpful and understandable that the MRC has now intimated that service users must be given a greater voice in services but further guidance regarding how exactly this is to be done in light of the necessity to also ensure these are theoretically informed is required.

8.3.3 Applying broader theories and building understanding

The potential tension between co-design and theoretically informed intervention design has been explored. This contention was a key challenge identified throughout this process, which emphasises the benefit of the adaptive approach implemented.

Behaviour change theories are useful in understanding behaviour and working to facilitate change, with these being cited as necessary in intervention design (Skivington et al., 2021a). However, this work has questioned the suitability of such theories in intervention design, especially those developed through co-design.

Theories can at times be reductionist in nature. Ogden (2016) suggested that instead of reducing this variability and creating a one size fits all model, such as the COM-B model, we should instead embrace variability to learn and progress research. Such a premise suits the necessity to reconsider the role of theories in the design of interventions. This reductionist nature is also reflected in this process, as it is through the use of behaviour change theories that the decision was made to prioritise key concepts and barriers. Although this was useful and necessary at this stage it does also highlight how rich data, focusing on individuals and their needs can be reduced to simple key concepts that likely do not reflect their entire experience or needs. However, it is not possible to cover all aspects in such processes, so such decisions must be made. Co-design does, however, enable the opening of prioritised concepts later, and this is reflected in the idea generation of Part B-Stage 3. These ideas encompassed some of the key concepts and barriers but also created a bigger picture of the wider needs.

Throughout the process I was aware that the behaviours were often seen as secondary by the participants or had been previously used to facilitate or achieve something greater, for example regaining function or getting back to a sense of self. This led me to question the aims of the research as did the heavy emphasis on the cancer journey more broadly. However, after discussions with my supervisors and the participants themselves, it was agreed the focus would remain on the behaviours. Yet, it is evident from the three overarching themes and discussion regarding the focus of the intervention that the behaviours are a smaller part of something more nuanced.

The emphasis on social interaction, the individual and access are key for future intervention and service design. However, there was also discussion regarding broader goals for a future intervention or service, or ways in which previous programmes had been used to facilitate and achieve broader goals, for example regaining function and regaining a sense of self. These considerations fit well within the theme of considering the individual but also merit consideration in their own right. It is due to this reflection that I began to question the use of behaviour change theories for the development of such an intervention or service and in turn explored Person centred models and the flourishing through leisure model (Anderson & Heyne, 2012). The sense of flourishing seems key, and the three themes identified social is key, enabling access and considering the individual, can be incorporated into this model. It is important to acknowledge that the leisure activities facilitate flourishing, instead of the end result being the behaviour change. This is an important distinction in this work and could change the way in which we think of behaviour change for older adults moving forwards. See Section 7.5.2 for an overview of this theory with regard to this research.

Next, the role of outcomes must be considered. Through reflection on theories of behaviour change and results of the overall process, it was evident that behaviour change as an outcome did not reflect the outcomes deemed important by those who may participate in such interventions. Instead, social interaction was more important, with the behaviours (physical activity, diet and reduced sedentary time) or intervention to improve these as potential catalysts to achieve this. Therefore, it is necessary to consider whether the end point of behaviour change theories are actually realistic endpoints, and instead consider the outcomes desired by participants as endpoints, instead of facilitators (i.e., goals). Previously it has been said that.

> “the ultimate measure by which to judge the quality of a medical effort is whether it helps patients (and their families) as they see it. Anything done that does not help a patient or family is, by definition, waste, whether or not the professions and their associations traditionally hallow it.” (Berwick 1997).

This sentiment is further reflected in the consideration of Patient Reported Outcome Measures (PROMS) (Devlin & Appleby, 2010). Such a premise, although referring to healthcare, supports the argument being made here, in that we must consider the outcomes desired and achieved by those actively participating in interventions, rather than those of the researcher or organisation. This fits neatly with the key tenets of co-design, and it is possible co-design could facilitate work to determine such outcomes before any future intervention or service is built, to ensure it targets what matters to those who can benefit.

Finally, instead of working to suit the organisation/funder we must work to suit the person. If that means the rejection of a theoretical basis to ensure the voices of participants can be truly heard, then that must be considered. This is not to say that behaviour change theory is not helpful, it will always have a place in the field of health psychology for example. However, to work and deliver in a person-centred manner it may be necessary to cycle between theoretical considerations and practicalities observed in the field. Employing a person-centred approach creates a facilitative climate where an individual is able to effect change. Recently the role of person-centredness has come to the fore in nursing and health care. The work of McCormack & McCance (2016) focusses on the necessity to enable an individual to flourish both mentally and physically, similar to the expected outcome of an intervention as discussed in this research. This has also focussed on the importance of relationships, and the impact these can have on an individual. The findings of this research support the necessity to consider relationships, due to the focus on building social interactions. However, from this process it is evident that the researcher should not be the one to determine what this change should be and instead this should come from the individual, similar to previous work exploring person-centred services (Mearns & Thorne, 1999). It is also prudent to consider not only person centred but community centred interventions, due to the focus on social interaction and necessity to ensure services are embedded and available locally. This move towards community centred interventions is also expected to create more sustainable change, which would be useful in moving forward and has been called for recently by the King’s Fund (Fell, 2021).

Another lens to consider the findings through, particularly the key themes Social is key, Considering the individual and Enabling access is through the premise of incidental change. I have proposed that the behaviours are secondary or indeed a catalyst to achieve greater goals. However, another perspective could be that the behaviours participated in are incidental consequences enabled due to the participation in a broader programme or through participating in behaviours to achieve broader aims, for example enhancing social well-being. Previous research around incidental physical activity for example, has generally focussed on small changes embedded in everyday life, such as increasing use of the stairs (Reynolds. et al., 2014). However, this work points to the potential for greater incidental interventions, where the focus is on the needs of the individual and social engagement but physical activity or dietary activities, for example those identified in this thesis-Walk and Talk and Garden to Plate incidentally enable improved behaviour participation. This in some ways opposes the idea of the behaviours as a catalyst to broader goals, but also lends itself to this in some ways. Regardless, it useful to consider both arguments, to understand how behaviour change may be achieved in this population without actually focussing on the behaviours or behaviour change.

Another consideration relevant to this premise is the role of message framing. Message framing can have a significant impact on individuals and their decision to take up a programme or activity (Keyworth. et al., 2018). It is possible that framing the programme or service as a means to meet new people and interact, emphasising that it will be tailored to individuals needs and all necessary facilities will be available to enable access could be more effective in engaging individuals than focussing on behaviour participation. This thesis would support such a premise. It may also be useful to work with those who may use and provide the service to build these messages, to ensure they are also relatable. Thus, regardless of whether the behaviours are a catalyst for some greater or incidental to something greater, the framing of messages around any service will be important and should incorporate the three key themes identified in this work 1. Social is key, 2 Considering the individual and 3. Enabling access.

8.4 Learning from preparation and evaluation

This study effectively engaged the community in the co-design process and more generally. The co-design process was also effectively evaluated.
Objective 1 (To engage the community of those who may use and or deliver a future behaviour change intervention for older adults living with and beyond cancer) was successfully achieved through Part A-Preparing. Part A-Preparing provided a platform to discuss the research with the target community and population, provided insight into services available and provided a footing within the community to effectively conduct the entirety of the research process.

Second, effective recruitment strategies were developed and implemented, leading to successful engagement of the community throughout the process. Exploration of the most effective recruitment methods can be found in Section 6.9. However, in short, endorsement of the research by trusted sources, including third sector organisations, colleagues and community leads was beneficial when recruiting both groups, with the work to achieve this endorsement only being possible through the inclusion of Part A-Preparing. The use of gatekeepers, who were generally community group leads, in this work was relatively informal wherein community leads distributed information to individuals in their groups who may be suited to the study, particularly for recruitment to Group 1-Older adults. It is possible this informal approach contributed positively to the recruitment alongside the relationships built throughout the process. Had a formal agreement been implemented as recommended by Singh & Wassenaar (2016), a sense of power imbalance may have become prevalent, a key issue which co-design works to overcome (McKercher, 2020).

Similarly, for Group 2 (Professionals/Volunteers), a sense of endorsement was key, with snowballing through existing contacts being the most effective recruitment method. There was a sense of trust built through one organisation introducing the research to another, or one colleague introducing the research to another. However, this process was time consuming and recruiting to Group 2 (Professionals/Volunteers) was generally difficult. Those who did participate and/or promote the work in some way, for example, through an email, believed in the potential benefits of the research or had a specific interest in the target behaviours. However, time constraints were a key barrier identified when working with and recruiting to Group 2 (Professionals/Volunteers). This has been reflected in other work where staff have indicated EBCD is a burden (Dimopoulos-Bick et al., 2018), as well as more generally in recruiting professionals to research (Hysong et al., 2013) and in engaging with co-design (Kirk et al., 2021). In this study embedding Part A-Preparing in the process, was most useful, as this enabled the snowballing and building of trust amongst professionals, creating a space wherein they worked to carve out time to participate. This sense of 'buy-in' would not have been possible were it not for the relationships built with services, organisations and communities. This emphasises the importance of preparation to not only engage the community in the research space but also create relationships within the community that enabled the progression of the process through effective recruitment.

Third, the prolonged engagement period of participants within this research and low attrition rates indicated that the community was successfully engaged with the project and the measures implemented to maintain this were effective. Within EBCD it is only 50% of those who take part in the initial interview stage will complete the process (Donetto et al., 2014). This work maintained an engagement rate of above 50% at each stage. This is likely to be due to the gradual and ongoing approach to building engagement embedded within EBCD, enabling an accrual of confidence and participants' sense of accountability. In addition to this some key means to maintain engagement were employed, including personal communication and check ins, mainly via email, when waiting to progress the study, as well as personal Christmas cards.

In engaging the community, it was also clear that the types of services and interventions being delivered in the community with and without a focus on the target behaviours were distinctly different to those being delivered in research settings, for example those identified within the systematic review (Chapter 2). All the services and interventions engaged with throughout Part A-Preparing were face to face and often group based activities, whereas in the systematic review most were home-based and individual (Chapter 2). For example, one of the services involved in Part A-Preparing provided a walking group, with distinct time for socialising and provided in a cancer specific community centre to create a sense of belonging. Such contrast highlights the difference between practice and research, which will be influenced by several facets, including funding, time and practicality. However, it is possible due to publication bias, as well as the focus on effectiveness in the systematic review that community-based interventions were missed from the review. Regardless, this is not expected to impact the results of the research.

The services and interventions available in the community were at times implementing co-design type methods to develop, implement and improve services. For example, work had been conducted by one service to identify needs of individuals living with and beyond cancer and create or improve services to suit these needs. This indicates that community was perhaps ahead of the curve in this respect. This emphasises a research practice gap, yet unlike the usual gap where it is anticipated it takes 17 years for research findings to be implemented in practice (although more so in biomedical research (Morris et al., 2011)) instead practice was ahead of research, likely due to the current focus on asset-based, person-centred services. In essence a practice-research gap was evident. This emphasises the likelihood that research can learn from practice and vice versa. This may be achieved through collaboration between academia and practice but also academic evaluations of practice to determine what works. An example of such an evaluation is that of the Transforming Care After Treatment programme (Campbell & Johnston, 2018). This need is also evidenced through the recent development of Public Health Intervention Responsive Studies Teams (PHIRST), which are collaborative teams working to identify what works on the ground to improve health and wellbeing (NIHR, 2022b).

The benefits of the engagement described, and the understanding developed regarding other interventions and services was only possible due to the community already in place. As described in Chapter 1, this community centred around a shared understanding, use of services and experience. This sense of community, although possibly not considered a typical community due to the disparate geographical locations, was key in the success of this work. Throughout the process it was clear individuals had a shared vision and really wanted to help others who may be diagnosed with cancer in the future. During the Part B Stages 2 and 3, it was evident individuals had a wealth of experiences in common which brought them together throughout the process. This may have been due to attending the same support centre, the same hospital, and having had the same treatment or simply realising they actually knew each other from previous social events and clubs. This is important to recognise and reflect on, as it indicates what a community can be, in that it is certainly more than a group of people living in the same neighbourhood. This process enabled and built a community within the wider community in the context of cancer care, it was evident those who participated had a sense of trust and belonging within the group and felt they could influence the process. All of which was possible due to shared experiences and the new shared experience of the process, as described previously by Chavis and Lee (2015).

With regards to evaluation of the process findings from Survey 1 and Survey 2 (Chapter 6), as well as researcher reflections, as an active participant in the process indicated the process was acceptable to all involved. Three key themes were identified in the evaluation: **'learning and doing'**, **'spaces and places'**, and **'relationships and roles'**, all of which were encapsulated by the overarching theme of **'Putting the co into co-design'**. These themes effectively relayed that the process was acceptable and related to some of the active ingredients that contributed to this.

Reflection box 13-Creating a shared community

Throughout the process I was aware that my perception of community may be different to those who were participating. I am aware the geographic area covered was quite disparate and this was done for practical reasons to ensure sufficient numbers at recruitment. However, from my perspective, previous understanding of services and learning about services in Part A, I felt that the area covered was appropriate and that there were sufficient common ties to merit the term community (i.e., aged 65 plus, cancer diagnosis, shared services and care facilities). Therefore, I was confident going into the process that a shared understanding would be possible and this was reflected throughout the process and discussions. To ensure this further I built in practical elements that helped create the community within the larger community. From simple things such as having a seating plan for the group sessions to ensure clusters and cliques weren't likely, to encouraging individuals to share their stories and giving time to build confidence. It may be that my perception of community was different to the participants, but by the end of the process we were a community within the larger community. In the future it may be useful to discuss such concepts when conducting similar processes. I feel this was only possible due to the co-design process and my work in ensuring I tried to share power and include everyone.

These themes also effectively portray what it is to conduct co-design and emphasise the need for evaluation of processes and not just of the outcomes of the process, as corroborated by Bowen et al (2013) and Yadav et al (2021). However, this evaluation also highlighted some points where improvement could be made, specifically from the perspective of the researcher. At times a larger team would have been useful in conducting the co-design process, to give more room for discussion and enable greater facilitation. However, discussions with supervisors and the use of second facilitators helped alleviate this issue. Consideration must be given to the team and roles within this in future research. This was a component of the setting up in EBCD (The Point of Care Foundation, 2022a) that was perhaps overlooked due to the fact this process was conducted as part of PhD project and so was to be an individual piece of work with the supervisory team already in place.

8.5 Strengths

Throughout the process care was taken to successfully recruit and develop relationships with the participants, all of which influenced their engagement with the process. In order to recruit, relationships and trust were built with community groups, leads and services throughout Part A-Preparing, as explored in Chapter 4. Through these relationships a total of 11 Older adults and 9 Professionals & volunteers were recruited. Although recruitment had limitations in the characteristics of the participants obtained, in that most were motivated and active due to the groups recruited from, it was also a key strength of this study, as it facilitated participation of often under-represented populations, particularly older males with the study. Moreover, several measures were undertaken to ensure and enhance engagement over the yearlong study period. These measures included Christmas cards, as well as brief catch up/update emails. Briefly, however, these measures can be seen as strengths of the study, as was the resulting prolonged engagement. Only two of 20 participants did not respond after the first data generation period, while all others responded and contributed where possible.

One particular measure taken to enhance engagement was the use of Christmas cards. All participants were sent a handwritten Christmas card directly from me. This resulted in some email follow up from participants, generally chit chat but more importantly a means to touch base with participants and maintain the relationship previously built up. Literature suggests Christmas cards are ineffective in achieving this (Coleman et al., 2021). However, I propose the manner in which I did this was slightly different to that of the Coleman study, as this referred to RCTs, with large participant numbers and therefore, would be unlikely to develop the same personal relationships. I believe that the Christmas cards built on my relationship and rapport with participants, which enhanced engagement with the process.

These relationships and rapport were initially established in the interview stage of Part B, where I provided participants with the opportunity to share their story and actively listened and engaged with it. This provided a foundation for the process to continue, as is intended in EBCD (The Point of Care Foundation, 2022a) and was further enhanced through social events in the following stages of the process. The social events were important to allow the build-up of relationships but also for the participants to get to know each other and ensure everyone felt comfortable in the process.

The growth from interviews and individual experiences to the development of an intervention, also enabled the consideration of individual experiences but where necessary methods enabled the group to move beyond this (i.e., using personas). The methods used were developed and implemented to best meet the aims of the study, through training, careful planning and consideration and extensive conversations with my supervisors. This was all enabled through the pragmatic and adaptive nature through which the methods were used, enabling varied methods and most importantly creating an environment where participants' voices were truly heard. Moreover, the validation and ranking processes are also likely to have contributed to this, as participants could see how what they were saying in each stage was carried forward to the next.

This sense of being truly heard, as well as being part of the group and enjoying the process are further reflected in Chapter 6 and are certainly a strength of the research. Participants expressed a sense of enjoyment in participating in the process during the evaluation measures, as well as in discussions with the researcher and one another during the social aspects (e.g., lunch). Moreover, the methods allowed for ample validation and sense checking, creating not only time to reflect on the outcomes of the group but also time to reconsider what has gone before and emphasise points that may have otherwise been glossed over. This was possible due to the combination of group discussions, tools and evaluation and ensured everyone could be heard and included throughout.

Finally, the process can be said to reflect real world experiences and situations, due to the specific focus on individual and group experiences. Owing to this it is likely the results are transferable across a wider population and should be drawn upon in future research and practice. Examples of how this may be done are discussed in Chapter 9.

8.6 Limitations

Five limitations of this research have been identified, primarily revolving around participants recruited, methods used, and outcomes achieved.

Firstly, the demographics of Group 1 (Older adults living with and beyond cancer), and, in particular, the fact that most recruited were motivated and already perceived to have a good diet and were participating in physical activity could have biased the process. Although this group was heterogeneous in some ways (i.e., reflecting different geographical areas, cancer types, social networks and experiences), the group were generally active and perceived themselves to have a good diet (Section 5.12). However, the use of personas provided the Groups an opportunity to consider those who may be less motivated and work to make the outcomes more widely transferable. In the future it may be useful to consider recruiting from a wider base of community groups or outwith such groups to achieve a more varied group of participants. However, recruiting those who are less motivated generally will likely be more difficult. Providing a fitting payment for participation, as recommended by the National Institute of Health Research (NIHR, (2022a)) may alleviate this issue further.

Second, there was a lean towards discussion and focus on physical activity, which was likely influenced by the means through which individuals were recruited. A number of individuals in both Groups 1 & 2 were recruited through community groups and services with a focus on physical activity, which may have led to a greater focus on this throughout the process. However, measures were taken within the process to centre the discussion around the aims, but more importantly participants were encouraged to lead the conversation, which resulted in focus on concerns other than the behaviours.

Third, there was difficulty in recruiting participants to Group 2 (Professionals/ Volunteers), and further difficulty in maintaining engagement with this group. The main reason for refusal to participate was a lack of time. Recruitment methods used through snowballing and the build of trust resulted in achieving the desired number of participants for this group, however, this was time consuming, and there was minimal engagement beyond Stage 1-Individual interview. In future research it may be necessary to consider remote means to involve professionals, as well as work to build a culture that embraces the benefits of research and in particular the contribution and benefits co-design can make.

Fourth, with regards to methods, participants found the development of the personas particularly difficult. The task was described as abstract and challenging. To overcome this the task was adapted, as participants indicated they would prefer to simply complete the sheet and then have the researcher build the personas based on their answers. This worked well and participants enjoyed discussing the personas developed in the next stage of the work. This emphasises the necessity to adapt and fit to suit the groups' needs.

Finally, some deviations from initial plans were made. It was clear some of the components of EBCD were not suited to the purposes of the research, e.g., emotional mapping/videos and instead other co-design tools and exercises were used. For example, emotional mapping did not suit the development of a new intervention and the creation of a video was not practically possible for several reasons, generally due to the location of the interviews. The general flow of EBCD was, however, followed moving from preparation/observation, to interviews, individual groups, then workshops and finally a celebration event. However, results obtained to the point of the workshop provided considerable insight and data to move forward in making key recommendations for future intervention design. Moreover, additional tools commonly used in co-design were incorporated into the process. This adaptive process is reflective of that intended from the outset and also corroborates recent sentiment by Greenhalgh et al (2019), where it was stated that:

> *"A single, one-size-fits-all framework may be less useful than a range of resources that can be adapted and combined in a locally generated co-design activity."*

Such sentiment emphasises the need for adaptive methods in co-design, enabling a person-centred approach to intervention development. This thesis is an example of such work.

8.7 Is it really co-design?

Considering my previous criticisms of and the perceived overuse of co-design as a tokenistic tool, I want to explore whether the process I conducted reflected co-design as defined in Chapter 3 of this thesis. To do this I implemented and reflected on the tool developed by McKercher (2020). This tool comprises four questions, considering each of the key components of co-design, with multiple choice answers. I will now answer each of these questions below and explore the extent to which this process reflected these components.

Question 1- Are people with lived experience, professionals and others involved (e.g., policy-makers, architects) working together?

This could be through researching, sharing and discussing insights, developing ideas, building prototypes or implementing new concepts.

Answer-Yes people with different experiences are working together.

Reflection-The process reported was a build up to a place where people with different experiences were working together, and the collaboration of staff/volunteers and older adults living with cancer was only achieved in the final Stage of the process. This is usual in EBCD. However, it is also usual in EBCD that more than one collaborative workshop is conducted. Therefore, this process has been reflective of co-design and specifically EBCD but only to a certain extent, due to time and resources available. This enables learning for what is necessary in the future to create and build more opportunities for people with different experiences to work together.

Question 2- Are co-designers (people with lived experience and professionals) making decisions?

Making decisions is different to giving recommendations.

Answer-Yes in a simple way such as using dot voting or polls.

Reflection-Throughout the process people were asked to prioritise key components through dot voting and ranking. However, this was done with the groups separately and then brought together by the researcher. When considering the point at which both groups were brought together, this was more a case of idea generation. It was the case that further decisions and prioritisation of these ideas would be made at this time, however, the participants indicated they would prefer I as the researcher to do this. Therefore, it is only possible to say shared decision making was made to an extent. Again, this provides key learning for me as a researcher that I can carry forward into future projects, and work to enable and empower individuals to be involved in a shared decision-making process. However, that is not to say that this should be forced, as this would go against the collaborative nature of co-design.

Question 3- Is there making?
Here are some tangible things you might be making: Campaigns, policies, products, services, programs or service. Or, here are some intangible things: Movements, coalitions, new relationships.
Answer-Our main activity is creating plans.
Reflection-The initial plan of this project was to include making in the development of a behaviour change intervention. However, instead the process only achieved the development of recommendations. These recommendations would not have been possible without the process, but it is necessary to acknowledge that no tangible output was achieved. This is a key component of co-design generally and EBCD. However, it is also worthy to consider that many projects only achieve the recommendation stage, as is described in Table 7, where the majority of articles reporting EBCD in cancer care, achieved only recommendations for change and not actual change. This again highlights a need for future consideration of the use of co-design, effective planning and a need to be adaptive.

Question 4- Are people with lived experience recognised for their time and reimbursed for any out-of-pocket expenses?
Answer-If they ask to be we'll pay people for their time and out of pocket expenses.
Reflection-Participants were offered only out of pocket expenses and had to request these. The process to obtain them was not easy, and was likely off-putting meaning, only two claims were made. This is reflective of poor systems within the University, which should be reconsidered to enable ease of claims. Moreover, I understand that

participants should have been reimbursed for their time, however, I did not have budget available for this. I am aware this is a flaw but understand it as a flaw in the way academic research, and in particular PhD studies are funded. Since completing the PhD, I have ensured all participants I work with receive payment for their time. I am aware, there are guidelines for this but I would suggest that further work is needed to shift academia to valuing lived experience and paying for input at an appropriate rate.

Using this tool retrospectively has been insightful experience and has emphasised key areas for improvement in my own practice in the future but also for systemic changes. It is also necessary to consider the extent to which this process reflected that of EBCD, as this was the chosen method. This is discussed further in the Limitations section and adaption to the process are reflected on Chapter 5 and Section 8.7.

8.8 Implications of adaptions to usual methods

Expanding on discussion of the strengths and limitations, it is important to consider and acknowledge potential implications of the adaptions made to the methods as explored in Chapter 5. Adaptions were predominantly made to ensure the progression of the process, for the inclusion of unheard voices and to fit EBCD to the aims of the PhD (i.e., to develop a new service or intervention as opposed to improving an existing service). This process has provided ample learning around the use of co-design, when it is appropriate and how methods can be adapted to suit the participants and the process. Having an adaptive approach was key from the outset, with a pragmatic lens adopted. Had the process been set, following the EBCD process as laid out in the toolkit specifically, it would have been an entirely different project. That is not to say this is a negative but simply that the tools, methods and adaptations used enabled the development and progression of the project as was. These tools were suited to the participants and the project's needs, with reflection and evaluation being positive. Future projects should consider taking an adaptive approach, ensuring the process is suited to the individuals and project needs, and not adhering to set methods that may not be as well suited.

Another important reflection here is the time and resources available when conducting a PhD. It was not possible to implement some of the methods, for example the video due to the resources and skillset available. This is another reflection on the need to be pragmatic in such instances. However, it is also important to consider and adapt how and why methods are being used and only use what is appropriate and necessary. In this instance videos were not appropriate or possible and so were omitted. This enabled the progression of the project and ensured the aims of development were maintained. Had a video been used it is likely this would have led to a process focussing on the full cancer journey. Therefore, it is necessary to take stock throughout co-design process and ensure methods are suited, relevant and acceptable. However, in this instance it was also useful to have EBCD and the overarching framework of this method as a backbone to allow for this progression and adaption. Thus, the implications of the adaptions were generally positive and it is useful to acknowledge and reflect on this to inform future work.

8.9 Chapter summary

Chapter 8 has provided an overview of the key findings with reference to existing literature. The three key recommendations were discussed, with barriers, facilitators, concepts and intervention elements embedded throughout to create an overview of what a future successful intervention may look like. In addition to this, theoretical considerations were explored, as were findings from the preparation and evaluation parts. Finally, strengths and limitations of the study were presented. Next, recommendations and implications for methods, theory and research are presented. After which, I explain what I have taken from the process and how I have implemented this learning in other work. Finally, contributions to knowledge and conclusions are described.

Chapter 9. Conclusions and recommendations

9.1 Chapter overview

Chapter 9 addresses first the methodological and theoretical insights gained through conducting EBCD and recommendations arising from these. Then recommendations for future research, personal learning and perspectives for the future are considered. The original contribution to knowledge made by this thesis is then described. Finally, overall conclusions are made.

9.2 Methodological recommendations

Key methodological insights and recommendations for the effective use of co-design in future research can be discerned from this work. These are particularly drawn through the results regarding my reflections of the process, as well the evaluation of the process (i.e., Chapter 6). In addition to the methodological recommendations, several recommendations for future research can also be drawn to expand and build on this work, as well as further probe some of the key questions raised. First, I will explore some of my key learning from using co-design and specifically EBCD.

At the first point of interaction with participants for data generation (i.e., Part B-Stage 1 Individual interviews) it became clear some of the tools commonly used in EBCD were not suited and, in fact, were not practical for the purposes of this research and the resources available, and therefore, other tools were used. For example, the use of videos to detail stories did not fit the aims of the research and was impractical. In addition, the idea of emotional mapping was adapted to suit the needs of this research, with barriers and key concepts being prioritised instead of emotional touchpoints. This decision was made based on the data being collected but also my improved understanding of co-design methods and tools as I progressed through the process. Therefore, I chose to use more generic co-design methods and tools but drawing on the core facets of EBCD. This iterative and adaptive process was key to the success of the study, and I would recommend anyone considering co-design in the future to embrace the messiness and be led by the participants. This has also been recently recommended by Greenhalgh et al (2019). The benefits associated with embracing this messiness and taking the time to conduct such work, can again be emphasised through the discussion in Section 3.3, exploring the build and access designed to a new train station in my local area. Had the planning team taken the time to work in a collaborative manner, embracing the needs of the users and considering the double diamond of design, this design could have been more successful and acceptable. Therefore, the need for co-design is wide reaching and the messiness although time consuming can have great benefits. A new double diamond has been developed, aiming to reflect the iterative nature of co-design (Drew, 2022). However, it is possible this does not go far enough and instead in reality co-design looks a lot more like Figure 37. Therefore, it is necessary to embrace and acknowledge this messiness, but also be aware it is what makes co-design work too.

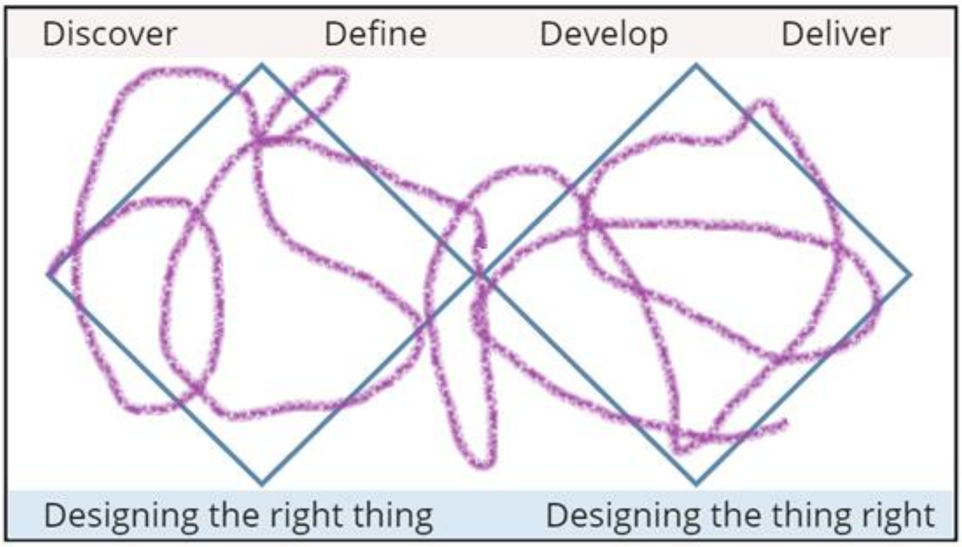


Figure 37: Messiness of co-design
(Adapted from (Ball, 2019))

Another consideration is the resources available to carry out the process. In many ways conducting this research as part of a PhD was a blessing in that I could adapt to the process, change the tools used and truly follow the needs of the participants without worrying about the implications for the 'desired' outcome or funders requirements. However, carrying out such work as part of a PhD was also quite an undertaking and, in some instances, I really felt the need for a wider team to lean on, in addition to the support from supervisors. However, at the same time this may have impacted the process, and the potential outcomes, as such rapport and relationships may not have been possible were more researchers involved. Regardless, I would ensure and recommend required resources are fully considered before undertaking future similar projects.

Finally, I would recommend taking a step back from the outset. To truly understand what will work for participants, we must first understand their needs, instead of applying our goals from the outset. I learned this as I progressed through the process it was clear my goals and priorities as a researcher were perhaps not matched from the outset to the participants. I adapted both my outlook and the process to incorporate these priorities wherever possible, which resulted in there being no standardised intervention manual, as was initially planned. However, I now feel the outcomes achieved and recommendations to be carry forward are much more useful than a standardised intervention manual would have been. In summary, my main recommendation for future co-design projects is to develop the aims with participants, removing any potential remaining top-down component by removing our power in creating the goals and outcomes. I am aware that in recommending this, I am also acknowledging that the process I conducted was perhaps not fully collaborative as suggested by the ladders previously described (Section 3.3). For example, there was a power hierarchy evident, wherein I felt in control of the process and in many ways the others were following my lead, as evidenced when a participant described me as the boss. Therefore, in future I will work to create an even greater sense of shared working and ownership and ultimately, the learning gained will lead to greater projects in the future. Considering everyone to be a co-designer, as opposed to researcher and participants in the future may also alleviate this tension somewhat by creating equal titles for everyone from the outset.

9.3 Theoretical recommendations

Further work is required regarding the use of theories in such intervention development. For example, the updated MRC framework for complex intervention development necessitates there should be a theoretical basis as well as participant involvement in design (Skivington et al., 2021b). However, work is needed to explore how we can bring these two realms together successfully. Interestingly when I attended a conference, I was asked how I could apply such a quantitative outlook (i.e., theories of behaviour change) onto such a participatory and essentially qualitative process. At the time I felt bringing these two points together was key in my research, however, I now realise that perhaps they do not fit quite as I had expected, and instead further thought is required on how to do this effectively but also on whether the theories really relay reality for people.

Work is also needed to further explore how theories fit and are integrated into co-design processes, determining a means to combine top-up and bottom-down approaches. This process has done this to a degree and the use of the adaptive approach has been vital in enabling this, as well as the move through fields and different theories, to identify those most suited and representative of the results. It is important to note the use of behaviour change theories throughout the process but also the move from these to more holistic and empowering theories at the end of the process to reflect the needs of the participants, as opposed to the aims and needs of the research. In this case these were the person-centred practice model (McCance & McCormack, 2016) and flourishing through leisure models (Anderson & Heyne, 2012). This will become more important as the use of co-design and participatory methods continues to expand. Moreover, as the updated MRC framework for intervention development calls for incorporation of participant input and theoretical underpinnings (Skivington et al., 2021b) further work is needed to explore this issue.

9.4 Recommendations for future research

In addition to the recommendations made for consideration of future co-design work, I also want to make recommendations for future research more generally. Five key recommendations for future research can be made based on this work;

1. Develop our understanding and tools available to engage professionals
2. Develop effective means to make people aware of and engage with services/interventions
3. Develop and use co-design methods/tools in wider populations, especially those who may be commonly underserved in research
4. Collaborate to enable widespread use of co-design and participatory methods
5. Evaluate future co-design processes

Firstly, I recommend further work is needed to engage professionals with these types of processes but also to enable professionals to engage with these types of processes. The professionals and volunteers I met throughout the process were very interested in the process and in making services suit participants. Some, particularly in preparatory phase were already practicing co-design to some extent and could already see the benefits of such tools. However, there was a high attrition rate of professionals within the main study process, and this generally attributed to competing demands and a lack of time to commit to the sessions. Therefore, work is needed to understand how we can successfully facilitate the engagement of professionals in such processes, perhaps through online and remote platforms (such as Padlet and Microsoft Teams) or different timings for sessions. To answer these questions, some brief consultation with professionals is required. The inclusion of management in this process may also be useful to explore the benefits of participating in such processes and create an understanding of what is needed to allow staff and volunteers time to commit to such processes.

Secondly, it was clear from the process the “how” particularly “how do we get the word out regarding available services interventions?” was a key consideration. This was explored as much as possible within the study with regards to the development and implementation of the intervention in hand. However, there is also scope to consider this issue with regard to other services and interventions. This point has recently been raised by other researchers, with Cunningham et al (2022) emphasising the need for an additional behavioural change technique to acknowledge this gap. However, this work focusses predominantly on social prescribing, which is a possible pathway for some, it was clear from this work there was more than social prescribing needed. In fact, it was suggested organisations should be talking to each other, understanding what is available and referring between each other, rather than the siloed type working evident at present. This siloed type of working was attributed to competitive funding, emphasising a potential flaw in the overarching system. Thus, some exploratory work around how people find out and in turn attend programmes, services and interventions is needed. As has been reflected in this work and that of Cunningham et al (2022), it is necessary to work to develop a great service but more importantly to work to ensure those who may benefit from the service or intervention are aware of it and can engage with it. Therefore, future collaborative work could explore this issue to determine means to overcome these issues and the siloed way of work often present.

Third, in carrying out such research it will be necessary to implement and develop commonly used co-design tools in wider populations. Although evidence is already available for the use of all the tools employed in this study as explored in Chapter 5 it would be interesting regardless to explore which tools are most suited to which populations, be that younger people, different illness populations, different professional populations etc. For example, in this work participants found it difficult to consider the development of the personas in Group 1 (Older adults living with and beyond cancer), and less so in Group 2 (Professionals/Volunteers). Yet, the tool more generally was successful in its use. It would, therefore, be useful to explore different population groups' perspectives of developing personas. Moreover, after creating a number of options for the future intervention, participants in this work felt they could not prioritise these further to make a set recommendation for each element considered and thus, the recommendations are fairly open in this instance. However, this may not be the same in all populations or with all project goals. Although I am certain the correct tools were used in this instance and this was reflected in Part C-Evaluating (Chapter 6), future research could explore the acceptability of these tools, as well as other tools commonly used in co-design with a variety of populations to make recommendations for best practice. However, it is key to remember the adaptive and pragmatic nature of the process and never lose this through standardisation.

Fourth, I am also aware that in some instances academia may not be the best place to facilitate such projects, and instead some focus should be placed on the possibilities within the community, public and third sector organisations. These organisations have different restraints in comparison to academia, and it is likely in working together from the outset will be beneficial with regards to funding, aims and outcomes.

Fifth, and finally, as the majority of recommendations focus on the use of participatory methods and further implementation of co-design, I recommend that future co-design work is evaluated to explore the acceptability of these processes more generally. This will enable our continued learning of such processes and ensure the development/enhancement of these. Often co-design is implemented but not evaluated, consequently missing the vital insights available. Therefore, I suggest evaluation of the processes be considered from the outset. This should also enable a move away from tokenistic, tick box type implementation of Patient and Public Involvement (PPI) project components due to the necessary foresight. Such progress will be particularly useful for the future as more and more funders are calling for Patient and Public Involvement (PPI) components, and the MRC framework now has an embedded PPI focus. Thus, the evaluation of co-design and more generally PPI projects will be key in facilitating our learning of best practice but will also force us to consider why we are implementing such methods and allow for consideration of the acceptability of these.

9.5 How the process has shaped my perspective on research and future work

From the beginning I was conscious it was necessary to reflect on my perspective and how this had shaped the research process and aims (Section 1.4). I also took time to reflect on my positionality and reflexivity, as advised by my examiners, evidence of this can be found in Appendix 30. Now coming to the end of the process it is necessary to reflect and understand how this has shaped my perspective and influenced the way I tackle current projects. At the beginning of the process, I was aware I was uncomfortable with solely quantitative methods and felt a need to explore what people actually want from interventions and services as opposed to imposing these on them. However, I am aware that throughout the process I worked to make sure I was comfortable within the process, and this sometimes influenced the methods I chose, as I was aware this was a steep learning curve. Now I am keen to use further participatory tools and methods and explore co-design and the benefits this can be bring more generally, focussing on a variety of topics. I have been working using co-design to develop a lung cancer screening programme, a social prescribing scheme and information materials to promote access to primary care (Brown, Sullivan, et al., 2022; Brown, Williams, et al., 2022). Throughout these projects the learning and knowledge I have gained from PhD has been invaluable and has shaped the methods used in these projects. This work has often been well received, with limited reviewers' comments in peer review, and my expertise in this area has been acknowledged and led to instances where I support others to use these methods, both junior and senior researchers.

As yet I have not managed to take a step back as I have recommended and work to understand what people need generally, rather than what they need within an already predetermined aim. This is likely difficult to do due funding restraints etc. but it is something I am striving towards. Such methods and research is becoming more common and so I will keep promoting the benefits of this and the key premise of **"doing with, not to"**.

Reflection Box 14-Understanding the PhD is a learning experience

It took me a while to understand that completing a PhD is a learning experience. However, now understanding this has made working through the process somewhat easier. I am aware I have made some mistakes, merged different theories and perspectives and definitely brought my quantitative background to what is a very qualitative process. However, this process and these mistakes or adaptions have enabled and created this learning experience. It may not have been possible to conduct such a process outwith the PhD, as other factors are at play, for example funding and targets. I am also aware that I still have a lean towards quantitative methods and sometimes this is evident in the way I write or initially think about analysis. However, this process has highlighted this, and it is something I will continue to work on, to ensure I can work with those who are often underserved and develop services that are suited to their needs. In all this has all been a great learning experience and I am looking forward to using the skills and knowledge I have gained in future projects.

9.6 Contributions to knowledge

From an empirical perspective this study adds to the current body of literature regarding the development of interventions and services for older adults living with and beyond cancer. I am making a case for a move away from a focus on behaviours and instead a move towards person centred, tailored services addressing the needs and goals of the individuals, which may in turn mean the behaviour is a means to a greater end, i.e., social interaction. Thus, the empirical contribution creates a detailed and rich case for social aspects and person centeredness, spanning research, services and everyday living. These findings contrast with the findings from the systematic review conducted, in which the majority of interventions provided were home-based individual interventions, with limited social interaction. It may be that group-based interventions, with peer-led elements and a key focus on the provision of social interaction, as well as tailored goals and components is more acceptable to the population of older adults living with and beyond cancer, and in turn more effective.

A methodological contribution to knowledge has also been made, as the methods used were used in a novel way for a unique purpose, with key learnings and recommendations brought to light for consideration in future work. The reflections detailed throughout the thesis will be useful for individuals considering the use of co-design and in particular EBCD in the future. The discussion regarding the tensions between co-design and behaviour change theories also add to the current evidence base and create a point for future research and debate regarding the best use of co-design and EBCD for intervention development. Finally, the acknowledgement that co-design can at times be tokenistic and the reflection on the extent to which this work reflected the key tenets of co-design is useful knowledge for future consideration, as is the reflection on the necessity and benefits of methodological adaptions.

Finally, although no theoretical basis was developed the thinking detailed around the use of theories and the possible contrasting philosophies of top down (theory driven) vs bottom up (person driven) work is useful and creates space for future similar discussions. This thesis has explored the role of behaviour change theory within and in relation to the results of a co-design process, as well as identified the necessity to consider broader theories to fully understand the results and determine effective recommendations for future work.

9.7 Conclusion

This thesis has explored a co-design process drawing on EBCD and other standard co-design tools and methods. Although the process deviated in some ways from more standardised EBCD methods, the insights are rich and useful for moving forwards with regards to both future use of co-design methods and future intervention development, implementation and evaluation.

The overarching aim of the study was to use co-design to develop intervention recommendations with and for older adults living with and beyond cancer to improve the behaviours diet, physical activity, and sedentary time. This aim was met, in that key recommendations for future intervention development were identified-focussing on the 3 key themes, (1) social is key, (2) consider the individual and (3) ensure ease of access to interventions or services. Furthermore, specific components and potential means of intervention delivery were identified and mapped broadly to the TIDIER framework for interventions (Hoffmann et al., 2014). These elements focussed on the, **What, Who, Where, When, How**, **Focus** and **Format** of the intervention. Details of each can be found in Chapter 5. It is also necessary to consider the sense that participants involved in the study were less interested in the specific behaviours, other than physical activity for some, and more interested in social contact and regaining a sense of self or “getting back to me”. In essence we must enable individuals to flourish after cancer and work with them to create services that facilitate this.

Objective 1: engaging the community was effectively met. The work undertaken to engage the community was successful, key groups were identified and relationships developed with those working in key areas related to the support of older adults living with and beyond cancer. It is expected this was a key factor in the success and engagement with the co-design process, due to the ‘buy-in’ evident within the community.

Objective 2: identifying key barriers and facilitators to participation was in part met. Key barriers and facilitators were often intertwined, with some facets identified as barriers for some and facilitators for others. However, the majority of barriers identified were identified by the professionals and volunteers involved in the study, as they had an overview of individuals who might find it more difficult to participate, in contrast to those who were involved in the study and were motivated and engaged in community efforts and keen for social contact. The key barriers identified were ranked and, in this process, grouped in to emotional, personal and practical.

Objective 3: determining or developing a theoretical basis was also met, although not in the way I had originally anticipated. Instead, the role of theories in these types of studies were explored and discussed. Theories of change and broader theories were considered in light of the findings and recommendations made regarding their role in future co-design processes, as well as future service or intervention development.

Objective 4: evaluating the process was successfully conducted. The process was successfully evaluated using mixed methods surveys embedded within the co-design process. The quantitative components of these surveys showed that participants felt involved, considered, and enjoyed the process, also indicating it was worthwhile. The qualitative component of this identified three key themes which effectively relay the sentiment of the evaluation, these were (1) spaces and places, (2) learning and doing, and (3) relationships and roles with an overarching theme of 'Putting the co into co-design'.

Overarching Aim: The overarching aim was met through the objective and also more specifically through the development of recommendations and potential elements for a future behaviour change intervention, targeting physical activity and less so diet and sedentary time. These elements and recommendations were expected to ensure the interventions was successful and acceptable. However, embedded within this was the acknowledgement that for some the behaviours may not be the most important factors, and should be considered as a potential catalyst to broader goals, as opposed to the main outcome of the intervention. The overarching recommendations focussed on three key themes 1. Social is key, 2. Considering the individual and 3. Enabling access.

In all, this process has added a wealth of insight and understanding to the current knowledge base around intervention design, targeting physical activity, diet and sedentary time for older adults living with and beyond cancer, an often-underserved population. All aims and objectives were met, with key recommendations for future interventions ready to be taken forward and implemented, i.e., 1. Social is key, 2, Considering the individual and 3. Enabling access. However, it is possible some rethinking around the outcomes and focus on behaviour change is required to ensure these are acceptable and effective. One final point to consider: is it possible we are making behaviour change and interventions too complex? Perhaps it is time to go back to basics, build in opportunities to socialise and reap the unintended benefits. Continuing to work in a collaborative manner through participatory methods such as co-design will ensure we really do learn what really matters to older adults living with and beyond cancer.

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Appendices

Appendix 1-Search strategy example systematic review

ID No	Search Term	Options/Limits	Results
S7	S1 AND S5 AND S6	Limiters - Published Date: 20070101-20170631 Search modes - Boolean/Phrase	(479)
S6	S2 OR S3 OR S4	Search modes - Boolean/Phrase	(411,628)
S5	TI (ag#ing OR older OR elder* OR geriatric* OR gerontol*) OR (MM "Geriatrics") OR (MM "Aged") OR (MM "Aged, 80 and Over") OR (MM "Aging")	Search modes - Boolean/Phrase	(133,398)
S4	(MM "Life Style, Sedentary") OR ("Sedentary") OR ("inactivity")	Search modes - Boolean/Phrase	(12,628)
S3	(MM "Diet+") OR (MM "Nutrition") OR (MM "Public Health Nutrition") OR (MM "Geriatric Nutrition") OR (MM "Diet Therapy+") OR (MM "Eating") OR (MM "Eating Behavior+") OR ("Diet*") OR ("Nutrition*")	Search modes - Boolean/Phrase	(233,465)
S2	(MM "Physical Activity") OR (MM "Activities of Daily Living") OR (MM "Exercise+") OR (MM "Therapeutic Exercise+") OR (MM "Leisure Activities") OR (MM "Walking") OR (MM "Sports+") OR ("Swimming") OR ("Yoga") OR ("Dance") OR ("physical activity") OR ("exercise")	Search modes - Boolean/Phrase	(207,875)
S1	(MM "Cancer Survivors") OR (MM "Cancer Patients") OR (MM "Neoplasms+") OR (MM "Neoplasms by Site+") OR (MM "Neoplasms by Histologic Type+") OR (MM "Oncology") OR (MM "Rehabilitation, Cancer") OR (MM "Oncologic Care") OR ("Cancer") OR ("Oncol*")	Search modes - Boolean/Phrase	(440,024)

Appendix 2-Data extraction variables systematic review

1. Aim of study
2. Design
3. Setting
4. Target behaviour
5. Target population
6. Outcome assessed (effectiveness and/or acceptability)
7. Description of methods 8. Description of intervention
9. Duration of intervention
10. Theoretical basis of intervention
11. Description of recruitment
12. Number of participants
13. Participant demographics
14. facilitators/barriers to intervention participation
15. Behaviour Change Techniques
16. Description of outcome measures to include whether the measures were standardised and/or objective
17. Follow-up period if conducted
18. Statistical analysis used
19. Description of results
20. Missing data
21. Inclusion of all outcomes
22. Attrition
23. Key conclusions by author
24. Limitations

Appendix 3-Study characteristics systematic review

Author, Year & Location	Study Design	Participant Demographics	Behaviour	Effectiveness or Acceptability	Intervention description	Measures	Measurement Time points	Reported Results
Bourdel-Marchasson et al (2014) France	Randomised Control Trial	N=336. Average age in usual care group=78.3 and intervention group=77.7. 54.5% male in usual care group and 47.9% in intervention group. Participants were current patients undergoing chemotherapy for a variety of cancer types-colon, stomach, pancreas, non-small cell lung, prostate, bladder, ovary, breast and lymphoma.	Diet	Effectiveness	Experimental group received a nutritional intervention consisting of dietary advice. The advice was tailored for each patient and relatives/carers were involved where possible. Dietary advice was complimented by an oral supplement if necessary. 6 face-to-face visits with dietician were planned throughout chemotherapy treatment period and a phone call was made if a gap of 2 weeks or more was prevalent between visits. The intervention lasted 3-6 months depending on the length of treatment. Control group received usual nutritional care provided in treatment setting.	A one day dietary record completed the day before each visit, 1 year mortality rate, chemotherapy management, hospitalisation for reasons other than chemo and 2 year mortality rate	Baseline and at each session thereafter, with a 1 and 2 year follow-up for mortality and hospitalisation incidence.	Significant improvement in dietary intake in intervention group compared to control group throughout intervention period. However, intervention group already had a significantly higher intake at baseline. No differences in 1 year or 2 year mortality or chemo management between groups
Buffart et al (2015) Australia/New Zealand	Randomized Control Trial	N=100. Inactive but able to walk 400m prostate cancer patients, previously treated with ADT and radiotherapy. No bone metastasis. Mean age 71.9 in intervention group and 71.5 in control group, average time since diagnosis 5.6 years	Physical Activity	Effectiveness	The intervention group received supervised aerobic and resistance exercise training program for 6 months followed by instruction to complete 6 months of home based exercises. The control group received printed material regarding PA and a pedometer for 12 months. Intervention period lasted 12 months.	Demographic and clinical data, EORTC QLQ-C30, 400 meter walk test, Godin Leisure Time exercise questionnaire, pedometer, fatigue measured by a subscale of the EORTC	Baseline, 6 months and 12 months	Effects on PA, fatigue, distress and falls self-efficacy did not differ significantly between groups. The intervention group exhibited significant improvement in 400-metre walk. Reductions in repeated chair rise time were significantly associated with improved global QoL, while reductions in fatigue were associated with improved

								QoL. Chair rise time mediated the effect of the intervention on QoL, as well as physical and social function. Reductions in distress and falls self-efficacy were associated with QoL. The intervention group displayed significant improvements in global QoL, physical function and social function at 6 months compared with the control group. At 12 months, there was a similar difference but this was insignificant. All other HRQoL subscales were insignificant between groups. Marital status and time since diagnosis significantly moderated intervention effects on global QoL.
Clutter Snyder et al (2007) USA	Randomized Controlled Trial	N=182. Adults within 18 months of diagnosis from breast or prostate cancer. Mean age of intervention group=71.5 and control group=71.9. The majority of participants were white, married, female, and educated.	Diet	Effectiveness	Participants received a personalised workbook detailing info regarding PA and diet. Followed by 6 telephone counselling sessions dedicated to nutrition providing feedback and creating strategies to achieve goals. A further 6 sessions were presumably dedicated to PA. The control group received a personalised workbook on general health topics e.g. falls/flu shots and 12 untargeted telephone counselling sessions.	3 day dietary recall and Diet Quality Index-Revised (DQI-R)	Baseline 6 months and 12 months follow-up	A significant increase in diet quality for intervention group at post-intervention measurement. However, no significant differences were identified at 12-month follow-up indicating the intervention effect is not easily maintained. DQI-R is an effective tool for evaluating diet quality.

					Intervention period lasted 6 months.			
Demark-Wahnefried et al., (2012) USA	Randomized Controlled Trial	N= 488. Overweight, older breast, colorectal and prostate cancer survivors, at least 5 years since treatment. Average age in immediate intervention group=73 and 72.9 in delayed intervention group. Participants were predominantly white, almost 50% male, mostly breast and prostate cancer patients, lower number of colorectal cancer patients.	Physical Activity and Diet	Effectiveness	RENEW intervention see Morey et al	Change in physical function was measured by physical function scale in SF-36, basic and advanced lower extremity function subscale of late life function and disability index. Physical activity measured by CHAMPS and diet via unannounced dietary recall phone calls assessing diet in the last 24 hours using a nutritional data system for research software. Self-reported height and weight estimations for BMI.	Results referring primarily to follow up of RENEW intervention. Measurements referred to at post-intervention for delayed group and 2 year measurement of immediate intervention i.e. (1 year follow up)	Both arms displayed significant improvements in diet quality, Physical activity and BMI at year 2. The delayed intervention arm displayed more specific significant results. No significant relapse over the year-long follow-up was evident for the immediate intervention arm, implying the intervention creates maintainable results, yet rates of functional decline increased over this time period
Dronkers et al., (2010) Netherlands	Pilot Randomized Controlled Trial	N=42. Participants were patients waiting to undergo elective abdominal oncological surgery, with good cognitive abilities and no other chronic conditions that may impair participation. Average age in intervention group 71.1, predominantly male	Physical Activity	Feasibility and preliminary effectiveness	2 sessions a week for waiting time period before operation. Sessions lasted 60 minutes and included set elements e.g. resistance training, warm up, etc. When Participants could not attend the sessions they were prescribed home based exercise including walking and given a pedometer, as well as a device for inspiratory muscle training. These exercises were tailored based on baseline measurements including the Borg scale of perceived exertion. The control group was provided with home based exercise advice.	Demographics and hand grip strength. Feasibility was assessed by adherence to advice, patient appreciation of advice and adverse events. Measures of effectiveness included maximal aerobic capacity, inspiratory muscle endurance, functional mobility-timed up and go test, LASA physical activity questionnaire, pedometer for walking time. Qol measured by EORTC and fatigue by the abbreviated fatigue questionnaire. Post-operative complications were also measured.	Baseline, Pre-operative and post-operative	Patients appreciated the intervention and felt it prepared them for surgery and did not report any discomfort, indicating it was feasible. A significant increase in inspiratory muscle function was observed but no changes in PA, walking (pedometer), QoL or any differences in post-operative complications.

Loprinzi, Cardina, Si, Bennett, & Winters-Stone (2012) USA	Sample from larger RCT	N=69. Older breast cancer survivors, who had completed treatment 2 years prior to enrolment and who were currently inactive. Average age=70.6. Majority of participants were white, married, retired and educated above high school level.	Physical Activity	Effectiveness and feasibility/acceptability	3 arms-aerobic exercise, resistance exercise or control. Intervention groups attended supervised exercise classes 3 days a week for 12 months. After the 12 months participants were asked to continue the exercise at home for 6 months. Control group consisted of stretching and relaxation exercises.	TTM variables-stages of change, processes of change, self-efficacy, decisional balance. Self-reported PA, as well as demographic characteristics e.g. Weight, BMI,	This study only refers to data from follow-up at 6 months post-intervention.	At 6 months, follow-up participants with higher behavioural processes of change use at the point of transition from intervention to no intervention were more likely to be active. Participants with higher self-efficacy were more likely to be active 6 months after the intervention
Maeda et al (2016) Japan	Prospective Non-Randomized Controlled Trial/Observational Study	N=19. Adults aged 85 or less undergoing surgery for lung cancer. Participants were excluded if they had a severe medical conditions e.g. renal failure. Average age in the control group=75.3 and the intervention group=72.4, majority of participants were male.	Physical Activity	Effectiveness	All participants completed pre-operative spirometer training. The intervention group received post-operative exercise sessions twice a week for 8 weeks, consisting of respiratory exercises and mobilization on a bench, then high intensity training of patients lower limbs on treadmill or bike. Exercise was tailored to the individuals based on the results of their cardio-pulmonary exercise test. Control group received usual care.	Forced vital capacity, forced expiratory volume and St George's respiratory questionnaire. PA measured using an accelerometer.	Pre-surgery, post-surgery and 2 months after discharge	Total PA decreased after surgery in the control group but not the intervention group. The intervention group were doing significantly more moderate-vigorous PA than the control group after surgery (p<.005). No changes in other measures observed, except significant increase in dyspnoea in control group pre-post but not in intervention group. In all PA decreased in control group from pre-/post-surgery but not in the intervention group.
Mina et al (2013) Canada	Randomised Trial-2 intervention groups	N=66 prostate cancer patients on ADT throughout the study period. Average age of AET group-72.1 and RET group-70.6.	Physical Activity	Effectiveness	Aerobic exercise training intervention (AET) was prescribed at 60-80% of heart rate. Participants were given a heart rate monitor, which enabled tailored prescription	Demographic info, disease specific HRQoL (FACT-P), patient oriented prostate utility scale (PORPUS) fatigue (FACT-F). Exercise adherence was measured by attendance to	Baseline, mid-intervention (3 months), post-intervention (6 months) and post-	From baseline to 12 months the AET group improved physical activity volume, waist circumference and body fat%. There was also a

		Predominantly white, married, retired and with high school education or above.			of AET based on heart rate; the monitor audibly indicated when they were outside the correct zone. The monitor was provided with walking in mind; however, participants who preferred to do activities other than walking were taught how to read their own heart rate. Participants were encouraged to increase their exercise time as the intervention progressed and strive for higher heart rates in their training zone. Resistance exercise training (RET) participants were given three resistance bands, an exercise mat and stability ball and were asked to perform 2-3 sets of 8-12 reps at 60-80% maximum rep. Each had exercise was classified as beginner, intermediate or difficult, participants were encouraged to progress through the stages were possible. Both interventions were home based with 12 supervised booster sessions throughout the initial 6 month intervention period. Participants were encouraged to continue with the exercises for a further 6 months, total intervention period=12 months.	booster sessions. PA measured by the Godin Leisure time exercise questionnaire with additional questions to enable changes to METs/min. Aerobic fitness measured by peak oxygen consumption. Further measures: grip strength, BMI waist circumference, body fat% using callipers and chest skin-fold thickness.	intervention follow up (12 months).	between group difference where AET group improved PA from baseline to follow up by an average of 13.9MET-hr-wk vs RET 2.5 METS-hr-week p=.037 (intention to treat analysis). From participants who completed all measures the AET group showed even greater improvements than in the intention to treat analysis. AET attended 16.4% of booster sessions and RET 5.5%
Morey et al (2009) USA/UK/Canada	Randomized Controlled Trial	N=641. Older overweight long term breast prostate or colorectal cancer survivors, at	Physical Activity and Diet	Effectiveness	Tailored information mailed out to participants and telephone counselling sessions. Wait list/delayed intervention	Functional status was measured using the SF-36 subscale, basic and advanced lower extremity function subscale from late life function and disability index.	Baseline, 12 months post-intervention and 24 months follow-up	PA, dietary behaviour and overall QoL increased significantly in the intervention group compared to the control

		least 5 years from end of treatment with no signs of future disease/progression. Mean age of intervention group=73 and control group 73.1, mostly white, female, and breast/prostate cancer.			control. Intervention period lasted 12 months.	The entirety of SF-36 was also used. PA was measured using CHAMPS. 24-hour diet recall via random unannounced telephone calls at baseline and at 12 months for diet quality. Self-reported height and weight for BMI, demographics, symptoms, other medical conditions,		group, physical function decline reduced less rapidly in the intervention group,
Nyrop et al (2014) USA	Pre-Post-intervention test	N=20. Older breast cancer survivors on aromatase inhibitor therapy. Mean age=71, predominantly white (85%) and with high school education or above	Physical Activity	Feasibility/acceptability and Effectiveness	Walk with Ease intervention-a low impact walking program. Participants are provided a workbook and asked to complete a PA diary and are told the importance of PA but then are expected to self-start the intervention and walk at home. Intervention period 6 weeks.	Demographics. Feasibility was measured by recruiting target population. Effectiveness measured by time spent walking, joint symptoms (pain scale, stiffness scale, fatigue scale,) self-efficacy (arthritis self-efficacy scale).	Baseline and post-intervention (6 weeks)	Deemed feasible due to success of recruitment, eligibility of participants and engagement with intervention. At 6 weeks all 3 walking measures showed significant improvement. Overall the proportion of participants achieving the goal of 150min/week increased from 21% to 50%. However, 12.5% also reduced their walking time. Joint pain, joint stiffness and fatigue decreased but were not significant from baseline to post-intervention.
Reynolds, Thibodeaux, Jiang, Francis, & Hochhalter (2015) USA	Pre-Post-Intervention test	N=72. Older adults with a diagnosis of any cancer but not currently on any active treatment. Must report the ability to participate in PA. Average age=70.4. The	Physical Activity	Feasibility/acceptability and Effectiveness	3 sessions per week for 8 weeks of fit and strong programme, which consisted of 60 minutes of group PA and 30 minutes of education in each session. Fit and strong was initially designed for arthritis but was later altered to suit	Demographics. Feasibility measured by recruitment and course completion. Effectiveness measured by minutes of PA, self-efficacy for exercise and quality of life in adult cancer survivors (QLCAS).	Baseline and post-intervention (8 weeks).	Deemed feasible due to achievement of specified recruitment rate and 68% retention rate. Participants were also interested in continuing with the programme after completion of the study. Also, significant increases

		majority of participants were female. 18 different types of cancer were represented. The median time since treatment was 7 years.			cancer survivors. There was a set curriculum for the sessions.			in PA, self-efficacy for aerobic exercise and symptoms related to depression and anxiety observed. Symptoms related to depression and anxiety were subscales of the QLCAS.
Sajid et al (2016) USA	3 Arm Pilot Randomized Controlled Trial	N=19. Sedentary, older adults with prostate cancer on androgen deprivation therapy. Average age70, predominantly white, married and retired	Physical Activity	Effectiveness	Arm 1-EXCAP. Participants were provided with an exercise kit. The EXCAP intervention consists of 2 components, aerobic and resistance training, walking programme with number of steps as goals and resistance band training. For the band training participants used 1 of bands each which had a different level of resistance. Participants were instructed to increase the resistance when possible. Arm 2-WiiFit. Exercise modules on Wii-fit were developed and implemented that were expected to mimic the exercise in EXCAP with the addition of a balance component. All exercise in both intervention groups was tailored to the participant at baseline measurement. Weekly reminders to complete measures were provided via the phone. The intervention period was 6 weeks. Participants in both intervention groups were encouraged to continue the intervention for a further 6 weeks but with no prompts	SPMSQ, SPPB, handgrip test, 6 min-walk test, chest press, pedometer, x-ray for skeletal muscle mass, daily diary for steps, demographic and clinical data.	Baseline post-intervention (6 weeks) and follow-up (12 weeks).	A significant increase in SPPB score in the EXCAP group (p=0.04) was observed, while a non-significant increase in this outcome was observed in the Wii fit arm. An increase in grip strength and chest press in the EXCAP arm at 12 week was observed but this did not reach significance. A significant increase in steps per day in EXCAP arm (+2720 steps per day) increase at both measurement times compared to 97 in the control group (usual care; p<.01). A non-significant increase of 382 steps in the Wii fit arm was observed. It is however, difficult to discern whether changes are at 6 weeks post-intervention or 12 week follow-up.

					from staff. Arm 3-control. Participants received usual care.			
Suh et al (2013) South Korea	Prospective Single Blind Randomized Controlled Trial	N=70. Gastrointestinal cancer survivors, at least 6 months from completion of treatment. Participants were excluded if they had another serious illness e.g. heart disease or arthritis. The average age was 71.1. Participants were predominantly married, educated and male.	Physical Activity and Diet	Effectiveness	CHP-K intervention, which consisted of Qi exercise (mind-Qi body training) and SOC counselling. QI involves shaking, stretching and joint movement combined with meditation. The Qi exercise was designed specifically with elderly cancer survivors in mind, with the meditation focussing on the affected organ. The intervention consisted of 1-hour onsite session each week and 20 minutes per day at home for 8 weeks. The counselling consisted of a 1-hour initial face-face session and a further 20-minute telephone session each week for the remaining intervention period. Based on the counselling a care plan and symptom management plan was set up. A text message prompt was sent to participants each week. The Control group received usual care.	A self-report booklet was used to measure physical activity. Nutritional status was measured using the patient generated subjective global assessment. Symptom experience measured using the M.D Anderson symptom inventory. Self-efficacy for health promotion and self-esteem were measured using a scale developed by the authors. Height, weight and other general demographics were measured.	Baseline, Mid-intervention (4 weeks) and post-intervention (8 weeks).	Significant improvements in PA, nutritional status, weight management, symptom management, self-efficacy and self-esteem were reported across and between groups.
Winger et al (2014) USA	Randomized Controlled Trial	N=641. Older, overweight adults, 5 or more years after breast, prostate or colon cancer. Overweight. Inactive participants only, with no contraindications for	Physical Activity and Diet	Effectiveness and feasibility/acceptability	RENEW intervention see Morey et al	Demographics and medical info. Telephone counselling session attendance, intervention period exercise and dietary behaviour. A self-monitoring log was used to measure physical activity and diet, as well as a fat gram counter booklet for saturated fat intake. Specific behaviours	Baseline, post-intervention (12 months) and follow-up (24 months).	Telephone session attendance was significantly but indirectly associated with health outcomes through intervention period exercise and dietary behaviour. Session attendance had a

		behaviour participation. Average age=73.6. Majority of participants were white and female.				measured included strength exercise, endurance exercise, fruit and veg intake and saturated fat intake. Physical function was measured using the 10 item physical function subscale from the medical outcomes study short form 36 (SF-26). Basic and advanced lower extremity function was measured using the late life function and disability scale. Mental health was measured using the 14 item scale from the SF-36, BMI was also calculated.		significant indirect relationship with other variables including mental health, physical function, basic and advanced lower extremity function and BMI. Session attendance is vital in facilitating improvement in health behaviours and other outcomes.
Yamamoto et al (2016) Japan	Pre-/Post-intervention test	N=22. Older adults with a diagnosis of gastric cancer and sarcopoenia waiting for surgery. Average age=75, 10 males and 12 females.	Physical Activity and Diet	Effectiveness	Patient self-report sheets were provided to monitor adherence to program and provide motivation. The program consisted of an exercise and a nutrition component. The exercise component consisted of handgrip training, walking, and resistance training. Handgrip training was done 20 times daily, a total of 7500 steps were recommended. 3 sets of 10 reps of resistance training exercises (e.g. sit-ups/push-ups/squats) were also implemented at 40-60% max threshold. Nutritional advice was also provided.	Adherence and duration of exercise, nutritional intake, body composition and sarcopoenia parameters. Post-operative clinical course e.g. complications.	Baseline and Post-intervention	Total calorie and protein intakes were significantly higher after the program. Four patients became non-sarcopoenic after the program. Gait speed and skeletal muscle mass increased but this was insignificant.

Appendix 4-Example recruitment information distributed by gatekeepers to Group 1

Hello,

My name is Lynsey Brown, I am a PhD student at Edinburgh Napier University. I am writing to you to invite you to take part in a research study I am currently running.

The study aims to develop a lifestyle programme for people aged 65 and over living with and beyond cancer. The programme will focus on lifestyle behaviours, for example diet and physical activity. If you are aged 65 or over and have had or have cancer I would like to hear your views and co-create something that suits the needs and requirements of you and others like you.

If this is you and sounds like something you would like to be part of please have a look at the information sheet attached. This will tell you all you need to know before you decide to take part. Should you decide to take part you will be supported to attend where possible.

If you decide to take part after reading the information sheet please get in touch with me using the contact details below. I'd appreciate it if you could get back to me ASAP if you are interested in taking part.

Lynsey Brown
[redacted]

Thank you for taking the time to read this information

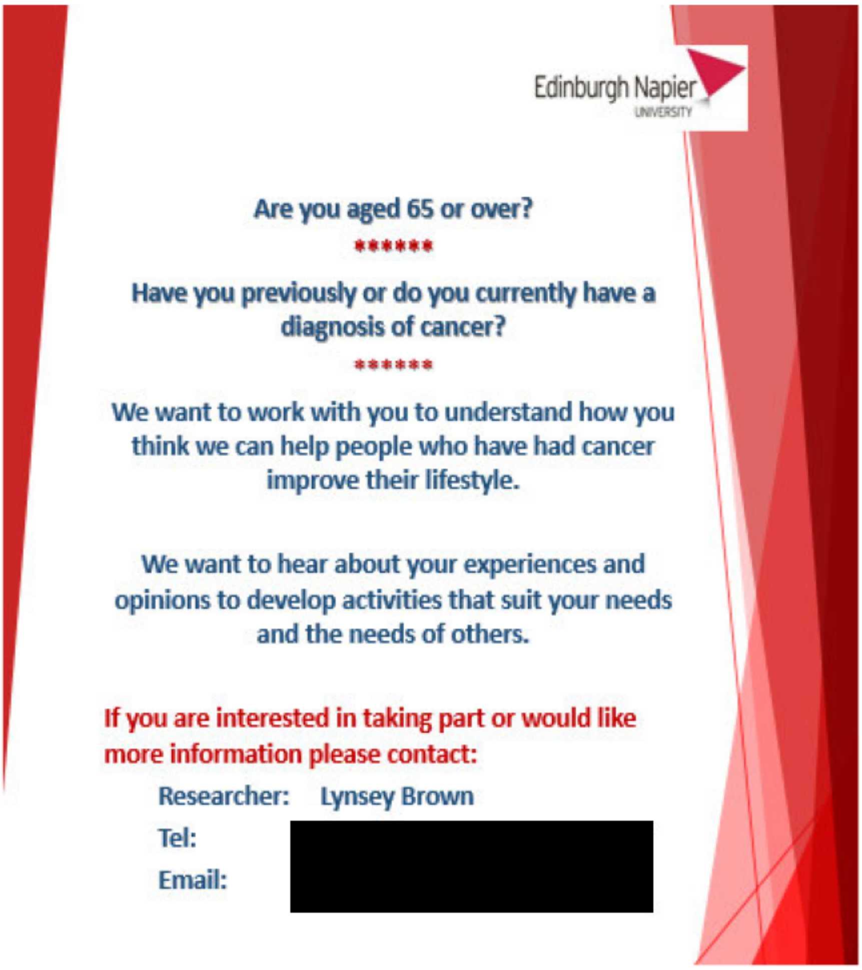
I look forward to hearing from you

Kind Regards

[redacted]

Lynsey

Appendix 5-Recruitment advertisement, Group 1



Edinburgh Napier UNIVERSITY

Are you aged 65 or over?

******

Have you previously or do you currently have a diagnosis of cancer?

******

We want to work with you to understand how you think we can help people who have had cancer improve their lifestyle.

We want to hear about your experiences and opinions to develop activities that suit your needs and the needs of others.

If you are interested in taking part or would like more information please contact:

Researcher: Lynsey Brown
Tel:
Email:
[redacted]

Appendix 6-Email invitation circulated to recruit to Group 2

Hello,

My name is Lynsey Brown, I am a PhD student at Edinburgh Napier University. I'm writing to you to invite you to take part in a research study I'm currently running.

The study aims to develop a lifestyle intervention for people aged 65 and over living with and beyond cancer. The intervention will focus on lifestyle behaviours, for example diet and physical activity. As you work with individuals in the target population, we would like to work with you and hear your views. You will be invited to take part in an interview and later focus groups/workshops with adults aged 65 and over living with cancer, in order to co-design a programme that suits the needs of all major stakeholders.

If this sounds like something you would like to be part of please have a look at the information sheet attached. This will tell you all you need to know before you decide to take part.

If you decide to take part after reading the information sheet please get in touch with me using the contact details below. I'd appreciate it if you could get back to me ASAP if you are interested in taking part.

Lynsey Brown

[redacted]

[redacted]

Thank you for taking the time to read this information

I look forward to hearing from you

Kind Regards

[redacted]

Lynsey

Appendix 7-Participant information sheet (PIS) Group 2

Participant Information Sheet-Group 2

Project Title

Using Co-design to develop a lifestyle programme for adults aged 65 and over living with and beyond cancer.

I would like to invite you to be a part of the development of a lifestyle programme for adults aged 65 and over living with and beyond cancer. Unlike other programmes which may be prescribed to participants, I would like to hear your views and create something which suits the needs and requirements of the individuals you support. Before you decide whether or not you would like to take part, it is important that you understand why I am carrying out this study and what exactly it involves if you agree.

This leaflet should help explain what I am doing, so please take time to read it carefully and discuss it with others if you wish. If there is anything you are unsure about or you want to find out more please ask us for more information.

Who am I?

I am Lynsey Brown, a PhD student from Edinburgh Napier University, working with a supervisory team from the University. This study is being conducted as the main body of research for my PhD.

What is the purpose of the study?

I am interested in finding out your views about physical activity, diet and sedentary time. I would also like to hear why you think adults aged 65 and over who have had or have a cancer diagnosis do or not participate in these behaviours and how you think we could promote these behaviours in this population. We will reflect on what you have said and use this to create a lifestyle programme designed specifically for adults aged 65 and over living with and beyond cancer.

Why have you been chosen?

You have been chosen because you work in supportive manner with adults aged over 65 who have previously had or have a cancer diagnosis.

Do you have to take part?

No, you do not have to take part in this study. If you do decide to take part you are encouraged to save and keep this Participant Information Sheet for your future reference. You are still free to withdraw from the study at any time and you do not need to give a reason for doing so.

What will you have to do?

If you decide to participate you will be asked to take part in a co-design process, which will consist of the following 3 stages. You will firstly be invited to take part in stage 1 and you may later be invited to take part in stages 2 and 3. You will be supported to attend these sessions. Stage 1 will take place in location mutually agreed by you and I. Stages 2 and 3 will take place within your local community/Edinburgh Napier University.

1. You will firstly be asked to take part in an interview that will include questions about your perceptions of the lifestyles of adults aged 65 and over who have or have had a cancer diagnosis. As well as why you think these individuals do or not take part in specific activities for example exercise. You will also be asked about your relationship with those you have supported. This interview will last approximately 30 minutes and will be video/audio recorded, if you agree to this. This recorded information will be used to inform discussion in stages 2/3 and some small segments could be played to facilitate this.

2. You may then be asked to take part in a focus group with other individuals who work/volunteer in a similar capacity to yourself. This group will further reflect on the barriers and facilitators of the behaviours physical activity, diet and sedentary time. In this session you will also be asked to contribute to some participatory tasks.   This session will last approximately 1-2 hours. At the end of this session you will be asked to complete a brief survey evaluating your experience of the session, this should only take 5-10 minutes. This session will also be video/audio recorded.

3. Finally you will be invited to take part in a co-design session. This group will include members of the research team, adults aged 65 and over who have had or have a cancer diagnosis and other support staff from within the local community. This session will focus on the needs, focus and development of the programme. You will be asked to contribute to further participatory tasks and provide feedback on the programme development. This session will be approximately 2-3 hours in length. At the end of the session you will be asked to complete a brief survey evaluating your experience of the session, this should only take 5-10 minutes. As with the previous sessions, this session will also be video/audio recorded. This session will also incorporate a celebration event.

Will your information be kept confidential?

You will be allocated a study number this will be used to ensure the information you provide is anonymous and to link your data throughout the study. This number will also be used for dissemination purposes. Only the research team will have access to the information you provide. All data from the study will be securely stored in either a locked cabinet or in a password protected file on the University's secure network.

Has this study been reviewed by an ethics committee?

Yes, the study has been reviewed by the Research Integrity Committee in the School of Health & Social Care at Edinburgh Napier University. There were no ethical objections to this study being carried out.

What will happen to the results of this study?

The findings of the study will be used to develop a lifestyle programme for adults aged 65 and over living with and beyond cancer. Therefore, the main output will be the programme recommendations/key components. The findings will also be used to form my PhD thesis and will be shared at national and international conferences, and published in academic journals. You will not be identifiable in any of these outputs, I will use a coding system and remove any personal details or identifiable feature, to ensure the information you provide is kept confidential. Stills from the videos may be used to illustrate the process and/or results, in which case steps will be taken to ensure you remain anonymous, for example your face will be blurred out. A summary of the findings of the study will be shared with all who participated after the completion of the study. All identifiable data will be deleted at the end of the study (i.e. after study results are shared with those involved), while anonymous data will be retained for 10 years (in line with University policy).

Who has designed this study?

This study has been designed by Lynsey Brown, along with her supervisory team from the School of Health & Social Care at Edinburgh Napier University.

Where can I get further information about this study?

If you have any questions or would like further information about the evaluation, please contact:

- Researcher: Lynsey Brown at the School of Health and Social Care, Edinburgh Napier University ([redacted]).
- Supervisor: Dr Richard Kyle at the School of Health and Social Care Edinburgh Napier University (email: [redacted].

If you wish to speak to an independent advisor about the project, or if you have any complaints, please contact:

Dr Anne Rowat
Chair, School Research Integrity Committee
School of Health & Social Care
Edinburgh Napier University
[redacted]

Thank you for taking the time to read this information.

Appendix 8-Participant information sheet (PIS) Group 1

Participant Information Sheet-Group 1

Project Title

Using Co-design to develop a lifestyle programme for people aged 65 and over living with and beyond cancer.

I would like to invite you to be a part of the development of a lifestyle programme for adults aged 65 and over living with and beyond cancer. The programme will be made up of some activities designed to improve diet and increase activity time. Other programmes like this may have been prescribed to you. Unlike these programmes, I would like to hear your views and co-create something which suits the needs and requirements of you and others like you. Before you decide whether or not you would like to take part, it is important that you understand why I am carrying out this study and what exactly it involves if you agree.

This leaflet should help explain what I am doing, so please take time to read it carefully and discuss it with others if you wish. If there is anything you are unsure about or you want to find out more please ask us for more information.

Who am I?

I am Lynsey Brown, a PhD student from Edinburgh Napier University, working with a supervisory team from the University. This study is being conducted as the main body of research for my PhD.

What is the purpose of the study?

I am interested in finding out about your views on physical activity, diet and sedentary time. For example why you are or are not physically active? And how you think individuals could be encouraged to be more active or improve their diet? We will reflect on what you have said and use this to create a programme and activities designed with your needs and ideas as the central focus.

Why have you been chosen?

You have been chosen because you are an adult aged 65 or over who has previously had or has a cancer diagnosis.

Do you have to take part?

No, you do not have to take part in this study. If you do decide to take part you are encouraged to save and keep this Participant Information Sheet for your future reference. You are still free to withdraw from the study at any time and you do not need to give a reason for doing so.

What will you have to do?

If you decide to participate you will be asked to take part in a co-design process, where we will work together with other people like you and people who support adults living with cancer. This process will run in 3 stages. You will firstly be invited to take part in stage 1 and you may later be invited to take part in stages 2 and 3. You will be supported to attend these sessions. Stage 1 will take place in location mutually agreed by you and I. Stages 2 and 3 will take place within your local community/Edinburgh Napier University.

1. You will firstly be asked to take part in an interview that will include questions about your current lifestyle, why you do or do not take part in specific activities for example exercise, as well as your relationship with those who support/ed you after your cancer diagnosis. This interview will last approximately 30 minutes and will be video/audio recorded, if you agree to this. This recorded information will be used to inform discussion in stages 2/3 and some small segments could be played to facilitate this.

2. You may then be asked to take part in a focus group with other people aged 65 and over who have had or have a cancer diagnosis. This group will further reflect on why you and others do or do not lead a healthy lifestyle. You will also be asked to participate in some tasks that will help you think about why this is. This session will last approximately 1-2 hours, there will be a break in the middle of the session. At the end of this session you will be asked to complete a brief survey evaluating your experience of the session,

this should only take 5-10 minutes. This session will also be video/audio recorded if you are happy with this.

3. Lastly you will be invited to take part in a co-design session. This group will include members of the research team, other people aged 65 and over who have had or have a cancer diagnosis and individuals who support those after their cancer diagnosis from within the local community. This session will focus on the needs, focus and development of the programme. You will be asked to contribute to further tasks which will help us create a programme or recommendations suited to you and the others involved. This session will be approximately 2-3 hours in length. At the end of the session you will be asked to complete a brief survey evaluating your experience of the session, this should only take 5-10 minutes. As with the previous sessions, this session will also be video/audio recorded. This session will also incorporate a celebration event.

Will your information be kept confidential?

You will be allocated a study number this will be used to ensure the information you provide is anonymous and to link your data throughout the study. This number will also be used for dissemination purposes. Only the research team will have access to the information you provide. All data from the study will be securely stored in either a locked cabinet or in a password protected file on the University’s secure network.

Has this study been reviewed by an ethics committee?

Yes, the study has been reviewed by the Research Integrity Committee in the School of Health & Social Care at Edinburgh Napier University. There were no ethical objections to this study being carried out.

What will happen to the results of this study?

The findings of the study will be used to develop a lifestyle programme or recommendations for adults aged 65 and over living with and beyond cancer. The findings will also be used to form my PhD thesis and will be shared at national and international conferences, and published in academic journals. You will not be identifiable in any of these outputs, I will use a coding system and remove any personal details or identifiable features, to ensure the information you provide is kept confidential. Stills from the videos may be used to illustrate the process and/or results, in which case steps will be taken to ensure you remain anonymous, for example your face will be blurred out. A summary of the findings of the study will be shared with all who participated after the completion of the study. All identifiable data will be deleted at the end of the study (i.e. after study results are shared with those involved), while anonymous data will be retained for 10 years (in line with University policy).

Who has designed this study?

This study has been designed by Lynsey Brown, along with her supervisory team from the School of Health & Social Care at Edinburgh Napier University.

Where can I get further information about this study?

If you have any questions or would like further information about the evaluation, please contact:

- Researcher: Lynsey Brown at the School of Health and Social Care, Edinburgh Napier University [redacted]
- Supervisor: Dr Richard Kyle at the School of Health and Social Care Edinburgh Napier University [redacted]

If you wish to speak to an independent advisor about the project, or if you have any complaints, please contact:

Dr Anne Rowat
Chair, School Research Integrity Committee
School of Health & Social Care
Edinburgh Napier University
[redacted]

Thank you for taking the time to read this information

Appendix 9-Informed consent form

Participant Consent Form

Project Title

Using Co-design to develop a lifestyle programme for adults aged 65 and over living with and beyond cancer.

Researchers Name

Lynsey Brown

Consent

In order to indicate your understanding of the study and agreement to take part, please initial the corresponding box for each of the following statements.

1. I confirm that I have read and understood the **Participant Information Sheet** (version 3). I have had the opportunity to consider the information and ask questions, and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without any of my rights being affected.	
3. The information I provide will be treated confidentially and will be stored securely in electronic and paper form.	
4. I give permission for the information I provide to be used in reports, publications and presentations with preservation of anonymity.	
5. I agree to being tape recorded / videoed	
6. I agree to be contacted by the researcher regarding the study	
7. I agree for anonymised video/tape recorded material to be published as part of this research	

8. I understand that my data will be stored for a period of 10 years before being destroyed ☐

9. I agree to take part in this study. ☐

Participation in this research is completely voluntary and your consent is required before you can participate in this research. If you decide at a later date that data should be destroyed we will honour your request in writing.

PARTICIPANT		**RESEARCHER**	
Name in Block Capitals	______________	**Name in Block Capitals**	______________
Signature	______________	**Signature**	______________
Date	______________	**Date**	______________

Appendix 10-Semi-structured interview schedule Group 1

Start by encouraging the participant to tell me a little about themselves, their experience with cancer and their health in general.

1. What does health/being healthy mean to you?
2. What do you do to stay healthy?
3. What stops you doing these behaviours?
4. What encourages you to do more of these behaviours?
5. If not already mentioned how has your cancer diagnosis/treatment impacted your ability to take part in these behaviours?
6. Do you think more should/could be done to encourage people who have had cancer to stay healthy?
7. Have you taken part in any programmes that were designed to promote health/health behaviours? If so when/what/how did it go and why was that the outcome?

We are particularly interested in physical activity, diet and sedentary time? (If not already mentioned ask if these behaviours are important to them?) Is it OK if I ask you some questions specifically about these behaviours?

8. Would you say you are more, about the same as or less active than others? **https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3313867/**

Enquire for further info

9. How long in a normal do you spend sitting? How much of that time is uninterrupted? Would you say you sit for more or less time than others?

Enquire for further info

10. Would you say your diet is better, about the same as or worse than others?

Enquire for further info

We are also interested in how your health and outlook is in general, is it OK if I ask some questions specifically about this?

For this the standardised survey SF-36 will be administered during the interview, which will take approximately 5-10 minutes to complete

Appendix 12-Behaviour participation questions

1. Would you say you are more, about the same as or less active than others similar to you?
2. Would you say you sit for more or less time than others similar to you?
3. Would you say your diet is better, about the same as or worse than others similar to you?

Appendix 13-Demographic questions Group 1

Participant ID:

What age are you?	What gender do you identify with?
What ethnic group do you identify with?	What is your current living status?
Where was/is your cancer?	When were you diagnosed with this cancer?
What treatment did you have?	What town/city do you live in?
What is your current cancer status?	Do you have any other long term illnesses?

Appendix 14-Debrief sheet

Thank you for Participating in this study

I hope you have enjoyed taking part, however, If this study has raised any issues or upset you in any way the resources and services below can assist you.

Macmillan Cancer Support	**Age Scotland**	**Samaritans**
Caledonian Exchange 19A Canning St Edinburgh EH3 8EG 0808 808 00 00 https://www.macmillan.org.uk/	Causewayside House 160 Causewayside Edinburgh EH9 1PR 0800 12 44 222 http://www.ageuk.org.uk/scotland/	25 Torphichen Street, Edinburgh, EH3 8HX Freephone: 116 123 email: jo@samartans.org https://www.samaritans.org/

If you would like to ask any questions or discuss anything raised in this study with someone involved in it or an independent advisor. Please contact myself, my supervisor or the independent advisor associated with this study using the details below.

Researcher **Lynsey Brown** School of Health & Social Care Edinburgh Napier University	**Supervisor** **Dr Richard Kyle** School of Health & Social Care Edinburgh Napier University	**Independent Advisor** **Dr Anne Rowat** Chair, School Research Integrity Committee School of Health & Social Care
[redacted]	[redacted]	[redacted]

Appendix 15-Semi-structure interview schedule Group 2

Start by encouraging the participant to tell me a little about themselves, their experience working with individuals who have or have had cancer.

1. What does health mean to you?
2. What behaviours would you say influence health and why?
3. We are particularly interested in physical activity, diet and sedentary time, If not already mentioned ask if these behaviours are important?
4. What stops people, particularly thinking about those you support, doing these behaviours?
5. What encourages the people you support to do these behaviours?
6. How do you think a cancer diagnosis and treatment impact people's ability to participate in these behaviours?
7. Do you think more should/could be done to encourage people who have had cancer to do more of these behaviours?
8. Are you aware of any current programmes designed to promote these behaviours that people you support have participated in? How did they get on with these programmes?

Appendix 16-Demographic questions Group 2

Participant ID:

What age are you?	What gender do you identify with?
What ethnic group do you identify with?	What is your current occupation?
Do you support individuals who have had cancer in this role or another role? If other what is this role?	
What town/city do you currently work in?	

Appendix 17-Topic guide for Part B-Stage 2, focus groups, Group 1

Task	Timing	Outcomes
Brief Intro & Consent forms Ice-breaker-What is your name and why are you taking part today?	10 mins	
Further explanation of purpose of today and group agreement	5 mins	Understanding of purpose of today and ensure everyone is agreed upon the way the group will work
3 practical questions Participants will be asked their views on 3 practical questions 1. Focus: What behaviours are most important to be targeted? 2. Format: What format would be preferred (face to face, online etc-regular/set time period)? 3. Timing: when in the cancer journey should the intervention begin/be offered? Materials Flipchart paper Pens	20 mins	To begin to consider some of the key practical aspects of a programme/intervention.
Feedback from interviews and identification of points to prioritise The facilitator will show the participants the mind map detailing the main concepts associated with behaviour/programme participation. Participants will then be asked to discuss which points they think are most important to take forward in order to achieve or maintain behaviour change	30 mins	Identify priorities for programme development.

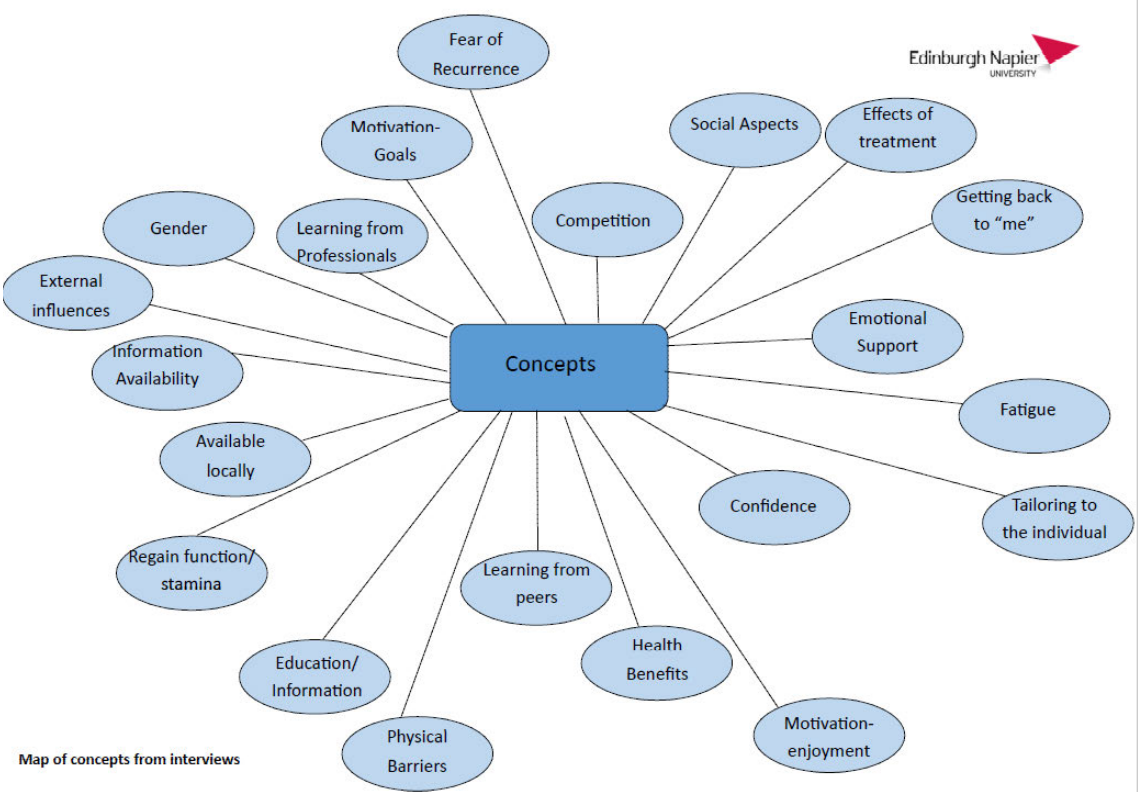
and to encourage participation in the programme-(using stickers to mark these) this will also include things that need to be considered that may negatively affect behaviour and participation. Participants will also be asked to add anything that is important that has been missed and asked if any points are surprising. Discuss: Gender, peer vs professional information/support, importance of social aspects and cancer specific. Materials A0 mind map of main findings Stickers		
Persona/character building Participants will be asked to individually consider who the typical user of such a programme/intervention may be and asked to complete then agree on a final typical user. Materials A4 sheet for individual character development (sheet 2) A3 sheet for collaborative development of persona/character	20 mins	To understand the perceptions of the expected typical user, including goals, motives etc. As well as create characters that can be contrasted and used in future sessions.
Rounding up	5 mins	Ensure everyone agrees with what I have taken away as the main points of importance from the focus group
Evaluation & Debrief Participants will be asked to complete a brief evaluation form and provided a debrief	10 mins	

Appendix 18-Topic guide for Part B-Stage 2, focus groups, Group 2

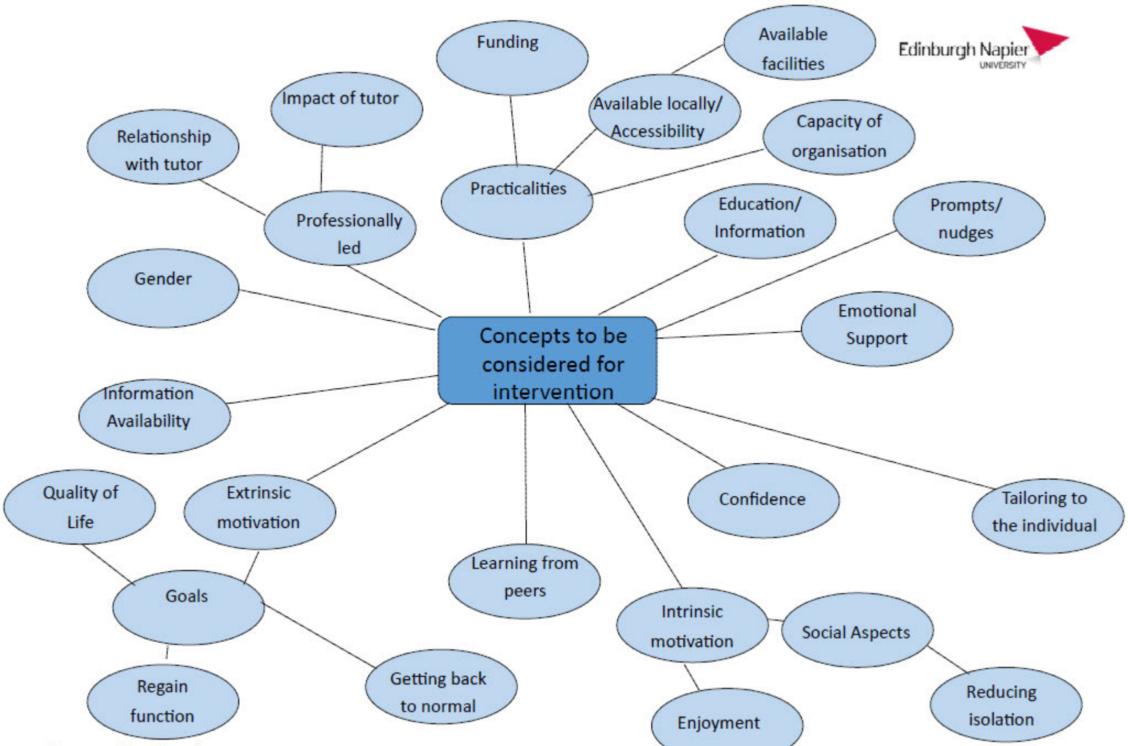
Task	Timing	Outcomes
Brief Intro & Consent forms Ice-breaker-What is your name and organisation?	10 mins	
Further explanation of purpose of today and group agreement	5 mins	Understanding of purpose of today and ensure everyone is agreed upon the way the group will work
3 practical questions Participants will be asked their views on 3 practical questions 1. Focus: What behaviours are most important to be targeted? 2. Format: What format would be preferred (face to face, online etc-regular/set time period)? Regularity? Fixed period or on going? 3. Timing: when in the cancer journey should the intervention begin/be offered? Materials Flipchart paper Pens	20 mins	To begin to consider some of the key practical aspects of a programme/intervention.
Feedback from interviews and identification of points to prioritise The facilitator will show the participants the mind map detailing the main concepts associated with behaviour/programme participation. Participants will then be asked to discuss which points they think are most important to take forward in order to achieve or maintain behaviour change and to encourage participation in the	20 mins	Identify priorities for programme development.

programme-(using stickers to mark these) this will also include things that need to be considered that may negatively affect behaviour and participation. Participants will also be asked to add anything that is important that has been missed and asked if any points are surprising. Discuss: Peer vs professional information/support, means of signposting/getting info out, importance of social aspects. Materials A0 mind map of main findings Stickers		
Barrier Ranking Participants will be asked to rank the barriers to intervention/behaviour participation from those have the greatest impact to those having the least. Discussion will be facilitated around why certain items have been ranked in certain ways. Materials Barrier cut outs	20 mins	To determine the most influential barriers to participation, in order to identify the barriers that must be addressed in programme development.
Persona/character building Participants will be asked to individually consider who the typical user of such a programme/intervention may be. Materials A4 sheet for individual character development (sheet 2)	10 mins	To understand the perceptions of the expected typical user, including goals, motives etc. As well as create characters that can be contrasted and used in future sessions.
Evaluation & Debrief Participants will be asked to complete a brief evaluation form and provided a debrief	10 mins	

Appendix 19-Key concept map Group 1-Stage 2

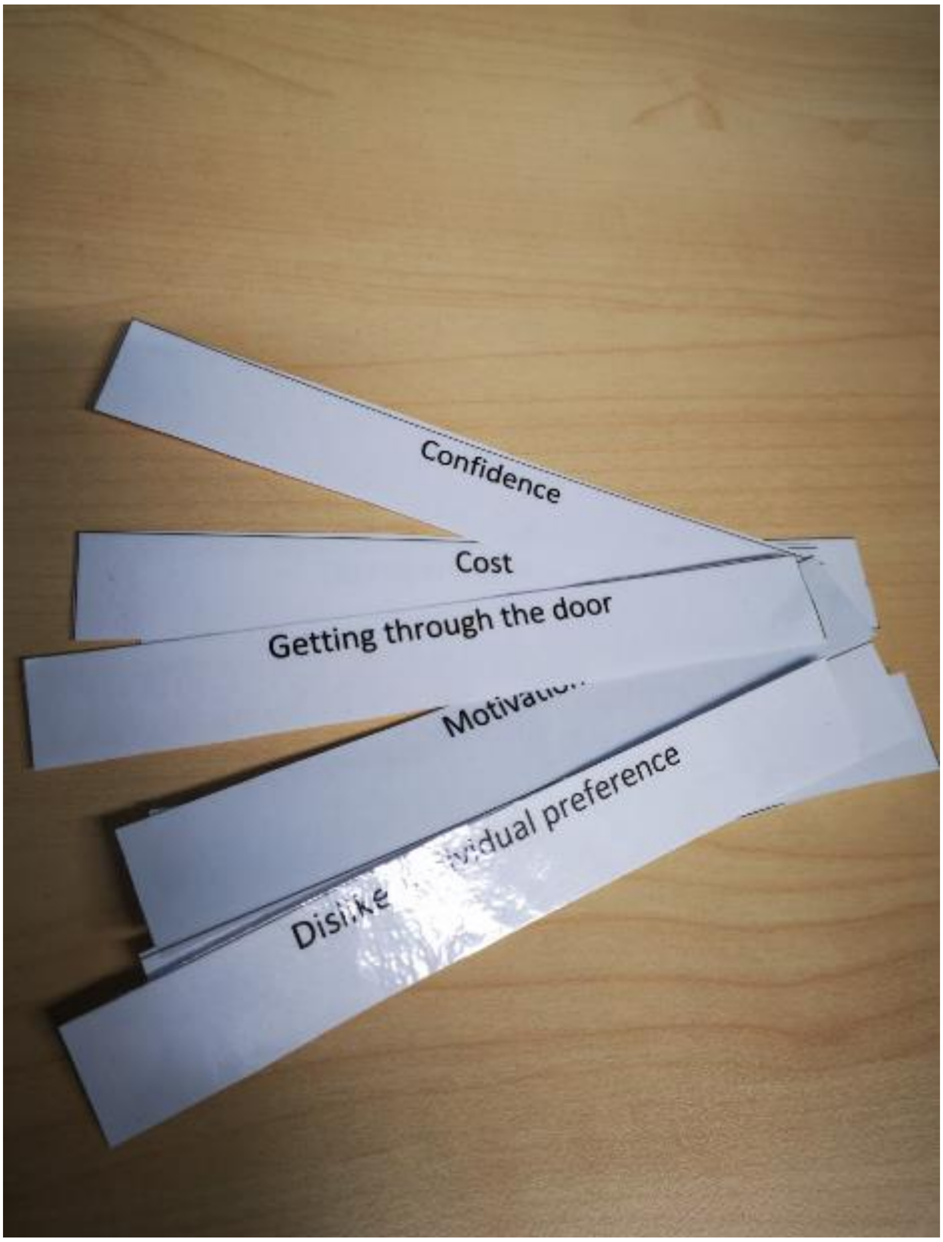


Appendix 20-Key concept map Group 2-Stage 2



Map of concepts from interviews

Appendix 21- Barrier ranking cards



Appendix 22-Topic guide Part B-Stage 3, workshop

Task	Timing	Outcomes
Brief Intro & Consent forms Group Agreement Ice-breaker-What is your name and an interesting fact about yourself?	10 mins	
Further explanation of purpose of today	5 mins	Understanding of purpose of today.
Group Feedback Feedback will be provided re the key concepts, features of the programme and barriers drawn from the focus groups with room for discussion. Materials A0 sheet with key concepts and decisions made or to be made. Barriers list, as created in past focus group. Pens Flipchart paper/post-its	20 mins	To update all participants on the work so far and highlight the key points that have come up from the focus groups.
Programme development Bearing in mind the key aspects and barriers-answer the below questions. Questions 1. What activities do you want to see in a lifestyle programme designed to improve diet, reduce sedentary time and increase physical activity for adults aged 65+ living with cancer? (links to focus on different behaviours and wider aspects) 2. Who is running it? (links into professional vs peer led) 3. Where is it being held? 4. How do people find out about it? Develop thoughts and ideas of the intervention	60 mins Link back to- Face to face Group activity On-Going vs finite programme? Professionally led vs peer led or both? Gender specific?	To begin to consider the design of the programme. To develop a brief story board of the programme designed.

Check off TIdieR components when doing this Materials Flipchart paper Giant post-it notes Pens		
Overcoming barriers Using the story board consider how the personas created would interact with the intervention concepts and ideas. Where would they get stuck? How could we help them overcome this? If participants aren't happy to use personas use barrier items instead to stimulate the discussion Materials Flipchart paper Giant post-it notes Pens Personas Barrier list	30 mins	To identify means of overcoming barriers and understand the barriers from the perspective of potential service users.
Rounding up	10 mins	Ensure everyone agrees with what I have taken away as the main points of importance from the group
Evaluation & Debrief Participants will be asked to complete a brief evaluation form and provided a debrief	10 mins	

Appendix 23-Script and example visuals to describe results from Part B-Stage 1 & 2 used in Stage 3

So, today is the final stage of the process where we will be working on designing a programme for adults aged 65 and over living with cancer to improve diet, increase physical activity and reduce sedentary time or break up sitting time. The day will be split into 3 stages, firstly I'll give you some feedback and let you know about all the key aspects and barriers that have come up so far. I then have a few questions for you to start to get you thinking about the design of the programme and what that will look like. And then finally we'll have a think about how some individuals would interact with what we design, where they might get stuck and what we can add in or take away to make the programme more suitable. This will be done using the personas we made in the last focus groups.

Ok, so before we start thinking about the design of the programme I just want to go through the important points that have come up so far, as well as some of the barriers and questions that we haven't managed to reach consensus on. So, as I said the intended focus of the programme we are going to develop is to improve diet, increase physical activity and reduce sedentary time. Most people agreed these behaviours are all important and fit together. However, some groups and interviews focussed on one behaviour more than the others. Some people also suggested other goals were more important for example getting their function back up, getting back to normal or as normal as can be and making new social networks or have social support and people to lean on. So for these people the behaviours may be secondary to these broader goals but a programme targeting the behaviours could also help to reach these goals. So someone may want to get more active to get their function back or come along to learn about diet and cooking to meet new people. Which all leads on to the next point in that the main finding was that everyone is different and the differences always have to be considered, so the individuals main goals have to be considered and if the behaviours come second then that's the way it is and the way that will work best for that person. Does that all make sense? Do you have any questions or anything to add?

Great, so the next bit is around the format of the programme. So everyone agreed it should be face to face, which is great and for the most part people seemed to discuss a group based programme when they discussed the prospect of programme, I think this links in well to the social aspects, which many people said were important. So, if you're all happy with that I'd like to take forward the idea of a group based programme? For the next 3 points there wasn't much consensus so I was wondering if we could make decision on these points now. So should the programme be on going or finite? Should it be professionally led, peer led or with aspects of both? And finally I just want to ask about gender as this has come up a few times, would a programme targeting both males and females suit?

Perfect, so now on to timing, for the most part people agreed that after the treatment was the time most people would interact with a programme like this, with a few people mentioning pre-hab and getting the info before the treatment but since the majority was for after treatment I thought we could move forward with that as the main time point. Is that OK with everyone?

So I'll just quickly go through the mind map of key concepts now.

Practicalities: Programme needs to be available locally with ease of access via public transport and access to facilities including toilets, seated areas etc. Cost must also be considered. It was also really important to develop something that could be sustainable and was available locally so people could get to it easily.

Learning from professionals-as I've touched on already learning from professionals was a key concept and contentious issue. But most people agreed it was important to learn from professionals, as you could trust the info but also that the relationship with the professional and their personality were important.

Social aspects-For most people the social side of things was deemed as very important, so having people to speak to learning from people in the same situation or having them lead the group also came up, as did the importance of group dynamic and size and the potential to reduce social isolation.

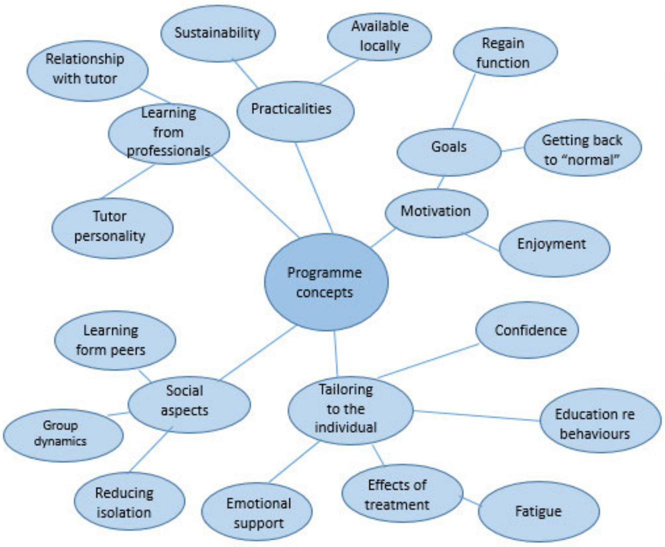
Tailoring to the individual-So as I've said already taking into the individual and their needs and goals is very important and some aspects that may be affected by this were also highlighted, so the emotional support needed, the effects of treatment in particular fatigue, the knowledge of the behaviours and potential need for education and finally their confidence.

Motivation-So in a way this links into a lot of what we have already said but basically I just want to reiterate that individuals can be differently motivated and I just have a couple of examples their of why people might participate in a programme and this is something we must consider as I've said before.

All these concepts are linked in a way.

Ok, so just quickly this is something we worked on in the last focus group which is a list of barriers to participation, so reasons why people might not take part, ranked in order from most important to least. As you can see quite a few are similar to the key concepts. So I just want to put this out so we are able to think about how some of these barriers might influence the programme we begin to discuss and consider designing.

So I suppose that's all a lot of info to take in before we move on to thinking about the design of the programme does anybody have any questions or anything to say?



Programme features

Focus:

Physical activity, diet and sedentary time. An interest in all behaviours was evident. Some groups had more interest in one of the behaviours. However, further interest in regaining function and being able to lead life as before seemed more important for some, as well as having social support and contact with others in similar situation. Main point from all discussions was everyone is different-so this must be considered.

Format:

Face to face
Group activity
On-Going vs finite programme?
Professionally led vs peer led or both?
Gender specific?

Timing:

Specific to each individual, understanding that every cancer experience is different and therefore, the timing of information provision is different for each individual but for the most part people agreed after treatment was preferred for participation in the programme.
Time of day?

Appendix 24-Pesona 1 Motivated

Person 1

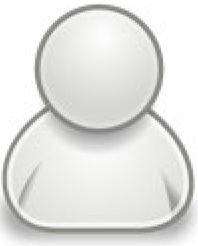
Edinburgh Napier
UNIVERSITY

I live out of town.

I think being active is important to keep fit and healthy. So I try to keep my steps up and take part in activities

I have always led an active life and made an effort to take part in activities, particularly team sports. I have never been able to sit still and have always loved trying new foods and recipes.

I don't know where to look to get info on programmes and activities.



I want to keep as fit and healthy as possible, for as long as possible by getting my function and ability back to as close as it was before diagnosis and treatment but I'm struggling with treatment side effects and fatigue.

I have a wide social support network of close family and friends.

I enjoy socialising.

I enjoy trying new things.

My family encourages me to take part in activities.

Appendix 25-Persona 2 Not motivated

Person 2

Edinburgh Napier
UNIVERSITY

I lead a generally sedentary lifestyle. I don't cook much, as I'm only cooking for one.

I live in the city centre

I want to maintain my independence

I wasn't very active in my younger years and have mostly stuck to foods I know. My past career involved sitting at a desk.

I have limited financial resources

I find the advice about diet confusing and contradictory and I'm not fussed about being active.

I have limited social support, and I'm quite isolated. People were around during my treatment but not so much afterwards.

I'm afraid of trying new things, especially if it involves groups of people.

I struggle to find the motivation to maintain a healthy lifestyle and have no confidence in my abilities.

Appendix 26-Example code file excerpt

Social aspects-Focus Group 2, Group 1

R2: And therefore, I think the group activity, the social contact, is very important. With the group, one of the things we all had in common is, we all have the same condition. So there's, no one's got any, you know, ego, agendas about it, because we're all, you know, happy to talk to each other about our condition. And I think if you're in a like-minded group, that's maybe a thing in itself. I think the walking, I mean, I've been involved in all sorts of walking things, hillwalking clubs in PLACE, and doing it together is, I think, pretty important.

R2: But when I've been to gyms, I don't find I necessarily interact with people. If it's a set class, there's other people there, but if you're maybe interacting with one trainer…

R2: yeah, you tend to move more on your own, I suppose. I think, there have been studies on television some time ago about the benefits of different things. I think they compared walking in the UK, to playing table-tennis in Japan, and it just happened to be, for example, what they chose. And the social coming together is very, very important, I think. Doing it in isolation is, it's harder and I don't think you get the same benefit from it.

I1: Would you both agree with that, around the social…?

R1: Oh, I think the social thing is very important.

R3: Uh-huh, it is, definitely.

R3: And, you know, even like the men, you know, they'll talk to you, or you know, a bit of banter between you. But no, it's a mixture.

R2: Well I think the personal contact, the face to face, comes back to that again, I think that's very important.

R3: I think so.

R2: Maybe even more so for our older generation.

R1: Uh-huh.

R2: I think that, there's an element, or certainly from my own experience, after I was diagnosed, when I really went into…generally, I'm an outward going person. But we all have our down spells, or a bad day, or whatever. But being diagnosed with something like that tends to, speaking from my own experience, I went into myself, I didn't really want to speak about it. You become, you feel more isolated, lonely. And a group thing, as you were saying, I think that would be a fantastic benefit.

R2: Because you could just go and have your treatment, you leave the hospital, you're back home, and you don't have contact with anyone. And that can have a detrimental effect. I think the contact is definitely very important.

I1: Yeah. Okay. I had something on my mind before, there. So although you say you wouldn't want to be taught by your peers, is it important to have peers there, so people who have also had cancer, or is it…?

R1: Well is that not the point of the exercise, that you are together with like-minded people who have been through the same thing. If I was there, and nobody else had experienced what I'd experienced, or similar things, I think I'd feel a bit kind of, why am I here.

I1: Right, yeah.

R3: Uh-huh.

R2: Uh-huh, that's a valid point.

I1: Okay.

R1: You know, what are all these other people doing here.

I1: So it's that commonality.

R1: Yeah, that's right, we're all in it together, kind of thing, or we've all got that one goal.

I1: Sort of a camaraderie, as well.

R1: Yeah, uh-huh.

R2: Absolutely, that's been a very strong point in this whole kind of thing with cancer. It's absolutely, one of the strongest things to come out of it, is the genuine camaraderie. I think as I was saying earlier, people come along, and they've been hit with this bolt of lightning, you know, this cancer thing. And when you come together, there's definitely a kind of common support, camaraderie, you know, help each other.

R1: Uh-huh.

R2: It came up recently, with some of the films about the First World War, in the trenches together. And they were in such a terrible situation, but there's a genuine coming together, they want to help anyone, in any situation like that. And it doesn't have to just be a common group of cancer, it could be any kind of cancer. Because trying to get a group together with the same cancer would be difficult. I think the whole variety of cancers, and men and women coming together, is a good thing.

I1: Yeah. Great.

R2: Togetherness is powerful I think.

I1: Learning together, and doing things together.

R2: Yeah, when you’ve got a similar condition. Because I think, as you were saying, you might feel, why am I here, if there's no one else got the condition. Whereas, there's a natural connection, I think, with people, you know, when you’ve got the same condition, or similar conditions, yeah, definitely.

R3: No, I didn’t. There was eight of us in the group. And we all had cancer of some kind. There was a woman who sat next to me, and she had ovarian cancer, she's just going through her treatment just now, and I said, you know, I'm two years down the line. And she said, oh that’s good to know.

R1: And she would have got a lot out of that, speaking to you.

R3: Yes, I think she did, uh-huh. I was in a fortunate position, that I didn’t lose my hair, or anything, where this lady had, and she had a wig, and there was a few of them, you know, had wigs. And I thought, as I always say, I'm not fortunate in what I've got wrong with me, but I am fortunate in how I've come through it. And it's, you know, it's not until you go to, like, these things, that you say, well, there's always somebody that looks worse than you, and, well, going through an awful lot more than you're going through. But no, I did enjoy the class.

I2: That’s good.

R3: As I say, everybody, the one that I go to, there's, like, there's one at 12 o’clock, and there's one at one o’clock, and I go to the later one. I've been to the 12 o’clock one a couple of times, but nobody speaks, and they just all get on with it. Like, it's a circuit that you're going round, doing the different exercises, but nobody speaks at the class. Where the one that I go to, everybody speaks.

I1: There's chat, there.

R3: And like yesterday, when we were speaking about going out for Christmas lunch, and getting that organised, you know.

R2: That’s the class I'd be going to.

I1: The one with the Christmas lunch.

R2: Well the one…Christmas lunch is an added bonus, definitely.

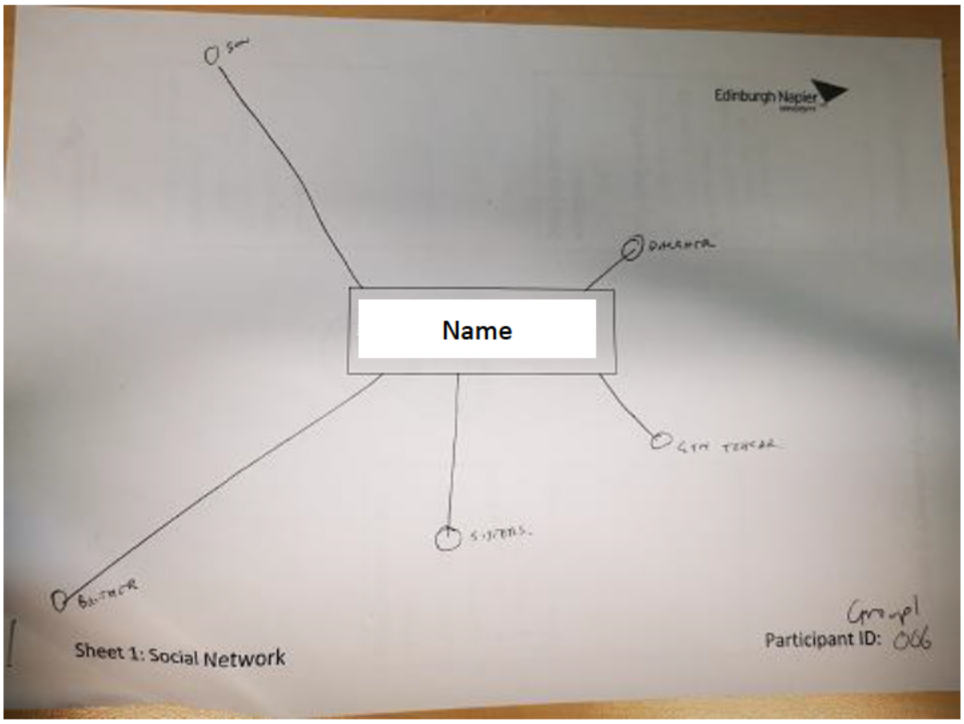
I1: Yeah.

I2: A class where there could be a Christmas lunch, because people want to see each other.

R2: That’s right, yes, very much so.

R2: You could potentially feel, if you got something like cancer, there's an element of hopelessness, while they're going on. Whereas if you get this therapy of, you know, the group activity, you know, your physical class, and lots of people who are chatting. And that would motivate you to come back and give you a sense of hope.

Appendix 27-Example complete social network map



Appendix 28-Survey 1, Part C-Evaluating

The following statements are designed to evaluate your perspective of the process so far and how much you agree with the outcomes and goals achieved or set so far. The statements can be answered on a scale from **1 (strongly disagree) to 5 (strongly agree). Thinking about today's session please tick the corresponding box that suits how you feel about the questions/statements below.**

STATEMENT	1-Strongly Disagree	2-Disagree	3-Neither agree nor disagree	4-Agree	5-Strongly Agree
I am happy with the way the process is going					
I agree with the priorities set out					
My views and opinions are taken into account					
I have the opportunity to voice my views and opinions					
The group hasn't taken my ideas on board					

Appendix 29-Survey 2, Part C-Evaluating

The following statements are designed to evaluate your perspective of the co-design/study process as a whole. The statements can be answered on a scale from 1 (strongly disagree) to 5 (strongly agree). Thinking about the entire process from the interview stage onwards please tick the corresponding box that suits how you feel about the questions/statements below.

STATEMENT	1-Strongly Disagree	2-Disagree	3-Neither agree nor disagree	4-Agree	5-Strongly Agree
I was comfortable throughout the process					
I would be happy to participate in a similar process again					
I felt like I was contributing to something worthwhile					
I enjoyed the tasks and activities we completed					
I found it difficult to engage with the process					
I felt part of the group throughout the process					
The timing of the sessions suited me					
The location of the sessions suited me					

Please use the box below to tell me how you thought the process went	**Please use the box below to mention anything you have gained or learned from the process**
Please use the box below to let me know what you thought was good about the process	**Please use the box below to tell me what you think could've/should've been done differently about the process**

Appendix 30- Critical reflections on the co-design process: The role of positionality, power and trust in relationships, and evidence

Introduction

As qualitative researchers our positionality with respect to our ethnicity, class, gender, age, employment, and past experiences influence the research process. It is therefore essential to both acknowledge and critically evaluate our positionality with regards to the research through reflexivity (Merriam & Tisdell, 2015; Nguyen-Phuong, 2020). To be reflexive we must interrogate the self and reflect on our positionality to critically examine the role of identity, perceptions, and other characteristics on the design and research process (Schiffer, 2020; Watt, 2007). The following discussion will reflexively explore the impact of my positionality on two key components of the co-design process, as used in this PhD. These components are: (1) Building relationships, and (2) Understanding the data. These components will be explored further with reference to power and trust, with final reflections on co-design more generally.

Building relationships

The first component of the co-design process to be critically explored is building relationships, I will consider those between myself and the participants, and those between the participants themselves. Building relationships is a key component of co-design and in particular Experience Based Co-design (EBCD), with set steps taken to ensure this, i.e. progression of interaction (McKercher, 2020; The Point of Care Foundation, 2024). Building these relationships is also only possible through effective communication and recruitment.

During my study, I anticipated difficulties with recruitment due to the nature of the population and my previous research experience. This led me to be acutely aware of the necessity to maintain relationships throughout the research process, regardless of the methods used. Therefore, I developed my understanding of the wider community of older adults living in Edinburgh, Fife and the Lothians, using participatory observation as opposed to non-participatory observation as recommended in EBCD (Donetto et al., 2014; The Point of Care Foundation, 2024). This participatory observation facilitated relationships with gate keepers, a key decision in the recruitment process and recommended means for recruitment to sensitive research (Turner & Almack, 2017), relying heavily on trust (McAreavey & Das, 2013). The process of engagement and recruitment sought in some ways to achieve a semblance of 'insider status' or integration into the community (Nguyen-Phuong, 2020), through this participation and the building of relationships with community leads. It was judged that non-participatory observation would not have the same effect.

I am aware I was only seeking insider status with a select group, influenced by my relationships within the wider community. This select group of gatekeepers/community leads in many ways resonated with my own positionality, with similarities in ethnicity, nationality, geographic location and interest in cancer care or behaviour change, while distinct differences were also evident for example age and experience. It is possible these differences created a need for the gatekeepers to nurture and support, a young and novice researcher, consequently influencing the participants selected for potential recruitment. All of which could have limited the diversity of those recruited due to the relationships built between me, the gatekeepers, and the pool of individuals they interact with. This may have enabled pre-existing familiarities and commonalities to engender a 'sense of trust'. The ease of relationships may have enabled me to shy away from reaching out to a more diverse population, which may have influenced the co-design process, the relationships developed and the possibility that certain aspects of the wider population of older adults living with and beyond cancer were omitted.

Establishing a sense of trust among participants is another necessary component of an effective co-design process (Clarke et al., 2021; McKercher, 2020). The co-design process conducted for this PhD embraced the importance of trust and worked to build trust and develop relationships. However, it is pertinent to question whether the homogeneity of the researcher and participants may have contributed to a 'sense of trust' which might not have emerged with a more diverse group? With co-design seeking to work with diverse populations in an equitable way, I acknowledge that cultural identity may have in part been a factor in the facilitation of this sense of trust. Had I sought a more diverse population, from a broader geographical area would rapport have developed so easily to build relationships as building blocks of trust? This is difficult to discern in hindsight but can be viewed critically as a potential limitation of the co-design process I conducted.

Reflecting specifically on the participants in my study, the diversity or lack thereof could be criticised regarding the extent to which these characteristics are like those of myself. For example, all participants were of white ethnicity, Scottish nationality and from a small geographical area within Scotland. This was considered positive at the time as the homogeneity quickly contributed to the development of relationships and trust between the researcher and participants, and among participants. These commonalities between myself and the participants, could have also offered a sense of comfort and safety. Such familiarities made what could have been a difficult situation to navigate, for myself and the participants, a little easier, particularly when building rapport and meeting people for the first time but also in maintaining that relationship. As a novice researcher this was also to be expected in some ways, the recruitment process and participants recruited were a comfortable option for me and in many ways felt safe. Be that safe in interviewing in someone's home where I knew the area, or safe in knowing that those recruited were interested in the research and had in many ways been approved by the gate keepers. This need to feel safe is a common phenomenon in human behaviour and in research practice, particularly for those learning and navigating methods for this first time (Åkerlind, 2008; Kalman, 2019; Maslow, 1958). However, in future I will find ways to increase diversity by building different relationships, moving towards discomfort, while maintaining personal safety.

Despite the potential disadvantages of a homogeneous sample, the counter argument can be made that participants involved in my study (i.e., older adults living with and beyond cancer) are generally underrepresented in research (Cherubini & Gasperini, 2017; Longevity, 2021). Specifically, the oldest old i.e., those over 85, older adults from areas of high deprivation and older adults from black and minority ethnic communities are more likely to be under-represented in health promotion activities (Liljas et al., 2019). In retrospect, it would have been useful to have acknowledged levels of deprivation in my participants and paid greater attention to more nuanced characteristics in highlighting the actual differences between individuals. It is interesting to note that one of my participants was over the age of 85 but dropped out of the study after the first interview. Owing to this experience I now prioritise optimising participant diversity such as levels of deprivation and ethnicity in my research.

Regardless of participant characteristics or experience, creating a sense of equality between all those involved in the co-design process is key to both the process and the development of relationships (Donetto et al., 2014; McKercher, 2020). However, I am aware that I was viewed as the leader of the process and group in my study. Throughout I tried to create a sense of equality, for example by using participatory methods, and implementing a process designed to facilitate trust and build relationships (Bergold & Thomas, 2012; McKercher, 2020; The Point of Care Foundation, 2024) but this was only effective at a surface level, with a sense of power imbalance still permeating throughout. This had an influence on the relationships I built with participants, with a sense that they were at times trying to appease the process, and myself as the leader, which also potentially influencing the second element to be discussed (Understanding the data).

Understanding the data

The second element of the co-design process I will reflect on is Understanding the data. Throughout the process I was the sole person analysing the data and making decisions about this process, emphasising the potential for the influence of my positionality, and particularly my experiences on the data analysis. At one point I became acutely aware of the extent to which my experiences could influence the analysis process and my understanding of the data, an understanding that could have been fed back to the group due to my role in the process. During the data analysis period, a close relative was diagnosed with cancer, and I had a particularly negative outlook at that time. In discussions with my supervisor, I realised I was bringing that experience into my understanding of the data, potentially influencing the analysis and findings. This led me to revisit the data. This is an important component of reflexivity and more so qualitative research (Ho, 2022). The adoption of tools to reduce such influence is also an important consideration in qualitative research.

Throughout my PhD, I was aware of the importance of the positionality of the researcher, especially given the qualitative lens. Therefore, during data analysis (given the specific personal experiences at that time) I made a point of reflecting on my positionality and impartiality through my field notes, but most importantly through regular discussions with my supervisors. This outlet provided me with a self-check and means to understand the influence that my personal experience may have been having. Had this check not been in place my views of the data and analysis could have later been adopted by the participants, as I shared the findings of each stage with them, as a means of validation. The process of validation is common in co-design and acted as a further check of our shared understanding (McKercher, 2020; The Point of Care Foundation, 2024). However, I was aware that the participants viewed me as the lead and may not have had the confidence to challenge my perspective, therefore, potentially adopting my beliefs and outlook regarding the data at that time.

Not only was it possible participants could be led to adopt my beliefs due to the impact of my experiences, I also became aware that I was internalising and aligning with the most dominant participants beliefs, i.e., the loudest participants were the most heard, a common issue in qualitative research (O'connor & Murphy, 2009; Stewart & Shamdasani, 2014). This will have influenced and have been influenced by the relationships built between the participants and I, as well as amongst the participants. Such influence may result in the development of services and products that meet only the needs of those who are dominant in the co-design group, due to the impact on the process and specifically the data analysis. This is, however, dependent on the skill of the facilitator and the reflexive process conducted throughout the work. This is something I grappled with when learning how to facilitate such groups and was a key point of discussion with my supervisors when conducting the data analysis. This is a common issue faced by novice researchers, such as myself (Kalman, 2019; O'connor & Murphy, 2009), and an issue more generally in qualitative research (Reed & Payton, 1997; Stewart & Shamdasani, 2014). However, I am aware that on reflection internalising the views of more dominant participants, and pre-conceptions based on my own experience and positionality are a risk to the integrity of data interpretation in the qualitative research process.

Owing to this potential influence of more dominant participants, including myself, the co-design process I conducted can be critiqued in its entirety. It is possible that I took on board the views of those loudest in the group, not only because they were the loudest but because their views aligned with my initial research objectives i.e., to develop a behaviour change intervention for older people living with and beyond cancer. During supervision, I acknowledged that this interaction may have influenced the data analysis and outcomes. This phenomenon emphasises the potential for co-design to reinforce the views of a select few in society, but more specifically in the participant group, including the researcher, emphasising a need to acknowledge and explore this throughout.

Finally, during the co-design process I became aware of tensions within participant relationships, particularly around differing experiences of those with lived experience of cancer treatment. Although, the cancer journey was a common connection point between participants, it was not central to this work, as the aims of the research focused on health-related behaviour. These experiences were in a way omitted, to an extent, when progressing the conversation but more so when conducting the data analysis and deciding what concepts to carry forward. It is possible had these been given more time or had they been pushed to the forefront, the process may have taken a completely different turn, specifically with more of a focus on discrepancies in care experience and how this can be improved. This omission was intentional and due to my positionality, through my understanding and desire to progress the process and data analysis, with a focus on the aim at hand. This course of action is not entirely aligned with co-design but is reflective of research processes more broadly, emphasising the tensions between the role and needs of the researcher/research, and the role and needs of the participant (Råheim et al., 2016), potentially culminating in a power imbalance or negotiation.

This premise of negotiating or sharing power is a key tenet of co-design and EBCD (McKercher, 2020; The Point of Care Foundation, 2024), which is reflected throughout this writing regarding Understanding the data. To some extent the reflection may read as though the power was dichotomous, with the balance often leaning towards me as the researcher, which could be rightly criticised as not aligning with the goals of co-design. However, this was not my experience when embedded in the co-design process, instead power and relationship dynamics were constantly changing, a dynamic that I influenced through my perspective and positionality, and at times struggled to navigate.

Further reflections

The philosophical conundrums evident within the discussion above can be related to the work of Foucault. Foucault addresses the relationships between power and knowledge, but instead of considering power as a dichotomy and individual possession (Cronin, 1996), Foucault (1975) describes power as being in constant flux. Power is said to influence and shape who we are, social structures and norms, while power and knowledge are inextricably linked (Christensen, 2023; Foucault, 1975, 2019; Miller, 1990). Discussions about the co-design process in my PhD mirror this state of flux and the notion of power as always circulating. If power is always circulating, shapes our identities and results in us policing ourselves based on norms and structures, do we perpetuate the norm? Put another way, co-design can only go so far in making change as the limited diversity in my co-design process, influenced by my positionality, reinforces the views of a select few through the circulation of power, leading to us reinforcing the status-quo (De Freitas & Martin, 2015).

This idea leads to the notion that even when wanting to enact change the way power is immersed in us or we are immersed in power means we can inadvertently fail to make the change. It is suggested this can be why revolutions fail. Revolutions generally refer to seeking a change be that in politics, religion or general social order (Yoder, 1926), co-design seeks potential change (development or improvement) in the way a service is governed or run (Moll et al., 2020; Robert et al., 2015). Although there are differences, understanding the role power plays in these endeavours emphasises how and why we can fail in making real change. It is possible that I didn't have the power to make the change I sought to influence, that we didn't have the power to make the change, that society wouldn't allow for change, and that co-design is used as a crutch to make us all think we can make change but evidently reinforces the structures and systems that are.

Throughout the co-design process I felt I had no power to share and limited capacity to enact change, the perspective of power as defined by Foucault (1975, 2019) to an extent discredits this assumption. The idea of circulating power, and my attempt to create equality, may have led to the participants trusting me, and the process. The relationships built were not a dichotomy, and we were forever in flux, negotiating the space and process together. However, this trust felt disingenuous on my part. I felt I was gaining more from the process than the participants, as I was successful in conducting the research and using this in part to fulfil the criteria for a PhD. This led me to question whether I was creating a sense of false hope for the participants, particularly that we could make large scale changes. Although I did not suggest this was a possibility in the study information, I was aware that this tension grew as I progressed through the process and learned more about the issues at play, and the resources required to implement any outcomes from the process. I was also aware of the potential impact of this on the relationships within the group and between me and the group. Although these did not sour, had there been no expectation setting this could have been a possibility. I discussed this at length with my supervisors and it was decided that disengaging with participants in a definitive way would be important to ensure any issues regarding expectations were considered and ameliorated. This is recognised as best practice in ethnographic research, creating boundaries and a definitive end to the process (Michailova et al., 2014; Monties, 2022). This seemed to be effective, however, in future processes I will consider the influence of power in all its forms and how this may impact potential outcomes, as well as the process itself. It is unfair to involve individuals in a process, where there is limited scope for change, and we must be aware of the resources and scope we have as researchers from the beginning.

Concluding remarks

Co-design as a whole and its use in the current landscape of healthcare, as well as the public sector more broadly can be critically scrutinised. Experience based co-design seeks to make changes to healthcare, but how often are these changes realised? Indeed, many EBCD projects in cancer have achieved recommendations for improvements only, with further work required to implement these (Section 3.4.3). Thus, it is important to consider from the outset our position in the landscape of intended change or improvement, and the individuals or resources we may need to implement the desired outcomes of participants in co-design processes. This is something I considered too late in the process, and likely contributed to the outcome of recommendations, as opposed to an intervention, as initially intended. This also connects with a potential criticism of co-design, with many funders calling on co-design and other participatory methods/inclusion as necessities. Co-design may now be becoming more of a tick box exercise, as opposed to an instrument for meaningful change and improvement. This sense of a tick box exercise may in some ways be perpetuating health inequalities and sustaining a hegemonic status-quo. Most importantly it may be eroding trust built with communities due to often broken promises, with the process being the outcome as opposed to the recommendations derived from the process being implemented (McLeod & Clay, 2018). This erosion of trust and potential for broken promises was a fear I had throughout the co-design process, as there was scope for such an outcome, especially after reflecting on my position more widely and the resources to hand. All of which may culminate in co-design being viewed as a ‘false generosity’, having no impact or impact only on the symptoms of the issues, rather than the issues themselves (Freire, 1970).

Throughout, this PhD I have come to consider co-design as a useful and valuable tool, that has potential to facilitate real change. I have also learned the importance to be reflexive and acknowledge my positionality, as it can influence the process generally but specifically as explored in this writing, the relationships developed, and my understanding of the data. I have also begun to consider the role that power, and trust play through different variations, and will continue to consider these elements as I progress in my career.

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