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**University of Southampton**

Faculty of Environmental and Life Sciences

School of Psychology

**Improving Quality of Life in Cancer Survivors: Understanding How a Digital  
Behaviour Change Intervention Works and How to Maximise its Implementation in  
Practice**

by

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Thesis for the degree of Doctor of Philosophy in Psychology

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# University of Southampton

## Abstract

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### **Improving Quality of Life in Cancer Survivors: Understanding How a Digital Behaviour Change Intervention Works and How to Maximise its Implementation in Practice**

by

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Many cancer survivors who finish treatment experience long-term consequences that can reduce their quality of life (QoL). Healthy behaviours (e.g. physical activity) can improve cancer survivors' QoL. A digital intervention, titled "Renewed", was developed to improve the QoL of breast, colon and prostate cancer survivors in primary care by providing support about physical activity, healthy eating, weight management and psychological well-being. For some, Renewed also included the option of brief support from a healthcare professional. A separate three-arm randomised controlled trial (Renewed, Renewed with support or control conditions) showed that those in the supported arm significantly increased their QoL at 12 months. Furthermore, prostate cancer survivors in the supported arm had better improvements in QoL compared to other cancer survivors. To enhance understanding of the trial results, this thesis aimed to conduct a process evaluation of Renewed to understand how the intervention achieved change in QoL, for whom, and under what circumstances. The overarching aims of this thesis were to explore, describe and characterise the mechanisms through which Renewed achieves change in QoL in cancer survivors and the barriers and facilitators to implementation by cancer survivors and healthcare professionals. Three papers explored these aims.

Firstly, a qualitative study exploring thirty-three cancer survivors' experiences using Renewed through interviews suggested that the majority found the intervention easy and convenient, with some reporting perceived behaviour changes with minimal use. However, some individuals were less motivated to use Renewed when they had comorbidities or if they joined the study to 'give back' or contribute to research. Additionally, prostate cancer survivors reported less availability of support outside of the intervention compared to breast and colon cancer survivors. Secondly, a quantitative usage analysis examined the relationships between using Renewed, accessing support, QoL and individual characteristics. This study demonstrated that while 55.1% (n=970/1760) of cancer survivors did not access the optional content, using Renewed more was related to better improvements in QoL. Finally, a qualitative interview study explored twenty-eight healthcare professionals' experiences supporting those using Renewed. This study found that an approach where the expertise is provided by the intervention and brief additional support provided by a healthcare professional is an acceptable way to overcome key barriers to supporting cancer survivors in primary care. Additionally, whilst most HCPs cope well with a non-directive approach, a minority may require more support to feel confident implementing this. Together, these findings suggest a digital intervention like Renewed may be suitable for implementation in primary care with minor changes. Implications suggest that accessing support may be important to motivate greater engagement but not a critical factor in improving QoL and that presenting novel information earlier in an intervention may help to motivate continued engagement.



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# Research Thesis: Declaration of Authorship

Print name: Jazzine Smith

Title of thesis: Improving Quality of Life in Cancer Survivors: Understanding How a Digital Behaviour Change Intervention Works and How to Maximise its Implementation in Practice

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Parts of this work have been published as:

Smith, J., Essery, R., Yardley, L., Richardson, A., Slodkowska-Barabasz, J., Foster, C., ... & Bradbury, K. (2022). Implementing a Health Care Professional–Supported Digital Intervention for Survivors of Cancer in Primary Care: Qualitative Process Evaluation of the Renewed Intervention. *JMIR cancer*, 8(2), e36364.

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Signature: Jazzine Smith..... Date: 26 October 2023





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## Definitions and Abbreviations

BCT .....	Behaviour change technique
BCW.....	Behaviour change wheel
BMI.....	Body mass index
CARE.....	Congratulate, Ask, Reassure, Encourage
CBT .....	Cognitive behavioural therapy
COREQ.....	Consolidated criteria for reporting qualitative studies
COVID-19.....	Coronavirus disease of 2019
EORTC QLQ-C30 .....	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire
GP .....	General practitioner
HCP.....	Healthcare professional
MRC.....	Medical research council
NHS.....	National health service
NPT.....	Normalisation process theory
PA .....	Physical activity
PBA.....	Person based approach
QoL.....	Quality of Life
RCT .....	Randomised control trial
STROBE.....	Strengthening the Reporting of Observational Studies in Epidemiology
TiDiER .....	Template for Intervention Description and Replication
UK.....	United kingdom
WHO.....	World health organisation



# Chapter 1 Introduction

## 1.1 Overview

This thesis presents a process evaluation of a digital intervention (called Renewed) developed to support cancer survivors' quality of life (QoL). The research that underpins the papers included in the thesis aimed to develop an understanding of how Renewed worked and the barriers and facilitators to implementation by cancer survivors and healthcare professionals. This introductory chapter sets out the background to, and context of, the topic of focus. It begins by providing a rationale for Renewed by describing what is known about current digital interventions for this population and their limitations. The design of a randomised control trial (RCT) to evaluate Renewed is outlined before introducing the concept of a process evaluation and explaining their importance and value in evaluating complex interventions like Renewed. Finally, the last two sections of the introduction outline the research questions underpinning this thesis, addressing how Renewed worked, whom it worked best for, and how it might be best incorporated into practice going forward to best support cancer survivors' quality of life. Specifically, the papers aimed to explore cancer survivors' and healthcare professionals' (HCPs) experiences of using Renewed and providing support, as well as examine cancer survivors use of Renewed and how this related to quality of life and individual characteristics.

This thesis has been written using a three-paper format and the contributing studies were nested within a larger programme grant that aimed to develop and test Renewed (RP-PG-0514-20001). The three papers within the thesis present a process evaluation of the Renewed intervention. This process evaluation comprises i) an exploration of cancer survivors' experiences using Renewed (paper one) and ii) an examination of which type of use was most effective in changing their quality of life (paper two). The process evaluation also explored HCPs' experiences in supporting cancer survivors to use Renewed (paper three) to inform what kind of support might best work alongside the intervention and how this may best be implemented in practice. An overview of each paper is provided in [Section 1.9](#).

## 1.2 The need for the Renewed digital behaviour change intervention

This section explains why Renewed was developed by detailing the problems affecting cancer survivors' QoL and outlining the limitations of current digital interventions that aim to support cancer survivors' QoL.

### 1.2.1 Cancer Survivors: Definition and prevalence

#### Prevalence

An estimated three million people diagnosed and living with and beyond cancer currently reside in the United Kingdom (UK) (Macmillan Cancer Support, 2020b). These individuals are typically called “cancer survivors” - a person “with a history of cancer, from the time of diagnosis through the remainder of their life” (American Cancer Society, 2021, p.1). Cancer survival in the UK has doubled in the last 40 years (Cancer Research UK, 2014), projected to increase to 5.3 million by 2040 (Macmillan Cancer Support, 2020b). In the early 1970s, the median survival time after cancer diagnosis was one year, by 2007 and 2011, it had increased to six years and 10 years, respectively. Currently, the median survival is over 10 years (Macmillan Cancer Support, 2020b).

#### Definition

There is ongoing debate around the term ‘cancer survivors,’ particularly with regards to how the individuals that it refers to relate to this term. The term ‘survivor’ has been perceived as indicating ‘cure’ or ‘self-empowerment,’ which has been considered as excessively heroic and over-emphasising the positive (Surbone et al., 2013). The term does not seem to acknowledge the possibility of recurrence, it does not seem to represent the many people who continue to struggle with cancer or its lasting impacts, and it may be considered to disrespect those who have died as a result of cancer (Rees et al., 2018; Surbone et al., 2013). There are variations in comfort levels across this population with the term ‘survivor,’ mostly notably, based on the type of cancer (Dalton et al., 2021) and age of the person (Wee et al., 2022). For example, there is some evidence that men with breast cancer may be more comfortable with the term ‘survivor’ compared to men with prostate cancer (Dalton et al., 2021). Additionally, those greater than 50 years old when diagnosed with cancer are more likely to relate to the term ‘survivor’ compared to those who are younger than 50 years old at the time of diagnosis (Wee et al., 2020).

The term “living with and beyond cancer” is becoming a more commonly acceptable alternative to the term ‘survivor’ (Surbone et al., 2013). This term refers to anyone who has had a diagnosis of cancer. This could be someone who has completed their treatment or having ongoing treatment for their cancer (NHS, n.d). This term is believed to better reflect the lasting impacts on patients

and their families (Surbone et al., 2013). To those with cancer, the term reflects adversity (realising cancer), restoration (readjusting life with cancer), and compatibility (reconciling cancer) (Le Boutiller et al., 2019). However, throughout this thesis the term 'cancer survivor' is used to be consistent with the language used in the wider programme grant. This was important for consistency across publications and avoiding any ambiguity during team discussions. The term 'living with and beyond cancer' was not used in the wider programme grant because the term was in its infancy at the time the application for research funding was submitted to develop and evaluate the Renewed programme in 2015. Whilst there had been use of the term among healthcare professionals and related communities as far back as 2009 (i.e. Davies, 2009), one of the first official published government documents to use that term wasn't until 2010 (National Cancer Survivorship Initiative 2010, 2013).

### **1.2.2 Quality of life in cancer survivors**

Many people who complete cancer treatment adjust well to life after treatment, but an estimated one in four cancer survivors in the UK live with long-term consequences of cancer and its treatment (Macmillan Cancer Support, 2013a). The phrase 'long-term' refers to not only enduring consequences that develop soon after treatment (e.g. fatigue) but also late effects that present many years after treatment is completed (e.g. heart disease) (Miller et al., 2019). This includes various physical and psychological consequences that trace back to the treatment of cancer, however long ago the treatment might have been given. Treatment for cancer may include chemotherapy, radiotherapy, hormone therapy, biology therapy or surgery, either alone or in combination (Miller et al., 2019). Each treatment may present different physical and/or psychological consequences that can affect individuals differently. Common consequences experienced after treatment include psychological problems, fatigue, weight gain, and pain, which can all impact the quality of life of cancer survivors. For example, after completing treatment, some cancer survivors experience persistent negative moods such as cancer-related fears (e.g. fear of cancer recurrence, 73%), anxiety (18%), or depression (12%) (Pitman, Suleman, Hyde, & Hodgkiss, 2018). Cancer-related fatigue is experienced by 30% of those who have completed treatment (Corbett, Groarke, Walsh, & McGuire, 2016). Often going untreated, cancer-related fatigue can contribute to diminished functioning, impact work functioning and reduce cancer survivors' quality of life (Reinertsen, Loge, Brekk, & Kiserud, 2017). Additional weight gain is often experienced after treatment among various cancers (Demark-Wahnefried et al., 2015), most significantly in breast cancer survivors (Vance, Mourtzakis, Mccargar, & Hanning, 2011). Women who have had breast cancer are 2.1 times more likely than cancer-free women to have gained at least 11 pounds (5 kilograms) five years after undergoing chemotherapy (Gross et al., 2015). Being

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overweight and obese can reduce quality of life (Larsson, Karlsson, & Sullivan, 2002). Lastly, pain occurs in approximately 20% to 50% of cancer survivors (Gallaway, Townsend, Shelby, & Puckett, 2020), with prevalence exceptionally high among breast cancer survivors (Glare et al., 2014). In the longer term, approximately 5% to 10% of survivors have chronic severe pain that interferes with functioning and quality of life (Glare et al. 2014).

Due to these consequences of cancer and its treatment, many cancer survivors have reduced quality of life. Quality of life refers to “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organisation, 2012, p.11). A survey by the National Health Service (NHS) England revealed that cancer survivors score significantly lower on quality of life (71 out of 100) compared to the general population (81 out of 100) (NHS Digital, 2022).

In the period following cancer diagnosis and treatment, it has been argued that cancer survivors' motivation and interest in adopting a healthier lifestyle increases in the hope of achieving improved health and reducing the risk of recurrence (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005). One of the key factors in improving cancer survivors' quality of life is providing support to manage the consequences of treatment through improving the self-management of healthy behaviours and lifestyle factors (Foster & Fenlon, 2011). Interventions for cancer survivors that include behavioural and lifestyle factors can offset the risk of recurrence and improve quality of life (Bourke et al., 2016). This presents a window of opportunity during which intervention and assistance to enable behaviour change might be more readily accepted. The following section explains how and why digital interventions may be a viable means of supporting this population.

### **1.2.3 Digital interventions: An approach to the management of the consequences of cancer and its treatment**

#### **1.2.3.1 Use of the internet**

Over the past decade, the number of people using the internet has trebled (Furness, Sarkies, Huggins, Croagh, & Haines, 2020). In 2021, 63% (4.9 billion) of the world's population used the internet, up 17% since 2019 (Telecommunication Union, 2021). Cancer survivors are increasingly using the internet for various reasons, including information seeking (e.g. complementary and alternative medicine, treatment options and symptom management), social support (e.g. seek and share experiences with other cancer survivors, emotional support) and practical uses (e.g. communicate with peers and HCPs, arrange appointments) (Holmes, 2019). Increased internet



use has contributed to a focus on developing digital self-management interventions for cancer survivors due to their potential to target previously hard-to-reach populations whilst providing potentially accessible, scalable, cost-effective and highly individualised interventions (Furness et al., 2020). As such, the internet already plays a role as a self-management resource among cancer survivors.

### **1.2.3.2 Digital health interventions and their evidence base**

Digital health interventions are technology-based interventions that can be delivered via various platforms such as text messages, emails, telephone, mobile applications, social media, and online websites, specifically aimed at promoting healthy behaviours (McAlpine, Joubert, Martin-Sanchez, Merolli, & Drummond, 2015). The World Health Organisation (WHO) describes digital health interventions as a cost-effective and secure way to use information and communication technologies to support health system needs (World Health Organisation, 2020).

Substantial systematic reviews and meta-analyses have provided evidence that digital interventions for cancer survivors effectively increase behaviour change and support self-management across a range of physical and psychological problems that have the potential to improve quality of life. Behaviour changes supported include those to manage psychological distress (Alberts, Hadjistavropoulos, Dear, & Titov, 2017), and fatigue (Abrahams et al., 2017), increasing physical activity (Roberts, Fisher, Smith, Heinrich, & Potts, 2017), managing diet (Kanera, Bolman, Willems, Mesters, & Lechner, 2016), sexual health (Matthew & Yang, 2020), return to work (Lamore et al., 2019) and peer support (Lepore et al., 2019). Each of these interventions targets one specific behaviour. Whilst these studies have provided evidence that digital interventions can effectively change health behaviours, they have not measured the potential impact digital interventions may have on QoL. Moreover, as previously mentioned, cancer survivors' QoL is impacted by many consequences of treatment (e.g. fatigue, weight gain, and pain). A multifaceted approach to improving the self-management of several health-related behaviours may better support the management of the range of consequences that cancer survivors face (National Cancer Survivorship Initiative, 2013). Therefore, it is beneficial for interventions for this population to target multiple behaviours because, in doing so, it is likely to have a greater chance of offsetting the risk of recurrence and improving the quality of life within this population (Bourke et al., 2016). Digital interventions that target multiple behaviours are often referred to as multi-domain interventions, defined as interventions which target two or more health behaviours either simultaneously or sequentially (Hafdi, Hoevenaar-Blom, & Richard, 2021; Prochaska & Prochaska, 2011). Furthermore, providing a choice of behaviours to engage in could foster a sense of autonomous motivation (Yardley et al., 2016), which is important in

## Chapter 1

building internal motivation to engage in behaviour change (Deci & Ryan, 2012). The following section summarises the current evidence regarding multi-domain interventions for cancer survivors.

### **1.2.3.3 Multi-domain digital interventions for cancer survivors**

A small number of multi-domain interventions exist with the aim of improving cancer survivors' QoL. However, these interventions or their evaluations have several limitations, indicating the need for further development and research in this area. Firstly, the effectiveness of some of these current interventions has been investigated amongst small samples and confined to one cancer diagnosis, limiting the generalisability of findings across cancer diagnoses. For example, a digital intervention, 'Healthy Living after Cancer', was developed to improve the quality of life of breast cancer survivors by targeting diet, weight and psychological problems (Eakin et al., 2015). In an RCT amongst 63 breast cancer survivors, those who had access to the intervention showed significantly improved physical, social, and role functioning in a quality of life measure compared to a control group (Ruiz-Vozmediano et al., 2020). This suggests that multi-domain digital interventions may effectively support QoL amongst breast cancer survivors. However, the small sample size of this RCT makes it difficult to draw conclusions about the wider population of cancer survivors.

Furthermore, conclusions cannot be drawn about how effects may differ across cancer types that may affect the experience of treatment consequences. This is important because research has shown that outcomes and engagement with digital interventions can vary between cancer types (van der Hout et al., 2021). While some current digital interventions in this population have been trialled amongst larger samples and have targeted multiple cancer types (Kanera et al., 2017; van der Hout et al., 2020), most of these interventions were only evaluated over a period of six months. For example, an RCT of a digital intervention, 'Oncokampas', was tested among 625 participants with various cancers (van der Hout et al., 2020). Oncokampas was developed to support cancer patients to take an active role in self-managing their symptoms and improving their QoL. The RCT of Oncokampas found that while the intervention did not improve outcomes in patient activation, those in the intervention group had significantly greater QoL outcomes compared to a waitlist group at one week, three months and six months follow-up. This suggests that a digital intervention can potentially improve QoL across a larger population with various cancers. However, the fact that this intervention was only evaluated over six months is problematic because research suggests that the effects on QoL found at six months with such interventions may not last longer-term (Willems, Bolman, et al., 2017; Willems, Mesters, Lechner, Kanera, & Bolman, 2017). This was demonstrated in an RCT of a digital intervention, 'Cancer

Aftercare Guide' (Willems, Bolman, et al., 2017; Willems, Mesters, et al., 2017). Cancer Aftercare Guide was a digital intervention that targeted returning to work, fatigue, anxiety and depression, social relationships, intimacy issues, physical activity, diet, and smoking cessation, to improve QoL among survivors of various cancers. The RCT of Cancer Aftercare Guide, amongst 409 participants, found that those who had access to the intervention had significantly improved QoL at six months compared to a waitlist control group. However, by 12 months, the change in QoL from baseline was insignificant among those who had access to the intervention. More research is needed to explore how QoL can be supported in the longer term and provide a greater understanding of multi-domain interventions for multiple cancer types. Such research could provide insights that lead to more effective and enduring support for a range of cancer survivors' quality of life. Considering the limitations of current multi-domain digital interventions to improve QoL among cancer survivors, there is a need for digital interventions that 1) are designed for various cancer survivors; 2) are evaluated amongst a large sample and 3) investigate intervention outcomes in the longer term.

Importantly, the addition of human support alongside multi-domain interventions for cancer survivors may increase engagement and boost outcomes in QoL (Yardley et al., 2016). Human support, such as healthcare professional support or peer support for example, when added to interventions for cancer survivors, has been shown to increase usage and enhance satisfaction (Boulley et al., 2018). None of the previously mentioned interventions included any form of human support. The potential importance of human support in this population is discussed more fully below.

#### **1.2.4 The need for human support alongside digital interventions**

##### **1.2.4.1 Rising demand on healthcare systems**

Healthcare professionals in primary care play an integral role in supporting people who have had cancer (Gopal, 2020). Primary care is the first point of follow-up for cancer survivors discharged from treatment in the UK (Adam & Watson, 2018; Taylor, Johnson, Peat, Booker, & Yorke, 2020). Following the increase in the prevalence of cancer survivors, there is a rising demand for NHS cancer services (Brown et al., 2014). Primary care is well placed to provide personalised holistic support for the physical and psychological problems cancer survivors face - for example, through advising on the benefits of healthy lifestyles and referral to behavioural programs (weight loss services) or community groups. However, there is a lack of clear guidance on how primary care staff can support cancer survivors (Taylor et al., 2020) and a lack of continuity of care which can hinder discussions relating to cancer and its long-term effects (Khan, Evans, & Rose, 2011). The

rising demand on cancer services, which are often under-resourced and over-stretched (Lee et al., 2022), means that in order to meet this demand and support cancer survivors effectively, there is a need to find efficient ways to best support cancer survivors in primary care.

### **1.2.4.2 Improving the care provided to cancer survivors in primary care is necessary**

The lack of clear roles and responsibilities among primary care staff in relation to post-cancer care can result in cancer survivors being at risk of unmet needs. For example, results from a UK national survey among HCPs in NHS settings and professional oncological organisations (n= 278) highlight a gap between the needs of cancer survivors and the extent to which these can be met in primary care services (Duncan et al., 2017). In particular, some cancer survivors desire ongoing psychological counselling and support, advice on alternative therapies, and more information on cancer survivorship, particularly concerning late-onset treatment effects (Khan et al., 2011). As well as lack of training and clear guidance in relation to this topic, HCPs' time constraints and lack of resources are often barriers to adequate cancer care follow-up (Lawrence, McLoone, Wakefield, & Cohn, 2016; Meiklejohn et al., 2016). Many current primary care-supported self-management approaches are labour-intensive (Duncan et al., 2017), and their relative expense and labour cost do not cultivate sustainability and access. Interventions that can be feasible and cost-effective are needed to overcome barriers to successful cancer survivorship care.

Many studies have demonstrated the efficacy of human support, alongside digital interventions, in increasing engagement (e.g. Boulley et al., 2018), reducing drop-out (e.g. Torous, Lipschitz, Ng, & Firth, 2020), and improving outcomes in health behaviours (e.g. Ozaki, Watai, Nishijima, & Saito, 2019) in other contexts. Human support may be provided in various formats (i.e. face-to-face or remote, individual or group meetings, telephone calls, text messages, emails, or online chat) from multiple sources (i.e. health professionals, researchers, or technicians) and may serve various purposes (i.e. answering technical queries, encouraging prolonged use, to providing substantial therapeutic input) (Dennison et al., 2014). Cancer survivors have expressed the value of healthcare professional support and welcome incorporating human support alongside digital interventions (Adam & Watson, 2018; Roberts, Potts, Koutoukidis, Smith, & Fisher, 2019).

Therefore, there is evidence that human support alongside digital interventions may work in other contexts and evidence that cancer survivors value a human element to support. Therefore, it is reasonable to suppose that adding human support alongside digital interventions for cancer survivors is likely to be beneficial. An intervention like Renewed presents an opportunity for this to be explored further.

In summary, cancer survivors experience many consequences after treatment, which can reduce their QoL (Macmillan Cancer Support, 2020b). Interventions are needed that target multiple

healthy behaviours, such as physical activity, healthy eating and psychological management that can potentially offset the risk of cancer recurrence and improve QoL (National Cancer Survivorship Initiative, 2013). Adding human support may boost the effects of, and engagement with, digital interventions (Yardley et al., 2016). Digital interventions with additional human support may be a viable method of providing self-management support to cancer survivors with the aim of improving their QoL. Evidence is limited about the effectiveness of digital multi-domain behavioural interventions to improve cancer survivors' quality of life. That which does exist, is limited by the fact that evaluations of such interventions have been conducted in small samples, amongst specific cancer-type populations, only investigated shorter-term outcomes, or have not explored the role of additional human support. When integrated with brief HCP support, the use of digital interventions in primary care may result in feasible and cost-effective interventions yet still provide cancer survivors with the HCP guidance and recommendations they value (Roberts et al., 2019). Therefore, to potentially best support cancer survivors' quality of life, an intervention for cancer survivors is needed that: 1) is designed for survivors with a range of different cancer types; 2) includes additional healthcare professional support; 3) is evaluated amongst a large sample; and 4) is evaluated in terms of long-term outcomes.

### **1.2.5 Justification for not conducting a systematic review**

During the planning phase of the process evaluation the idea of conducting a systematic review to investigate the effectiveness of multi-domain interventions to improve quality of life among cancer survivors was considered. Ultimately the decision not to undertake a full systematic review was based on two factors: a lack of studies, and limited time and resources. At the time this was considered (late 2018 – early 2019), a soft search of relevant databases using the MeSH terms of multi-domain digital intervention, quality of life, cancer survivors, and health behaviour change revealed that the number of available studies that met the requirements was very low i.e. less than 5. Requirements included: QoL as a primary outcome, multi-domain intervention, multiple cancer types targeted, English language, adult participants. Thought was given to the possibility of broadening the research questions so as to include interventions for single cancer-types and/or single-domain focused interventions, or studies that investigated QoL even if not the primary outcome. The issue with broadening the scope to be inclusive of these topics was that a number of systematic reviews existed that had examined single-domain interventions for either single or multiple cancer-types (e.g. Forbes et al., 2019; Roberts et al., 2017; Triberti et al., 2019; Slev et al., 2016). An investigation where effectiveness of multi-domain interventions among multiple cancers was investigated was needed to fill the gap in knowledge about how cancer survivors engage with such interventions. Additionally, considering studies where QoL was not the primary outcome

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would have meant including studies that may not have been powered to detect a change in QoL and therefore risked not adding the relevant knowledge needed to inform design and evaluation of Renewed.

The time to collect and analyse all process evaluation data was limited due to the studies being conducted in parallel to the RCT of the Renewed intervention. Therefore, the process evaluation studies were designed to focus on areas most salient to understanding how an intervention like this is used and how it works. Conducting systematic reviews on those the broader research questions (e.g. interventions where QoL was not the primary outcome) would have been most beneficial during the development stage of the intervention, rather than the process evaluation. Indeed, research was conducted during the development phase of Renewed regarding the effectiveness and acceptability of these type of intervention among various cancer survivors (Corbett et al., 2018; Corbett et al., 2019), which was used to inform the design and development of Renewed. Instead, examining and evaluating the few studies that evaluated or developed multi-domain digital interventions to improve the QoL across multiple cancer types, as done in Chapter one, provides useful insight into the background and limitations of those studies, while still affording the time to explore research questions most salient to the aims of this thesis and evaluation of Renewed.

The methods used to find the relevant studies reviewed in chapter 1 included searching electronic databases (MEDLINE, PsycINFO and Embase) with no restrictions on the date of publication. Google Chrome was also used. A combination of scientific subject headings and free-text terms were selected to find publications pertaining to multi-domain digital interventions, cancer survivors, health behaviours and quality of life. Further details about the literature search are provided in Appendix A.

### **1.3 The Renewed intervention**

The Renewed intervention was designed to meet the needs outlined above, to improve quality of life among cancer survivors in primary care. Renewed was designed for breast, colon and prostate cancer survivors, and those on active surveillance with prostate cancer. These cancers were chosen as they were deemed to represent varying issues in needs and preferences across gender and age, which may support generalisability to other survivor groups (Krusche et al., 2019). Those on active surveillance with prostate cancer were included because they are comparable for most generic- and disease-specific health-related QoL dimensions to those who have completed treatment for prostate cancer (Thong, Mols, Kil, Korfage, & Van De Poll-Franse, 2010). Renewed

was developed using an evidence, theory and person-based approach (Yardley, Morrison, Bradbury, & Muller, 2015). The development of Renewed is discussed in detail by Bradbury et al., (2019). The intervention development work was conducted prior to this PhD (Bradbury et al., 2019; Corbett, Cheetham, et al., 2018; Corbett, Singh, et al., 2018;)and included a scoping review, development of guiding principles, a behavioural analysis and qualitative interviews. Renewed aims to improve QoL by targeting psychological well-being, physical activity, weight management and healthy eating. A rationale for targeting each behaviour or practice is provided in the section below.

### **1.3.1 Practices to enhance psychological well-being**

Psychological problems such as depression, anxiety and fear of cancer recurrence can reduce QoL among cancer survivors (Yi & Syrjala, 2017). Improving such psychological problems may positively affect QoL among cancer survivors (Zhang et al., 2019). The psychological support content included Cognitive Behavioural Therapy (CBT) and mindfulness practices to support psychological well-being. CBT (Beck, 2020) and mindfulness approaches may support cancer survivors' psychological well-being. CBT aims to help individuals learn to alter their thoughts (cognitions) and actions (behaviours) (Beck, 2020). Mindfulness practices focus on increasing awareness of the thoughts, feelings, and actions that hinder progress (Xunlin, Lau, & Klainin-Yobas, 2020). Systematic reviews suggest CBT can effectively support cancer survivors' QoL and psychological well-being (Ye et al., 2018). Mindfulness-based interventions can lead to significantly lower anxiety, depression, fatigue and stress and improve QoL among cancer survivors compared to control groups (Xunlin et al., 2020), which may endure over long periods of time (Mackenzie, Carlson, Ekkekakis, Paskevich, & Culos-Reed, 2013).

### **1.3.2 Physical activity**

Reviews have shown that physical activity can improve cancer survivors' physical, social, and emotional functioning and improve factors related to QoL (Balhareth, Aldossary, & McNamara, 2019; McNeely et al., 2006). For example, Eyl et al., (2018) found positive associations between physical activity and QoL among cancers in 5 out of 6 studies that compared active and non-active cancer survivors. Similarly, Van Dijck et al., (2016) reviewed 13 studies, six of which focused on participants who completed cancer treatment. Four out of six studies suggested that physical activity improved QoL, including general health, pain, fatigue, anxiety, depression and physical functioning.

### **1.3.3 Weight management**

Many cancer guidelines recommend survivors maintain a healthy weight (e.g. Macmillan Cancer Support, 2020a). A Cochrane review of 20 RCT studies found that weight loss interventions can reduce body weight, body mass index (BMI) and waist circumference and improve the overall QoL in overweight or obese breast cancer survivors, particularly those incorporating diet, exercise and psychosocial support (Shaikh et al., 2020). For example, an RCT found that a 15-week clinically based weight loss programme improved QoL in cancer survivors, particularly in physical functioning and insomnia symptoms.

### **1.3.4 Healthy eating**

Healthy eating is an important aspect of cancer survivorship. Health guidance suggests that a balanced diet based on fruit, vegetables, and whole grains while limiting saturated fat, red meat and alcohol could be beneficial for health and survivorship (Muscaritoli et al., 2021). A healthy diet (e.g. low in fat, high in fruits, vegetables, and whole grains) was associated with improved QoL among cancer survivors, particularly higher physical functioning, better sleep, and lower pain (Porciello et al., 2020). Furthermore, systematic and meta-reviews suggest that a healthy diet can reduce the risk of cancer recurrence and mortality (Schwedhelm, Boeing, Hoffmann, Aleksandrova, & Schwingshackl, 2016; Xing, Xu, & Shen, 2014).

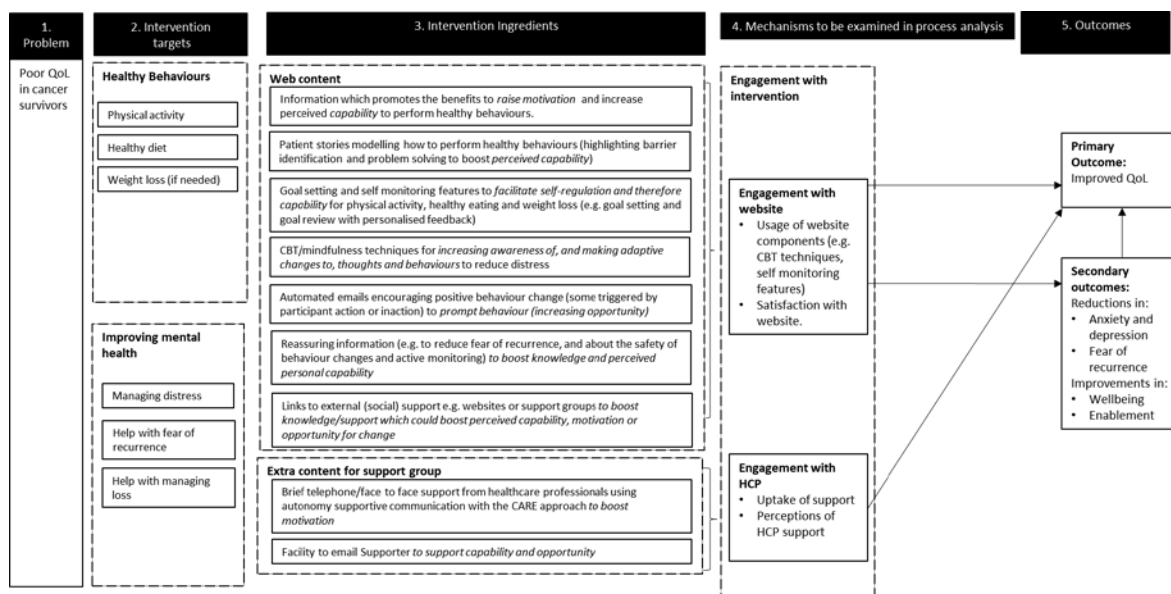
### **1.3.5 Renewed logic model: how the intervention is expected to work**

During intervention planning, a logic model was developed describing how the intervention was expected to produce change (Figure 1). The logic model had five parts, the first of which described the intervention's problem: reduced QoL among cancer survivors. The second part described the behaviours that Renewed targeted in order to improve QoL. These were health behaviours (e.g. healthy diet) and mental health (e.g. managing distress). The third part described the behaviour change techniques (e.g. goal setting, increased information about health consequences), behavioural sources (e.g. psychological capability, physical opportunity), intervention functions (e.g. education and persuasion), and constructs of Normalisation Process Theory (NPT) (e.g. coherence (understanding of a new intervention) that were incorporated to maximise engagement with Renewed and optimise implementation. The fourth part described the mechanisms through which Renewed was expected to influence behaviour. These were engagement with Renewed, and thereby the behavioural change techniques (BCTs), behavioural sources and functions. For those in the website plus support arm, an additional theorised mechanism of change was through engagement with support sessions via a Supporter (a HCP).



This part of the logic model was the primary focus of investigation for this thesis and paper two in particular. The final section of the logic model outlines the anticipated changes that using the intervention would produce – improvements in QoL and reductions in mental distress.

Figure 1 - Renewed logic model



*Reproduced with permission from Bradbury et al., (2019)*

### 1.3.6 Renewed intervention

Renewed is a web-based digital intervention designed to provide support for increasing multiple healthy behaviour changes among cancer survivors to increase their QoL. The Renewed intervention includes a website 'Renewed' (arm 1) and optional brief support from a healthcare professional (arm 2). Renewed begins with an introductory session, 'Core Content', which contains information on the benefits of healthy behaviour changes and brief advice on how to make behaviour changes, with signposting to other resources. Users on active surveillance with prostate cancer receive additional information about active surveillance to provide reassurance, as this group can be anxious about monitoring being used in place of treatment (Watts et al., 2015). Users are then given personalised suggestions of how the optional content within Renewed can help them based on answers to a QoL measure (EORTC QLQ-C30; (Aaronson et al., 1993)) before reaching the Homepage. From the Homepage, intervention users could use additional optional content within Renewed. Renewed's four optional content were: Getting Active, Eat for Health, Healthy Paths (Geraghty et al., 2016), and POWeR (Dennison et al., 2014; Little et al., 2016; Smith et al., 2017; Yardley et al., 2012). Cancer survivors randomised to the 'Renewed with support arm' also had the option of brief support sessions with a healthcare professional. [Table 1](#) describes the Renewed intervention in more detail.

Table 1 - Renewed intervention description

Contents	Description
Core Content	<p>Contains an introductory session which provides an overview of what to expect from Renewed. Renewed then provides tailored suggestions about which contents of the programme would be most helpful for managing the particular symptoms each participant is experiencing, based on answers to a QoL measure (their European Organisation for Research and Treatment of Cancer score (EORTC QLQ-C30 score; (Aaronson et al., 1993)) response. Links are given to additional resources not provided by Renewed (e.g., financial help, community support, return to work). Users undergoing surveillance for prostate cancer are provided with reassuring information about the safety and efficacy of active surveillance. After completing the Core Content, users are introduced to the homepage, from where they can access the other optional contents of Renewed.</p>
Healthy Paths	<p>Healthy Paths is designed to reduce stress and improve mental health well-being, through mindfulness-based and CBT techniques. Cancer-specific modules provide techniques for dealing with fear of cancer recurrence and feelings of loss following cancer. Links to support the management of difficult feelings and emotions are provided.</p>
Getting Active	<p>Getting Active is designed to encourage moderate physical activity through a range of interactive contents and behavioural change techniques. An initial quiz is used to increase motivation for physical</p>

	<p>activity and address cancer-specific physical health concerns (i.e. fatigue, pain). Suggestions for increasing physical activity gently are given and participants can then choose an activity option, such as exercising at home or walking, before being encouraged to set achievable personal goals. Goals are reviewed weekly and tailored feedback is provided. Users were given the option to order a free step counter. Links to other physical activity resources are provided (e.g. benefits of physical activity, local activities near users).</p>
Eat for Health	<p>Eat for health was designed to enhance knowledge of healthy eating and increase motivation to make changes to eating habits – a diet which is high in fruit and vegetables and low in fat, sugar, alcohol, and red/processed meats. Participants complete a short quiz to learn about the benefits of healthy eating. Common concerns about changing diet are addressed and an easy to follow eating plan is presented which uses a traffic light system. Meal plans and healthy eating recipes are also available. Participants are encouraged to set healthy eating goals which can be reviewed and updated. Tailored feedback is provided. Provides a goal setting and reviewing facility to enable self-monitoring of diet. Additional links to support healthy eating are provided (e.g. drinking alcohol, eating problems).</p>
POWeR+ (Positive Online Weight Management)	<p>POWeR is a digital weight management intervention shown to be effective, described in full elsewhere (Little et al., 2016). Participants can choose between a low calorie/low carbohydrate eating plan and a walking/any other physical activity plan. Provides physical activity support (e.g. walking or any other physical activity). Weight and goals</p>

	are reviewed weekly and tailored feedback is provided. Twenty-five sessions provide strategies to support weight loss (e.g. coping with cravings, relapse prevention).
Optional Support sessions ( <i>for those in the 'Renewed with support' arm</i> )	Ten-minute support sessions were offered at two, four and eight weeks after cancer survivors had begun the study via telephone or face-to-face. The role of the Supporter was to provide a listening ear to help cancer survivors decide which changes they might like to try, encourage cancer survivors to try out a change or keep going with changes. Supporters were asked not to give advice; rather all advice would come from Renewed. Instead, they were asked to use the 'CARE' approach: Congratulate, Ask, Reassure and Encourage (Bradbury et al., 2017). CARE aimed to facilitate an autonomous supportive relationship which promotes patient empowerment and aimed to achieve longer-term adherence to behaviour changes (Bradbury et al., 2017).

### 1.3.7 Healthcare professional support

HCP support was designed to boost adherence to both using the website and engaging with offline behaviour changes (e.g., physical activity) by promoting autonomous motivation. Survivors of cancer allocated to the Renewed with support arm were able to access support sessions provided by an HCP, delivered using the “congratulate, ask, reassure, and encourage” (CARE) approach (Bradbury et al., 2017). CARE is based on the self-determination theory and aims to facilitate an autonomy-supportive relationship that promotes feelings of autonomy, competence, and relatedness (Smith et al., 2017), thus building internal motivation for change (Koponen, Simonsen, & Suominen, 2017). CARE was designed to be easy to deliver and fit within HCPs' busy schedules, without practitioners needing to become experts in a particular condition or way of treating that condition as this more detailed behavioural support was instead provided by the website.

Supporters were practice nurses, practice-based health care assistants, or clinical research nurses who were part of a comprehensive research network outside of general practitioner (GP) practices, a model representing delivery of care similar to that provided by private companies supporting digital interventions in the NHS, who tend to provide phone rather than in-person support and do not have access to patient records (Changing Health, 2012). At the start of the study, supporters completed brief 15- to 20-minute web-based training outlining the study procedures and how to provide support to cancer survivors using the CARE approach. Before the sessions, the supporters were asked to send emails to cancer survivors 2 and 4 weeks after the participants began the study. Friendly email templates were provided, which were framed around the CARE approach, asking how cancer survivors were getting on and encouraging them to get in touch for a support session if they wished. Support sessions of 10 minutes were offered 2, 4, and 8 weeks after the participants had begun the study via telephone, email, or face to face. [Table 2](#) shows a brief summary of the key messages from supporter training on how to provide support.

Table 2 - Summary of supporter training key messages

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**Brief summary of the guidance given to Supporters on how to provide support**

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Use the CARE approach with participants during support sessions:

- **Congratulate the participant, e.g.:**  
“That’s great that you want to get more active”
- **Ask the participant e.g.:**  
“Have you decided to make any of the changes that Renewed suggested might be helpful?”
- **Reassure the participant, e.g.:**  
“Yes, doing more physical activity is safe and should help you to feel better.”
- **Encourage the participant, e.g.:**  
“Keep going with that as it should start to help you to feel better soon.”

Tips for providing support:

- Be warm and friendly
- Praise any achievements
- Listen and show understanding

Sessions should take place:

- 2, 4 and 8 weeks after the participant sign up for Renewed.
- Send an encouraging email at 2 and 4 weeks using through the Supporter website. Editable pre-written email templates are available.
- Log all emails and appointments on the support log

If a participant does not contact for support:

- Send encouraging email

If you find it hard to talk to the participant for only 10 minutes:

- Start the session by saying:  
“Nice to speak to you today. This is just a short appointment, we have around 10 minutes to talk. It would be great to hear how you’re getting on with Renewed.”
- In the last few minutes say:  
“We are coming to towards the end of our time, is there anything else that you wanted to discuss quickly today?”

- Let the participant know that the session is about to end, say:  
“Thank you for your time, it’s been nice to chat with you”

If the participant asks for advice:

- Ask them what they think would work best for them, or what they think would be best to do.
  - It’s okay to ask “what does the website say to do in that situation?”
  - If participant is concerned about whether making a change is safe, you can reassure them that everything recommended on Renewed is safe.
- 

## **1.4 Outcome evaluation of Renewed: randomised control trial**

Following its development, Renewed was subject to a RCT in order to assess whether use of Renewed, with or without healthcare professional support, resulted in a significant improvement in QoL amongst intervention users compared to individuals who had access only to generic advice where participants received access to an NHS Live Well website that provided advice about healthy living (NHS, 2022).

### **1.4.1 Recruitment of participants to the Renewed randomised control trial**

Participants included in the studies that are the subject of the papers included in the thesis were a subgroup of those recruited to take part in the RCT of Renewed intervention. The Renewed RCT recruitment and procedure is describe more fully elsewhere (Krusche et al., 2019). A brief summary is provided here. Cancer survivors were recruited from General Practitioner (GP) practices across Southampton, Wales and Bangor via survey mail outs during October 2017 – March 2021. Eligible participants for the Renewed trial were those who had finished treatment for breast, prostate, or colorectal cancer within the past ten years or were on active surveillance with prostate cancer. Cancer survivors also needed to have reduced QoL (as defined by scores 85 or below on European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire measure (EORTC QLQ-C30; (Aaronson et al., 1993), be aged 18 years or older and have internet access. After screening, participants were randomised to one of the three trial arms: 1) Renewed: web-only intervention, 2) Renewed with support: web-based intervention with additional guidance and support (HCP) support, or 3) Control: Generic advice and follow-up. Some of the participant materials for the RCT trial can be found in Appendix B.

### **1.4.2 Key findings of the Renewed randomised control trial**

The final sample included 2,712 breast (n=1,416), colon (n=432), and prostate (n=864) cancer survivors who were randomised to either the 1) Renewed arm (n=903), 2) Renewed with support arm (n=903), or the 3) Control arm (n=906).

The results showed that, at 12 months, the Renewed with support arm had significant improvements in QoL compared to those in the control arm. Furthermore, subgroup analysis showed that all cancers showed improvements in QoL compared to those in the control arm, but this improvement in QoL was greatest among those with prostate cancer compared to breast and colon cancer survivors.

## **1.5 Enhancing outcome evaluations: Process evaluations**

### **1.5.1 The role of process evaluations**

Whilst Renewed has already been the subject of evaluation through a RCT, when evaluating a complex intervention, it is important to also explore how it worked and to understand and optimise its implementation. RCTs of complex interventions provide an evaluation of efficacy, answering the question 'does it work', but tell nothing of 'how it works' (Munro & Bloor, 2010), ignoring the role implementers, participants and context can play in how the intervention is implemented and experienced. Process evaluations of complex interventions seek to understand how an intervention worked, as well as how it was implemented, its mechanisms of action, and how outcomes differ from one context to another, answering the question of 'what works, for whom, under which circumstances' (Moore et al., 2015; Skivington et al., 2021). Thus, combining process evaluations with RCTs can enable intervention developers and evaluators to develop a detailed understanding of how the intervention worked that can support stakeholders in interpreting effectiveness (Oakley, Strange, Bonell, Allen, & Stephenson, 2006). As Renewed is a complex intervention, its evaluation would be enhanced by a process evaluation, which is the focus of this thesis. The different parts of a process evaluation are discussed below.

### **1.5.2 Implementation**

Implementation refers to how delivery is achieved, and what is actually delivered. Examining *how* an intervention is implemented involves considering how the intervention may achieve its effects in everyday practice. This means considering factors such as training for intervention providers, resources, support and organisational factors (Moore et al., 2015; Skivington et al., 2021).

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Examining *what* was implemented includes assessing what was delivered compared to what was intended. This involves examining factors such as fidelity (the consistency of what is implemented with the planned intervention), reach (the extent to which a target audience comes into contact with the intervention) and dose (how much intervention is delivered). In relation to Renewed, examining factors such as barriers and facilitators to HCPs providing support as intended and cancer survivors using Renewed give insight into how delivery is achieved. Examining how much cancer survivors use Renewed or support sessions gives insight into what is delivered.

### **1.5.3 Mechanism of action**

Mechanisms of action refer to how the delivered intervention produced change. Intervention users actively interact with and have experiences with interventions. It is through these interactions and experiences that change is produced (Moore et al., 2015). Therefore, it is important to examine how users interact with interventions to understand how they work. Process evaluations may test and refine the theory of how the intervention is expected to produce change through a combination of quantitative and qualitative methods. Key causal assumptions may be quantitatively tested, while qualitative data may lead to refinement of the logic model. Qualitative methods may allow additional mechanisms to be identified which were too complex to be captured via quantitative methods or might not have been anticipated (Moore et al., 2015; Shaw et al., 2018). In relation to Renewed, quantitative usage analysis allowed the testing of the intervention's logic model assumptions of how change was produced and provide insight into how cancer survivors interacted with Renewed. Qualitative interviews with cancer survivors complemented usage analysis to provide in-depth experiences of how users interacted with the intervention

### **1.5.4 Context**

Examining context considers how anything external to the intervention may affect implementation and outcomes (Shaw et al., 2018). Contextual factors may affect how an intervention is adapted or modified to fit within specific environments (Jansen, Foets, & De Bont, 2010). Moreover, contextual factors may affect the way users interact with or experience an intervention. Even where an intervention is relatively simple, its interaction with its context may still be highly complex (Bonell, Jamal, Melendez-Torres, & Cummins, 2015). Therefore, contextual factors must be considered across all aspects of a process evaluation. In relation to Renewed, the potential impact of contextual factors were explored through qualitatively examining barriers and



facilitators to cancer survivors engaging with Renewed and quantitatively examining moderators to usage.

## 1.6 Understanding engagement with Renewed

Engagement has been defined as both the subjective experience of the intervention user and the extent to which the intervention is used (Perski, Blandford, West, & Michie, 2017). The logic model of Renewed hypothesised that change will be produced through effective engagement with Renewed, and for those in the Renewed with support arm, effective engagement with support sessions. To investigate the mechanisms of the logic model this process evaluation focused on exploring participants' engagement with the intervention. Particularly, this process evaluation sought to understand what effective engagement was in this context. Effective engagement refers to sufficient engagement with the intervention to achieve intended outcomes (Yardley et al., 2016).

Examining effective engagement with Renewed required exploring both how the intervention was used as well as the subjective experiences of cancer survivors using Renewed. In relation to exploring usage of digital interventions, many usage analysis studies have focused on the relationship between usage and outcomes, specifically investigating how much usage of a digital intervention is needed to achieve outcomes (e.g. Donkin et al., 2013). Many of these studies have often concluded that greater usage of the digital intervention will lead to better outcomes (e.g. Enrique, Palacios, Ryan, & Richards, 2019). These conclusions would suggest that to achieve the best outcomes, digital intervention developers should focus on techniques and strategies to maximise usage. However, while an individual may have high usage of an intervention, this does not necessarily mean that they are interacting with the behaviours more than someone who used it less (Donkin et al., 2013). The relationship between usage and behaviour change is not always linear. Sometimes, even brief usage can produce interaction with behaviour change and achieve outcomes similar to those who used it more (Castro, Haug, Filler, Kowatsch, & Schaub, 2017). As a result, recent research has distinguished between promoting maximum engagement and promoting 'effective engagement'. The concept of effective engagement recognises that the extent to which an intervention is used is not equivalent to their performance of behaviour change. Some individuals may need to use the intervention less, while some may need to use it more before they are able to perform behaviours. An examination of usage alone will not be sufficient to capture what is effective engagement with Renewed for a couple reasons. Firstly, an examination of usage alone overlooks users' experiences and interactions and how these may differ from one context to another. Secondly, a usage analysis of Renewed alone would be unable

to capture the distinction between using Renewed compared to performing behaviour changes offline outside of the intervention and reveal little about how this was experienced. Therefore, usage analysis should be complemented by other methods that can give insights into subjective user experiences (Yardley et al. 2016). In-depth qualitative interviews with cancer survivors using Renewed allow an understanding of users' experiences, their socio-demographic context and why they interact with Renewed in the ways they do (O’Cathain et al., 2019), and can be used to understand usage and outcomes of the intervention (Yardley et al., 2015). As a result, quantitative usage analysis explored how Renewed was used and examined the relationships between usage, outcomes and participant characteristics. To complement this, qualitative interviews with cancer survivors explored their experiences using Renewed, barriers, and facilitators to use and perform behaviour changes. This, combined with usage analysis, provided a better understanding of effective engagement in this context.

### **1.7 Using theory to aid the evaluation of Renewed’s potential implementation**

Using theory in process evaluation studies can provide mechanism-based explanations for relationships between interventions, implementers, and contexts (Kislov, Pope, Martin, & Wilson, 2019) and strengthen the research's generalisability and ability to build on the wider literature (McEvoy et al., 2014). Consequently, guidance advises on greater use of theory in process evaluation research (Skivington et al., 2021). Implementation theories aim to understand and/or explain influences on implementation outcomes (Nilsen, 2015).

The CFIR provides a list of 39 constructs arranged across five domains (intervention characteristics, outer setting, inner setting, characteristics of the individuals involved, and the process of implementation) which interact to influence implementation and implementation effectiveness (Damschroder et al., 2009). CFIR can provide a practical guide for systematically assessing potential barriers and facilitators in preparation for implementing an intervention. It has been applied to a wide range of healthcare intervention evaluations, with a wide range of objectives, units of analysis, design and methods (Kirk et al., 2016).

However, it has been argued that CFIR places particular emphasis on the individuals receiving the intervention and does not give enough emphasis to the context in which the intervention is being implemented, and the perspectives and experiences of stakeholders and those delivering the interventions (Christie et al., 2018). As a result, CFIR was not deemed to be a suitable framework for this thesis as part of the aims were particularly concerned with the experiences of HCPs

delivering support to cancer survivors using the intervention, and exploring how well this would normalise among HCPs in everyday practice. A framework that places greater emphasis on these factors was judged to be more suitable.

One such framework is Normalisation Process Theory (NPT) (May & Finch, 2009). NPT was developed to identify and explain the processes through which new or modified practices of thinking, enacting, and organising work are operationalised in healthcare and other institutional settings (May & Finch, 2009). NPT provides a framework to enable understanding of how a new intervention becomes part of normal practice, emphasising how work must be changed individually and collectively by multiple stakeholders involved in the implementation (Finch et al., 2018). It has successfully been applied to several complex healthcare interventions across topics in UK primary care settings to evaluate factors related to implementation success (Huddleston et al., 2020). Data exploring HCPs' experiences providing support to those using Renewed were compared to NPT to help explain which factors may contribute or hinder the potential to implement Renewed successfully. NPT was chosen for the study in this thesis study because the aims were particularly concerned with the *work* that individuals and groups have to do for new technology or practice to become embedded and sustained in routine practice. A description of NPT is provided in Table 3.

Table 3 - Normalisation Process Theory outline as described by McEvoy et al., (2014)

<b>Construct</b>	<b>Definition</b>
<i>Coherence</i>	The work individuals and organisation have to go through to understand a new practice in order to promote or inhibit it. These processes are energised by investments of meaning made by participants.
<i>Cognitive participation</i>	The work individuals and organisations have to go through to enrol users and engage with a new practice. These processes are energised by investments of commitment made by participants.
<i>Collective action</i>	The work individuals and organisations have to go through to enact a new practice. These processes are energised by investments of effort made by participants.
<i>Reflexive monitoring</i>	The work of formal or informal appraising an intervention to develop participants' comprehension of the effects of the intervention. These processes are energised by investments in appraisal made by participants.

## **1.8 Thesis aims**

In order to conduct a process evaluation of Renewed, the specific aims of the research were to:

1. Explore, describe and characterise the mechanisms through which Renewed achieves change (or not) in quality of life in cancer survivors.
2. Explore, describe and characterise Renewed's potential to be implemented in practice.

## **1.9 Overview of the three papers**

The overarching thesis aims outlined above shaped the three studies contained in the thesis. An overview of the three studies is provided in this section.

### **1.9.1 Paper 1: Experiences of using a supported digital intervention for cancer survivors in primary care: A qualitative process evaluation with cancer survivors**

#### **1.9.1.1 Overview of paper**

Qualitative studies examining user experiences are increasingly used in process evaluations of digital interventions (French, Pinnock, Forbes, Skene, & Taylor, 2020). This paper presents a qualitative process study of cancer survivors use of Renewed to provide potential explanations of how Renewed may have achieved its effects and why it provided benefit for prostate cancer survivors more so than breast or colon cancer survivors and explore any perceived changes in participants' QoL. These insights were crucial to understand and inform the implementation of Renewed and implications for future digital interventions for cancer survivors. It was also decided to explore barriers and experiences of using Renewed in relation to the Coronavirus disease of 2019 (COVID-19) pandemic. This allowed exploration of contextual implications relating to use of Renewed and experiences of use (Kislov, Pope, Martin, & Wilson, 2019). Interviews were collected and analysed before obtaining knowledge of Renewed RCT outcomes. Once RCT outcomes were later available, data were considered in relation to RCT findings.

## **1.9.2 Paper 2: Usage of a healthcare professional-supported digital intervention for cancer survivors in primary care: A quantitative process evaluation**

### **1.9.2.1 Overview of paper**

This paper presents a quantitative process study of cancer survivors' use of Renewed during the RCT. The intervention logic model hypothesised that change in QoL would be produced through effective engagement with Renewed and engagement with Supporter sessions for those in the Renewed with support arm. There was a need to understand what effective engagement was in the context of Renewed. By examining the relationships between how participants used Renewed, their characteristics, access to support and QoL, a greater understanding was provided of what was required for effective engagement for this intervention.

## **1.9.3 Paper 3: Implementing a healthcare professional-supported digital intervention for cancer survivors in primary care: a qualitative process evaluation of Renewed**

### **1.9.3.1 Overview of paper**

This study presents a qualitative process study of healthcare professionals' experiences of supporting cancer survivors using Renewed. This study explored HCPs' experiences of providing support to cancer survivors using Renewed and potential barriers and enablers of successful implementation of Renewed in practice in order to understand how Renewed was normalised (or not) and the work needed to implement the intervention in healthcare successfully. This study captured data that can help inform how similar interventions can be implemented in routine healthcare whilst understanding how best to support cancer survivors in primary care. Research for this study was completed before obtaining knowledge of the Renewed RCT outcomes.

## **1.10 Author contributions**

The three papers and thesis introduction and discussion chapters were lead and written by me. I was responsible for undertaking plans, data collection and analyses of each paper. Disseminating the research to the public and response to reviewers were undertaken by me. My supervisory team provided advice and critical feedback on all stages of the research process (protocol, data collection, analysis, write-up and dissemination). All supervisors were named as co-authors on the three papers. The additional details of the supervisors' contributions are listed below, followed by details of contributions by additional authors.

### **1.10.1 Supervisory team**

Dr Katherine Bradbury, primary main supervisor (60%). Secured PhD funding in collaboration with LY and AR. Co-developed the Renewed trial and contributed to the early conception for the Renewed process evaluation.

Dr Rosie Essery, second/co-supervisor (20%). Contribution to subsequent plans for the Renewed process evaluation.

Professor Lucy Yardley, second/co-supervisor (10%). Co-principal investigator of the programme grant and contributed to the early conception of the Renewed process evaluation.

Professor Alison Richardson, second/ co-supervisor (10%). Co-developed the Renewed trial and contributed to the early conception of the Renewed process evaluation.

### **1.10.2 Additional authors**

Additional authors were co-applicants of the grant programme. Each co-applicant provided critical feedback on subsequent manuscript drafts of the three papers and feedback on responses to reviewers. They were included as co-authors on each paper. The programme co-applicants are listed below.

Professor Paul Little (co-principle investigator of the programme grant)

Professor Eila Watson

Professor Claire Foster

Dr Chloe Grimmet

Dr Adam W.A. Geraghty

Dr Geoffrey Sharman (patient and public involvement team)

Tamsin Burford (patient and public involvement team)

Roger Bacon (patient and public involvement team)

Lesley Turner (patient and public involvement team)

Additionally, a number of co-authors outside of the programme co-applicants contributed to some of the research papers. Details of their contributions are listed below.

Dr Joanna Slodkowska-Barabasz: Assisted with data collection in Papers one and three.

Cassandra Chavlet: Assisted with data collection in Paper one.

Dr Beth Stuart: Provided advice on data analysis and manuscript drafts of Paper two.

Dr Sebastian Pollet: Assisted with data extraction, data analysis plans and manuscript drafts of Paper two.

Dr Jin Zhang: Assisted with data extraction plans and manuscript drafts of Paper two.

### **1.10.3 Patient and Public Involvement**

Patient and public involvement (PPI) in research is considered important, with suggestions that PPI is useful to improve the quality and relevance of research outcomes (Boivin et al., 2018). Patient and public members can be involved at every stage of the research process: identifying and prioritising (i.e. identification and prioritisation of research areas), commissioning (e.g. giving a broader perspective to the review process by bringing into consideration the issues that are important from a public perspective), designing and managing (e.g. help ensure that the research and its design are relevant to the needs of people), undertaking (e.g. conducting the research by collecting data and/or analysing data), disseminating (e.g. help write and summarise research findings in ways that is accessible to a public audience), implementing (e.g. support and strengthen the way research is taken up in practice) (Involve 2012; Turk et al., 2017). The wider CLASP programme grant has four patient and public contributor co-applicants whose role included, for example, developing the protocol, agreeing on the key questions, the choice of primary outcome EORTC, the choice of cancers, and the way the application is presented. The role patient and public contributors played in relation to the process evaluation is outlined in this section.

Patient and public contributions were first utilised in Paper three (Chapter five), providing critical input in the write-up of the manuscripts for journal publication. Patient and public contributors were only brought into the research process after the first draft of the manuscript was generated because I had not appreciated the value this would bring to the research process. Though their feedback was valuable, it could not, at that stage in the research process, fully contribute to ensuring the design of the study was relevant to the needs of the population -a matter of great significance for a project of this nature. It has been argued that patients and public contributors are more successful at contributing to the dissemination of research if they have been involved in the earlier stages of the research (Turk et al., 2017). Learning from this, for papers one and two (Chapters three and four) (analysis of which concluded after the publication of paper three), patient and public contributors were involved in the design and management of these studies

## Chapter 1

from the outset, and similarly involved with dissemination as with study three. For study one, this was achieved through discussion which shaped interpretation of data and data collection. For instance, after discussing some initial qualitative interview data with PPI, members highlighted the varied experience of availability of support across cancer groups and suggested this be explored in the subsequent qualitative interviews with Renewed participants. In regards to paper two, patient and public contributors were involved in identifying research questions and reviewing analysis. Working with patient and public contributors in this way resulted in research that was considerate of the needs of the public in order to achieve real benefit in practice. For example, patient and public contributors suggested it was important to consider how access to, and value of, the option of healthcare support may differ across cancer types. This was not something that was considered before. In light of this paper one explored this possibility and found that prostate cancer survivors may perceive more benefit from the option of support as they expressed not having access to it outside of the intervention. The implication of this was to suggest that interventions that include support particularly target those who have less access to support in their own social networks, for instance prostate cancer survivors. Patient and public contributors provided constructive feedback on papers one and two of the process evaluation and were offered authorship on these papers to reflect their contribution to research.

### 1.11 Structure of the thesis

In summary, the studies included in the thesis form a mixed methods process evaluation of Renewed. This evaluation sought to understand how Renewed worked, who it might have worked best for, and how to successfully implement it in practice to best support cancer survivors' QoL. The remainder of the thesis is organised into the following chapters:

- Chapter 2 outlines the methodological approach underpinning the thesis and a discussion pertaining to the specific methods used in each study.
- Chapter 3 is a qualitative study that explored cancer survivors' experiences using Renewed.
- Chapter 4 is a quantitative study that explored how cancer survivors' used Renewed and examined the relationships between usage, access to support, participants' characteristics and outcomes in QoL.



- Chapter 5 reports a qualitative study exploring the experiences of HCPs supporting those who used Renewed.
- Chapter 6 concludes the thesis with a general discussion that characterises the key findings of each study in relation to how these address the aims of the thesis. Implications of the research are outlined before concluding with considerations of the limitations of the thesis and proposals for future research.



## Chapter 2 Methodological approach

### 2.1 Epistemology

Qualitative and quantitative research methods were used to conduct a process evaluation of Renewed. Qualitative and quantitative methods typically reflect different epistemologies. Qualitative research is typically associated with constructivism, while quantitative research is typically associated with positivism. Constructivist epistemology suggests that all knowledge is constructed from a particular ideological, social or personal position (Cornish & Gillespie, 2009). From this perspective, as knowledge is locally situated and contextualised, understandings are sought through subjective means (Bishop, 2015). On the other hand, a positivist epistemology suggests that only one form of knowledge is 'true', and this knowledge can be obtained outside of ourselves (Cornish & Gillespie, 2009). From this position, understandings are sought through objective means (Bishop, 2015). Epistemology influences how researchers design, analyse and evaluate research. Consequently, it has been argued that mixing the qualitative and quantitative methods is incompatible (Bryman, 2016). However, there is also an argument that suggests that the differences between these approaches can be overcome and form a more pragmatic approach (Yardley & Bishop, 2017).

Pragmatism acknowledges the epistemological differences between qualitative and quantitative approaches but does not see these differences as incompatible. Instead, the focus is placed on the extent to which the research achieves its desired purposes and consequences (Bishop, 2015). Pragmatism suggests that knowledge is a tool for action, judged according to its consequences in action (Cornish & Gillespie, 2009). In a pragmatist approach, the question is not 'Does this knowledge accurately reflect the underlying reality?' but rather 'Does this knowledge serve our purposes?' (Rorty, 1999). All actions (e.g. collecting and interpreting, or knowing) are evaluated as being appropriate based on how much they achieve their goal. This will depend on the knowledge and purposes of concern (Yardley & Bishop, 2015). Instead of focusing on methods, researchers emphasise the research problem and use the best methods to drive knowledge about the problem (Creswell & Creswell, 2018). Pragmatism is not committed to any one system of reality. This applies to mixed methods research in that draws from both quantitative and qualitative assumptions when researchers engage in their work.

Medical Research Council (MRC) guidance on evaluating complex interventions suggests evaluation research should use qualitative and quantitative methods to answer complex

questions about implementation, context and mechanisms (Skivington et al., 2021). Following this guidance, this thesis comprised a mixed methods process evaluation. Mixing methods was considered the most appropriate approach to drive knowledge about how Renewed produced a change in QoL among cancer survivors and how it was implemented. Mixed methods research is best suited for exploring engagement in digital interventions because qualitative methods can explore users' subjective experiences, as in Paper one, while quantitative usage analysis can examine the extent to which the intervention is used (Moore et al., 2015), which was the focus of Paper two. As a result, this thesis is consistent with a pragmatist approach, which recommends adopting the most appropriate methods for the research question.

## 2.2 Renewed trial setting

The Renewed trial took place between October 2017 to March 2021 with participants recruited from primary care practices across Southampton, London, Oxford and Bangor. The experiences and behaviours explored among the participants in the Renewed trial may differ from participants in usual care, outside of the Renewed study. Research has shown that participants involved in cancer-related clinic trials tend to be more altruistic (Truong et al., 2011). Particularly with digital health research among older people, people who agree to take part have been found, on average, to be slightly younger, have a higher level of education, report better memory, have higher social participation, and higher familiarity with and greater use of digital technologies compared to those who decline to take part (Poli et al., 2019). Furthermore, as the intervention was only implemented in certain regions, it is possible that individuals outside of these areas may have unique characteristics and experiences that differ to the individuals in this sample. For example, the North East of England has the highest incidence of cancer across England (NHS digital, 2021), while the economic growth is believed to fall behind the rest of the UK as a whole (Economic Statistics Centre of Excellence, 2019), and the health and wellbeing gap between the North East and the rest of England remains significant for many health indicators (Office for Health Improvement and Disparities, 2021). The experiences of having cancer and the availability of resources, and perceptions of how to manage their consequences from treatment may be different in the North of England compared to those of participants in the Renewed RCT. In this way, the findings presented in this thesis should be considered in light of these sample characteristics. The implications of sample characteristics for understanding how Renewed may be implemented and engaged with are discussed in Chapter 6, Section 6.5. Furthermore, the COVID-19 pandemic has impacted key services in primary care (UK Parliament, 2023). Before the pandemic, digital tools and intervention were slow to be implemented at scale. During the pandemic, digital intervention were implemented rapidly to allow care to be delivered when

physical contact was not possible (NHS, 2022). Since the pandemic, key services changes include the use of digital tools to deliver services to patients and having meetings and consultations remotely (Baird and Maguire, 2021). Initial consultations are more likely to take place remotely compared to in-person (Baird and Maguire, 2021). In light of this, it is possible that an intervention like Renewed may implement more successfully as digital interventions in primary care are becoming more normalised.

## **2.3 Methodological approaches**

### **2.3.1 What is a mixed-methods design?**

Mixed methods involve the integration of quantitative and qualitative methods at some stage of the research; collection, analysis, or interpretation (Östlund, Kidd, Wengström, & Rowa-Dewar, 2011). It has been argued that mixed methods are particularly useful in process evaluations because they allow a broad understanding of the phenomena and how an intervention works (Östlund et al., 2011; Skivington et al., 2021). Quantitative methods in process evaluations can allow theory testing by specifying narrow hypotheses, typically from the intervention logic model, which is tested through collecting and analysing numerical data. Qualitative methods in process evaluations can be used to generate in-depth insights into phenomena or generate new ideas for research through collecting and analysing non-numerical data (e.g., audio language, text, written, or video) to understand experiences or identify barriers and facilitators to engagement or implementation of the intervention (Moore et al., 2015). Using mixed methods draws upon the strengths of each method to provide a stronger account of the phenomena while minimising the limitations of each method (Creswell & Creswell, 2018). When using mixed methods, it is important to clearly state the emphasis placed on each method (emphasis) and the purpose of mixing methods to allow readers and researchers to understand how conclusions are drawn (O’Cathain, Murphy, & Nicholl, 2010).

### **2.3.2 Rationale for using a mixed-methods design**

It is important to provide a clear rationale for using mixed methods to improve the research process's transparency and validity. Greene et al., (1989) proposed five reasons for using mixed methods; triangulation (seeks to converge, corroborate or correspond results from different methods); complementarity (seeks elaboration, enhancement, illustration or clarification of results from one method with the results of the other method); development (seeks to use the results of one method to help develop or inform the other method); initiation (seeks the

discovery of insights results from one method with questions of results from the other method) and expansion (seeks to extend the breadth and range of inquiry by using different methods for different inquiry components). The rationale for using mixed methods should be driven by research questions (Bishop 2015). Process evaluations are designed to answer various questions, including assessing intervention, barriers to implementation, and participant and provider experiences of the intervention and implementation (Harden et al., 2018).

This process evaluation used both quantitative and qualitative methods to enable a gradual accumulation of knowledge of how the intervention was delivered and how it works. Quantitative methods were able to explore links between specific components of Renewed and outcomes in QoL, intermediate processes and contextual influences. Qualitative methods provided an in-depth understanding of mechanisms of action, how context affected implementation, or why those delivering or receiving the intervention did or did not engage as intended.

### **2.3.3 The contribution of quantitative and qualitative methodologies**

Quantitative research is characterised by deductive approaches, such as experimental designs, and surveys, allow testing of prior hypotheses with the potential to generate generalizable findings, if based on large and representative samples (Tariq & Woodman, 2013). Commonly used quantitative methods in process evaluations include self-report questionnaires, structured observation or secondary analyses of data (Moore et al., 2015). However, quantitative methods do not explore deeper underlying meanings and explanations to generate hypotheses about how or why things are happening, or explaining complex social or cultural phenomena (Rahman, 2017; Tariq & Woodman, 2013) that may relate to either outcomes or experiences of using the intervention.

Conversely, qualitative research aims to explain rich descriptions of views, beliefs and meaning. Common qualitative methods used in process evaluation include one-to-one interviews, focus groups and observations (Moore et al., 2015). However, the inferences drawn from qualitative methods are subjective and unique to the person or situation, and the generalizability of those inferences is uncertain (Munro & Bloor, 2010).

If researchers desire to understand all aspects of how a digital intervention works, combining both quantitative and qualitative data can provide a richer and more complete description of the processes with internal and external validity (Yardley & Bishop 2017). Quantitative and qualitative data can work to complement each other, where quantitative provides usage metrics, reach, frequency, depth, and breadth, and qualitative approaches provide rich data on individual experience. For example, a mixed method engagement study on a self-management app designed

for breast and prostate cancer survivors used quantitative methods to investigate participants' logged usage data and qualitative interviews to understand how participants perceive the app (Crafoord, Fjell, Sundberg, Nilsson, & Langius-Eklof, 2020).

Two qualitative process studies and one quantitative process study of Renewed were undertaken. One of the qualitative studies involved interviews with cancer survivors using Renewed, while the other involved interviews with the healthcare professionals supporting those cancer survivors using Renewed. In-depth qualitative analysis of user experiences can illuminate how participants interact with the intervention and its contents to produce change and identify additional potential mechanisms too complex to be identified through quantitative analysis (Renouf, Bradbury, Yardley, & Little, 2015). The quantitative study analysed usage data and baseline questionnaire data of cancer survivors. Quantitative analysis provides a route to testing intervention theory by analysing hypothesised moderators and potential mechanisms of action (Moore et al., 2015). Usage data can reveal the extent to which an intervention is used and provide insight into user engagement (Miller et al., 2019).

#### **2.3.4 Decisions on how to mix methods**

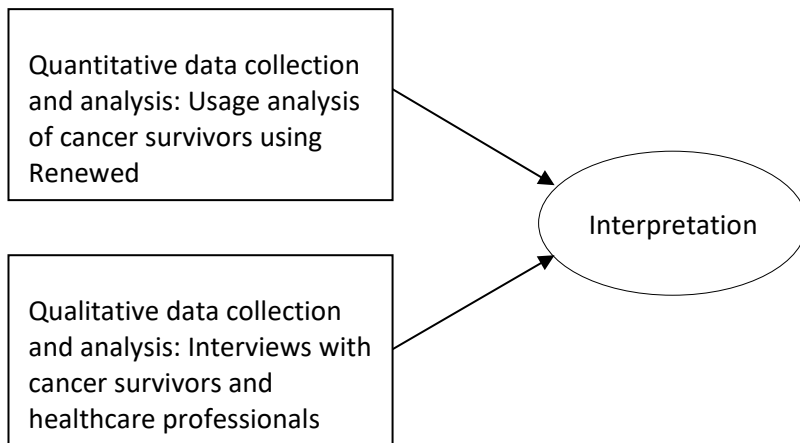
Decisions on how to mix methods are dependent on two things: timing (of data collection) and emphasis (one method given priority over the other) (Bishop, 2015). The timing and the emphasis will determine how the data will be mixed, depending on various factors, including the study's aims, purpose and rationale (Östlund et al., 2011). Creswell & Creswell (2018) describes three ways to mix methods: explanatory, exploratory, and triangulation. Each method has different timing and emphasis suited for certain aims, purposes, and rationale. Triangulation was the chosen approach to mix methods in this thesis.

Triangulation in mixed methods refers to collecting both quantitative and qualitative methods independently, and integrating them at the point of interpretation or analysis (Creswell & Creswell, 2018). This design preserves the integrity of both methods (Yardley & Bishop 2017). In this design, researchers collect quantitative and qualitative data, analyse them separately, and then compare the results to see if they merge, complement, or enhance the different findings. For example, a researcher could use qualitative methods to explore participants' experiences of performing a behaviour and use quantitative methods to test if performance of that behaviour is related to changes in outcomes. These methods could then be combined to assess the mechanisms of the behaviour. Triangulation was chosen for this process evaluation because keeping both qualitative and quantitative methods data separate allowed different but complementary insights on the same topic (McBride, MacMillan, George, & Steiner, 2018). This

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was important to ensure that novel insights were not overlooked. Furthermore, the ability to conduct the various studies separately meant that studies could be carried out simultaneously and within a shorter period, ensuring that data was collected and analysed before RCT trial outcomes were known to avoid biased interpretation (Oakley et al., 2006). An illustration of data collection and the mix of methods underpinning the work in this thesis is provided in Figure 2.

Figure 2 - Triangulation design of the thesis



## 2.4 Quantitative measures

This thesis sought to understand the mechanisms through which Renewed achieved change (or not) in the QoL in cancer survivors and explored Renewed's potential to implement in practice. Part of this involved understanding the theory of how the intervention was expected to work, as depicted in the intervention logic model (Figure 1). Quantitative methods were best suited to examine this as they provide a route to testing intervention theory by analysing hypothesised moderators and potential mechanisms of action outlined in the logic model (Moore et al., 2015). A rationale for the quantitative methods is provided in this section.

### 2.4.1 Rationale for the inclusion of variables

#### 2.4.1.1 Usage variables

Usage was measured by the overall number of times participants accessed Renewed and its optional content. Total logins measures the sum of all logins throughout an intervention. Research suggests that engagement is multifaceted, and usage should be measured at different levels, such as duration, depth and amount, thereby providing the breath of usage. However, access to many usage measures was not feasible for this study. Renewed is an intervention with a wide range of content and behaviour change techniques contained across many pages, so the



complexity of collating and analysing these variables was not feasible for analysis in Paper two (Perski et al., 2017). As a result, the overall number of times accessed was considered a good representation of usage because it provides an objective measure of the extent of use over time (Perski et al., 2017; Smith & Liu, 2020). Furthermore, looking at the number of times each optional content of Renewed (e.g., Getting Active) was assessed to capture which optional content was most used.

#### **2.4.1.2 Quality of life variable**

Self-reported QoL scores 12 months after commencing the Renewed trial were chosen as the outcome variable. This allowed the investigation of potential factors associated with longer-term improvements in QoL to be assessed, as outcomes found at six months are not always sustained at 12 months (e.g. Willems, Bolman, et al., 2017; Willems, Mesters, et al., 2017).

#### **2.4.1.3 Demographic variables**

The demographic variables included in this study were baseline QoL, baseline anxiety and depression, age, gender, type of cancer participants had, years since completing treatment, education level and BMI scores. Ethnicity was not included as a variable in the analyses. The lack of diverse ethnicities in the Renewed RCT trial meant that it was not possible to include this variable in analyses because the largely uneven distributions across the ethnicity groups would have affected the power and robustness of the analysis (Field, 2009). Baseline QoL, anxiety and depression can be related to how individuals rate their quality of life as well as the extent to which they can engage with an intervention (Brett et al., 2019 ; Jones et al., 2021 ; Ribeiro et al., 2020) While evidence regarding demographic factors influencing usage and outcomes in digital interventions is inconsistent (Ryan, Bergin, & Wells, 2018), there is some research to suggest that these factors could potentially influence usage, experiences and outcomes (e.g. cancer type (Kanera et al., 2016; van der Hout et al., 2021), , gender and age (Ruland et al., 2013) and time since treatment (Tollosa, Tavener, Hure, & James, 2019). There was a need to examine the potentially moderating influence demographic characteristics may play in usage and outcome in the context of Renewed.

#### **2.4.2 Sample size**

Paper two sample was comprised of cancer survivors in the Renewed and Renewed with support arms of the Renewed RCT trial. The sample size of the RCT trial was determined through a power calculation that is discussed more fully by Krusche et al., (2019).

## **2.5 Qualitative measures**

While the quantitative measures explored engagement of Renewed by examining the extent of usage, the qualitative methods were best suited to understand the subjective experience of engagement with Renewed. Specifically, qualitative methods were best suited to explore the research questions concerning cancer survivors' and HCPs' experiences of using Renewed or providing support and identifying barriers and facilitators to engagement. Qualitative methods were best suited to explore this as they illuminate how participants interact with an intervention and provide in-depth accounts of user experiences. A rationale for the qualitative methods used is provided in the next section.

### **2.5.1 Interviews**

Common qualitative methods used in process evaluations include one-to-one interviews, focus groups and observations (Moore et al., 2015). Qualitative one-to-one interviews were conducted with cancer survivors and healthcare professionals. Qualitative interviews involve questions intended to elicit participants' views, opinions and experiences (Creswell & Creswell, 2018). Open-ended questions were used to allow participants to describe their experiences and views in their own way freely and to focus on whatever was most salient to them. As such, interviews provided an in-depth understanding of how participants interacted with the intervention (Yardley et al., 2016), which is crucial for understanding how they work and therefore offered an appropriate method of investigation for the current research questions.

### **2.5.2 Semi-structured interviews**

Semi-structured interviews were used to collect data with cancer survivors and HCPs. Semi-structured interviews are interviews which follow a mix of a structured and unstructured format (Cachia & Millward, 2011). An interview schedule that covers the main topics of the study is used to guide the interview. However, additional questions may be introduced to follow up on participants' responses to allow further elaboration of the points raised. While an interview schedule is used to guide the interview, the discussion should not be followed strictly, allowing order to vary (Kallio, Pietilä, Johnson, & Kangasniemi, 2016). Semi-structured interviews are suitable for studying people's perceptions and opinions of complex and emotionally sensitive issues (Barriball & While, 1994). In a semi-structured interview, it is possible to focus on meaningful issues for the participant, allowing diverse perceptions to be expressed (Cridland et al., 2015).

In intervention process evaluation studies, guidelines suggest that interview schedules should relate to the intervention's logic model (Moore et al., 2015). As a result, the interview schedules were developed to explore the experiences of cancer survivors and HCPs to better understand how Renewed may have achieved change or identify factors potentially influencing successful implementation. For paper one, the interview schedule covered topics including experiences of using the Renewed intervention, any behavioural changes made whilst being in the Renewed study, experiences of healthcare professional support received within Renewed, and experiences of using Renewed during the COVID-19 pandemic. For paper three, the interview schedule covered topics including Supporters' experiences of providing support alongside Renewed, perceptions of online Supporter training, experiences of support appointments, perceptions of the CARE approach and Supporters' perceptions of the Renewed programme. The interview schedules were developed iteratively. This meant that interview questions evolved over time and were adjusted based on insights from previous interviews. This was done to allow insights from early interviews to be explored in later ones. For example, earlier interviews revealed that many participants who accessed support sessions did not access all three sessions. As a result, later interview questions were refined to explore why some did not access all three sessions.

### **2.5.3 Telephone interviews**

All interviews were conducted by telephone to minimise inconvenience for participants and make data collection more efficient in light of participants being geographically dispersed. Telephone interviews have been considered a complementary fit to semi-structured interviews and as equally viable as face-to-face interviews (Cachia & Millward, 2011). For example, compared to face-to-face interviews, telephone interviews resulted in equal responses in terms of length of transcript and type and depth of response (Sturges & Hanrahan, 2016). Telephone interviews enable researchers to target hard-to-reach populations and take less effort and demands than face-to-face interviews (Fenig, Levav, Kohn, & Yelin, 2011). They are easy to arrange and rearrange for both interviewer and interviewee and may enhance investment compared to face-to-face interviews (Cachia & Millward, 2011).

### **2.5.4 Sampling**

Purposive sampling was used to recruit cancer survivors from Renewed trial database and healthcare professionals from the Renewed supporter database. In a qualitative study, a relatively small and purposively selected sample may be employed to increase the depth (as opposed to breadth) of understanding (Palinkas et al., 2015). Purposive sampling is used to select

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respondents most likely to yield appropriate and useful information (Campbell et al., 2020). A maximum variation sample was used, which considered a range of contextual and demographic factors that may affect the intervention's experiences with or effectiveness. For Paper one these factors were age, gender, cancer type, years since completing treatment, level of education and renewed usage. See [Section 2.3.1.3](#) for a rationale for incorporating these factors. For Paper three, purposive sampling was based on job roles (nurse, research nurse, healthcare assistant) and the number of cancer survivors HCPs supported.

### **2.5.5 Timing of data collection**

Attention should be paid to the time at which data are collected, and how this may influence the issues identified (Moore et al., 2015). For Paper one, the interview data were analysed in parallel with data collection, which enabled future participant interviews to be informed by the emerging insights and allow future exploration. While data were collected before trial outcomes were known, analysis was not completed until final trial outcomes were known so that data could be used to examine trial findings. For Paper three, data collection was not able to be conducted in parallel to data analysis due to time constraints.

### **2.5.6 Analysis of qualitative data**

Inductive thematic analysis was used to analyse interviews using Braun and Clarke (2006)'s six-step method, and a coding manual was developed using techniques from Joffe and Yardley (2004). Thematic analysis is a method of identifying patterns or themes within qualitative data. This method was chosen because it is especially useful for examining differences among research participants and generating unanticipated insights (Nowell, Norris, White, & Moules, 2017). Moreover, thematic analysis's epistemological free position was another reason this method was considered appropriate (Braun & Clarke, 2006). While grounded theory was considered as a potential option for analysis as it is an inductive approach, which in the case of process evaluations could enable researchers to generate theories of factors influencing behaviour change, (Charmaz & Thornberg, 2020), the limited time restraints meant that this method was not suitable. Instead, as thematic analysis is fluid and invites a 'mash-up' of methodologies (Braun & Clarke, 2006), it was possible to borrow elements from grounded theory (memoing and constant comparison with coding manual and raw data), and framework analysis (i.e. charting framework used in participant analysis to facilitate comparison between groups), which facilitated rigour during analysis and enhanced understanding of themes.

Braun and Clarke (2006) distinguish between two approaches to identifying themes: inductive and deductive. An inductive approach is data-driven, with themes identified through the data itself. A deductive approach is theory-driven, with themes identified based on theoretical interests, often developed through literature reviews. The analysis in this study will identify themes inductively. Inductive analysis was chosen for this thesis to facilitate novel insights and possibly identify unanticipated mechanisms within the logic model. This was also in line with the PBA approach of understanding experiences through a psychological context rather than using theory to deductively collect and interpret data to understand user experiences (Yardley et al., 2015).

Braun and Clarke's (2006) description of thematic analysis described a theme as "some level of patterned response or meaning" (Braun and Clarke, 2006, p.10) which they later suggested left too much room for confusion (Braun & Clarke, 2021). This resulted in many researchers developing themes with a shared topic (e.g. facilitators) but not a shared meaning (e.g. motivation as important for behaviour change) (Braun & Clarke, 2019a; Braun & Clarke, 2021). In an updated description of what they refer to as 'reflective thematic analysis', Braun and Clarke describe a theme as "patterns of shared meaning, united by a central concept or idea" (Braun & Clarke, 2021, p.14). When this updated description and guidance became available to the author, analysis for Paper three was almost complete, and well progressed for Paper one. However, in light of this new information, where appropriate, data were revisited and themes reviewed with reflection given to the understanding of a theme and whether the themes in the papers reflected a shared meaning or a shared topic. Where possible updates were made so that these data reflected a shared meaning and told a useful story in relation to the research question. As an end result, all the themes reported were not generated through the technique of reflective thematic analysis as it was not possible to redo much of the analysis, but some themes were revised to be more reflective of a shared meaning and present a rich story of the data.

### **2.5.7 Sample size**

A provisional sample size was determined using an estimation of how much information power was needed to potentially generate adequate data to tell a rich, complex story in relation to the research question (Malterud, Siersma, & Guassora, 2016). Five factors are used to determine how much information the sample will hold: 1) the aim of the study, 2) sample specificity, 3) use of established theory, 4) quality of dialogue, and 5) analysis strategy. Information power suggests that the more relevant information a sample holds, the fewer participants are needed. Especially relevant to Paper one was the desire to achieve a diverse sample (factor number 2), so more participants were necessary. In addition, for Papers one and three, more participants were needed to reach the quality of dialogue due to being a novice researcher.

## Chapter 2

Once data collection had begun, the final sample size was determined based on data saturation. In this thesis, saturation was not defined as 'no new information', as there is always a potential for new insights as long as data are being collected. Instead, the final sample size was determined based on whether the data contained adequate richness and complexity for addressing the research questions (Braun & Clarke, 2019b).

### **2.6 Summary**

This chapter provided an overview of the epistemology underpinning this thesis and set out a rationale for the methods chosen for each study. This thesis presents a mixed-methods process evaluation of Renewed in which quantitative and qualitative data is mixed through a triangulation design. The following chapters will detail each of the three studies conducted as a part of this thesis.

## Chapter 3 Experiences of using a supported digital intervention for cancer survivors in primary care: A qualitative process evaluation (Paper 1)

This paper was published in the Journal of Cancer Survivorship in July 2023.

### 3.1 Abstract

**Background:** Increasing healthy behaviours (e.g. physical activity) can improve cancer survivors' quality of life. Renewed is a digital intervention developed to provide behaviour change advice with brief healthcare practitioner support. A three-arm randomised controlled trial (Renewed, Renewed with support or a control condition) suggested that prostate cancer survivors in the supported arm had slightly greater estimates of improvements in quality of life compared to other cancer survivors. This study explored participants' experiences using Renewed to understand how it might have worked and why it might have provided greater benefit for prostate cancer survivors and those in the supported arm.

**Methods:** Thirty-three semi-structured telephone interviews with cancer survivors' (breast, colorectal, prostate) from the Renewed trial explored their experiences of using Renewed and their perceptions of the intervention. Data were analysed using inductive thematic analysis.

**Results:** Some participants only used Renewed modestly but still made behaviour changes. Barriers to using Renewed included low perceived need, joining the study to advance scientific knowledge or 'to give back', or due to perceived availability of support in their existing social networks. Prostate cancer survivors reported less social support outside of Renewed compared to participants with other cancers.

**Conclusion:** Renewed may support healthy behaviour changes among cancer survivors even with limited use. Interventions targeting individuals who lack social support may be beneficial.

**Implications for cancer survivors:** Cancer survivors' experiences may inform the development of digital interventions to better serve this population.

## 3.2 Introduction

There are an estimated three million cancer survivors in the UK, projected to increase to 5.3 million by 2040 (Macmillan Cancer Support, 2020b). Those that complete primary treatment are at greater risk than the general population of developing several health-related problems during the transition from treatment to life after cancer (Macmillan Cancer Support, 2013a). These include anxiety, depression, fatigue and weight gain, contributing to reduced QoL (Macmillan Cancer Support, 2020b). Following this increase in the growing number of cancer survivors, there is rising demand on NHS cancer services (Brown et al., 2014).

Digital interventions may help improve cancer survivors' QoL through providing support with issues like psychological distress management, physical activity, healthy diet, and weight management (Onyeaka et al., 2021). A digital intervention, "Renewed" (Bradbury et al., 2019; Corbett, Cheetham, et al., 2018; Corbett, Singh, et al., 2018; Krusche et al., 2019), was developed to target multiple health behaviours in order to improve QoL of cancer survivors. Renewed includes the option of brief health care professional support with the aim of being implemented across NHS primary care services. The addition of HCP support alongside a digital intervention could be of perceived value for cancer survivors (Roberts et al., 2019) and an important factor in increasing engagement (Dennison et al., 2014; Yardley et al., 2016).

A RCT of Renewed compared improvements in QoL among cancer survivors who received either Renewed, were randomised to either 1) Renewed: web-only intervention, 2) Renewed with support: web-based intervention with additional guidance and (HCP) support, or 3) Control: Generic advice and follow-up. Cancer survivors in the control arm were given a link to the NHS Live Well website which provides support for mental health, healthy eating, exercise, sleep, smoking and alcohol, sexual health and addiction (NHS 2022). Results showed that the impact appeared to be slightly greater for those with prostate cancer who were given access to human support compared to those with breast or colorectal cancer.

Whilst Renewed has already been the subject of evaluation through an RCT, when evaluating a complex intervention, it is important to also explore how the intervention worked, for whom and under what circumstances. Thus, combining process evaluations with RCTs can enable intervention developers and evaluators to develop a detailed understanding of how the intervention worked that can support stakeholders in interpreting effectiveness (Oakley et al., 2006). Qualitative process studies can explore how users interact with an intervention to produce effects and why users did or did not use the intervention as intended (Moore et al., 2015). For example, our previous qualitative process study exploring HCPs experiences supporting those using Renewed found that an approach where the expertise is provided by the intervention and



brief additional support provided by a healthcare professional is an acceptable way to overcome key barriers to supporting cancer survivors in primary care. Additionally, whilst most HCPs cope well with delivering non-directive support, a minority may need more support to feel confident implementing this Smith et al., 2022. Similarly, understanding how cancer survivors interact with digital interventions like Renewed and what may serve as potential barriers or facilitators could inform the design of future digital interventions for this group and others with long-term conditions, and may also have implications for how cancer survivors can be best supported in primary care (Moore et al., 2015). A process evaluation can also help to understand the reasons why certain groups appeared to benefit more than others (Moore et al., 2015; Yardley et al., 2016). Following guidance for conducting process evaluations, interviews were conducted and analysed before knowledge of the RCT outcomes to avoid biased interpretation (Moore et al., 2015; Oakley et al., 2006). The findings were then considered alongside the trial results when these became available later. While data were collected before trial outcomes were known, analysis was not completed until final trial outcomes were known so that data could be used to examine trial findings. This allowed exploration for potential explanations of trial findings.

Therefore, this study aimed to explore how and why cancer survivors used Renewed as they did. Specifically, it aimed to explore: 1. What factors may serve as potential barriers and facilitators to cancer survivors' using Renewed and performing the recommended behaviours?; 2. Why Renewed may have provided benefit to prostate cancer survivors and not those with other cancers; 3. Any perceived changes in participants' quality of life and how these were experienced whilst engaging with Renewed.

### **3.3 Methods**

#### **3.3.1 Design**

This qualitative process evaluation was nested within the Renewed RCT (Krusche et al., 2019). Cancer survivors were invited to participate by their GP surgeries. After online screening, they completed baseline measures via Renewed before being randomised to one of three conditions; 1) Renewed: web-only intervention, 2) Renewed with support: web-based intervention with additional guidance and support, or 3) Control: Generic advice and follow-up. The process evaluation employed semi-structured qualitative interviews to explore participants' experiences of participating in the Renewed RCT and using Renewed (arms 1 and 2). The COnsolidated criteria for REporting Qualitative studies (COREQ) checklist (Tong, Sainsbury, & Craig, 2007) were used to guide reporting of this study (Appendix C).

### **3.3.2 Intervention<sup>1</sup>**

A full description of Renewed is presented in [Section 1.3](#). Briefly, Renewed is a web-based intervention developed for breast, colon and prostate cancer survivors, as well as those with prostate cancers on active surveillance. Renewed consists of an introductory session (core content) and optional content that provides support with psychological well-being, physical activity, healthy eating and weight management. Those in the Renewed with support arm also had the option of brief support from a healthcare professional.

### **3.3.3 Participants**

Cancer survivors were eligible for the Renewed trial if they had finished treatment for breast, prostate or colorectal cancer within the last 10 years, or were on active surveillance with prostate cancer. Additional eligibility included self-reported reduced QoL (as defined by scores 85 or below on EORTC QLQ-C30 (Aaronson et al., 1993)) and access to the internet. Full inclusion criteria can be found in the RCT protocol (Krusche et al., 2019).

Cancer survivors for the qualitative process study were sampled from two arms of the Renewed trial and invited to take part in telephone interviews (Appendix D.1). Purposive sampling was used to target a maximum variation across factors that might influence the intervention's acceptability or effectiveness. These included age, gender, years since finishing treatment, education level, cancer type and level of Renewed usage. Usage was categorised into two groups: 1) Those that only accessed the Core Content (low users), 2) Those that completed the Core Content and accessed at least one optional content of Renewed (high users).

### **3.3.4 Procedure**

Cancer survivors were identified for interviews through the Renewed participant database and invited via email or phone calls. Following online informed consent (Appendix D.3), interviews were conducted via telephone between February and April 2019 by two trained qualitative interviewers (JS, JSB). Interviews ranged from nine minutes to one hour 30 minutes, and the median interview length was 26 minutes. While most interviews were close to the median time length, a couple interviews were longer than an hour due to participants' tangential responses. One interview was nine minutes due to the participant no longer wanting to continue the

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<sup>1</sup>To avoid repetition, the full description of Renewed has been removed from this chapter and replaced with a brief description. In this way, the paper presented here is different to what was submitted for publication.

interview. Further interviews to capture any differences in participants' experiences of using Renewed during the COVID-19 were conducted by CC, who received training in qualitative interviews.

Semi-structured interview schedules were co-developed by a qualitative researcher (JS), who was not involved in the development of Renewed, and a health psychologist and experienced qualitative researcher (KB) (Appendix E). Open-ended questions were used to allow participants to freely describe their experiences and views in their own way and to focus on whatever was most salient to them. Topics covered included: experiences of using the Renewed intervention, any behavioural changes made whilst being in the Renewed study, experiences of healthcare professional support received within Renewed, and experience of using Renewed during the COVID-19 pandemic.

### **3.3.5 Analysis**

Individual interviews were audio-recorded, transcribed verbatim and anonymised. Inductive thematic analysis was conducted using Braun and Clarke's (Braun & Clarke, 2006) 6-step process to develop themes related to participants' experiences of using Renewed and being in the study. A charting framework was used to support comparisons across participant characteristics (cancer type and usage levels, and Renewed trial arms (Srivastava & Thomson, 2009). Identification and validation of developing themes was achieved through an iterative process of data analysis with frequent discussions between JS, KB and RE. Data were collected concurrently to data analysis, allowing sampling to be adapted to reflect analytic insights. Coding was performed using NVivo software (Version 12.0.0 (International, 2018)). Deviant cases were considered to ensure that minority views were not overlooked (Seale, 1997). A coding manual was developed which was updated to reflect the ongoing analysis (Joffe & Yardley, 2004) (Appendix F). An audit trail (Appendix G) and reflective log (Appendix H) were completed to maintain rigour during analysis.

## **3.4 Results**

### **3.4.1 Participant characteristics**

Thirty-six participants were interviewed. Data from three participants were excluded from the analysis as they could not remember using Renewed and/or being in the study. Thirty-three participants were included in the analysis; 16 were in the 'Renewed with support arm' and 17 were in the 'Renewed arm'. The demographic and clinical characteristics of the included participants are reported in Table 5.

Table 4 - Participant characteristics

<b>Baseline Characteristics</b>		
<b>Age (years)</b>		
Mean (S.D)		62.8 (10.20)
Range		36 – 82
<b>Baseline EORTC QLQ-C30 score</b>		
Mean (S.D)		73.5 (11.3)
Range		39.4 – 84.1
<b>Cancer group</b>		
	Colon	10/33 (30.3%)
	Breast	14/33 (42.4%)
	Prostate	7/33 (21.2%)
	Prostate active surveillance	2/33 (6.1%)
<b>Renewed RCT group</b>		
	Renewed	17/33 (51.5%)
	Renewed with support	16/33 (48.5%)
<b>Gender</b>		
	Male	14/33 (42.4%)
	Female	19/33 (57.6%)
<b>Ethnicity</b>		
	White	33/33 (100%)
<b>Time since last cancer treatment (years)</b>		
Mean (S.D)		3 (2.9)
Range		0-9
<b>Age when left education (years)</b>		
Mean (S.D)		18 (3.5)
<b>Renewed usage</b>		
	Accessed up to the core content	19/33 (58%)
	Accessed the optional content	14/33 (42%)
<b>Support Sessions (for those in the 'Renewed with support arm)</b>		
	Accessed support	9/16 (56%)
	Chose not to access support	7/16 (44%)

### 3.4.2 Themes

Four themes were developed: 1) Using Renewed to support behaviour change, 2) Participant's perceived need for support from Renewed, 3) Barriers to using Renewed and performing behaviour changes, and 4) Personal touch and added value of human support. The themes contribute to an understanding of perceived changes in quality of life and how these related to engagement with Renewed, why Renewed may have provided greater benefit for prostate cancer survivors and factors that may have served as potential barriers and facilitators to participants' engagement with Renewed and the recommended behaviours. The analysis considered the role of participant characteristics (age, gender, the year participants finished education, years since

end of treatment, cancer type and Renewed usage), in the accounts of their experiences, but analysis did not reveal any noticeable differences based on age, gender and the age participants finished education. The results include an illustration of different experiences within these themes relating to both cancer type, level of Renewed usage and years since finishing cancer treatment. Representative quotes are included to illustrate key points. Participants are referred to by their ID number, Renewed usage level, cancer type, and Renewed RCT trial arm to provide contextual understanding.

### **3.4.3 Using Renewed to support behaviour change**

#### **3.4.3.1 Renewed supported autonomy with behaviour change**

Many participants expressed that they liked being able to use Renewed at their own pace and in their own time and locations. They highlighted the benefit of choosing what to look at on Renewed and deciding which behaviours they wanted to perform. The majority of participants expressed that they found Renewed easy to access and use, having access from their own home, instead of having to travel to a GP. Also, the ability to go back and review information and activities made Renewed more accessible to many participants schedules and learning patterns.

“You can take whatever you want...choose and change, you don’t have to keep to one plan. If you’ve got more confident you think ‘oh well, I’ve done this but, later on I can do a bit of this also’...it always reminds you also that if you don’t have time now you can go back on the home page, so it doesn’t put pressure on you.” (*Participant 16, high user, 56 years old, female, breast cancer, Renewed arm*).

Participants described being able to use Renewed in a way that best suited their needs and goals. For example, within Renewed, feedback about which parts of Renewed an individual may find most helpful was given at the end of the Core Content, based upon participants' answers to a quality of life measure which highlighted the symptoms participants were finding most bothersome. Participants sometimes reported this feedback helped them to make a decision about which behaviour changes to perform.

“The programme [core content] suggested the websites [support contents] I might like to look at, like the POWeR one for losing weight ‘cause that, identified the things that I needed to work with. And I thought that was really good. So the things that I focussed on was the losing weight one. And the exercise basically. So I didn’t really look at anything more than that.” (*Participant 15, high-user, 65 years old, female, breast cancer, Renewed arm*).

However, the majority of the time, participants already had an idea of which behaviour changes they wished to undertake, regardless of the feedback provided at the end of the Core Content. For example, one participant who had been recommended all support contents of Renewed, spoke of not choosing to use Healthy Paths because she knew what other behaviours she wanted to work on.

“I never did the Healthy Paths one, because it wasn’t really a priority for me...I was more interested in the three that I have used, because it was focussing me on, you know, I want to keep my health up, and I want to keep fit. But weight’s a problem, and it [Renewed] focusses you, I think.” (*Participant 20, high-user, female, colon cancer, Renewed arm*).

#### **3.4.3.2 Engagement with Renewed related to ‘offline’ behaviour change**

Participants were also able to choose to use Renewed as little or as much as suited them. As a result there were differences in reported changes in behaviour based on participants' usage levels. It appeared that many participants who only accessed the Core Content reported no, or very few, changes in their behaviour.

“Looked around it, but haven’t really taken up on any of the suggestions it makes.” (*Participant 22, low-user, male, colon cancer, Renewed arm*)

On the other hand, a few participants who only accessed the core content expressed that whilst they may not have used Renewed much, it was enough to begin making behaviour changes.

“I followed some of the diet advice. And taking yourself off out for a walk and things like that, which I did try. Just to make my lifestyle a bit healthier.” (*Participant 8, low-user, female, breast cancer, Renewed arm*)

Similarly, many high users appeared to use Renewed to begin making behaviour changes. They would sometimes stop using Renewed once they had accessed what they perceived as sufficient information to implement the changes, often with support from their own ‘offline’ tools and resources (i.e. Fitbit, calendars).

“Trying to get my weight down, that sort of thing. I found that all that very useful and I made up the little calendar thing, but once you referred to these suggestions on the site, I didn’t really feel a great deal of need to go back to them, because I put what I could into action, and did it.” (*Participant 6, high-user, male, prostate cancer, Renewed with support arm*).

#### 3.4.4 Patient's perceived need for support from Renewed

Patient motivation to use Renewed often appeared to be determined by whether they perceived a need for the type of support Renewed offered. Several factors seemed to contribute to patients' perceptions of need for this type of support. For example, some participants put emphasis on the importance of learning something new from Renewed. A few high-users reported that the content of Renewed was novel.

"One of the sections [Healthy Paths] put you onto the BBC one, which I've used before. But it put me down the clean eating one, which I hadn't really considered...So when you look at the recipes, it reminds you to have snacks like walnuts or something. And they're things that you don't necessarily think about...So sometimes if you have it written out for you, which it was in this case, you just think, I might try that, or give that a go, or that's a good idea." (*Participant 20, high-user, female, colon cancer, Renewed arm*)

However, many low users felt that it was too basic and did not teach them anything they did not already know or were already doing. In these instances, participants would often not continue to use Renewed beyond the Core Content where would have been exposed to the more detailed and novel content that was contained in the optional contents.

"I would say I'm actually quite well informed but for a lot of people that aren't, it's very useful. I thought I knew enough about my dietary stuff." (*Participant 27, low-user, female, breast cancer, Renewed arm*).

A few participants did not find Renewed suitable for them, as they believed they already lived a healthy lifestyle.

"I go cycling for exercise. And I've kept that up as much as I am possible...I thought, 'yes, been there, done that.'" (*Participant 22, low-user, male, colon cancer, Renewed arm*)

Two participants spoke of not being motivated to use Renewed because it had been a while since finishing their treatment, and they felt as if they were no longer in need of this sort of support.

"And perhaps five years ago, when I was five years in and just coming out of the treatment and starting anew, without help, then I was on my own, you know, after the five years of treatment when you're seeing someone all the time, it would've been absolutely perfect." (*Participant 28, low-user, female, breast cancer, Renewed with support arm*)

A few individuals who did not engage much with Renewed appeared not to be especially motivated to use Renewed in order to make behaviour changes because they reported having existing resources which they could use to support them and preferred to use those.

“I was already making my own changes with Lighter Life...So there was really nothing there that I could take up.” (*Participant 32, low-user, male, prostate cancer, Renewed arm*)

In contrast, for a few others, a lack of social support in their lives motivated usage of Renewed. For example, deviant case analysis showed that one high user expressed that they used Renewed frequently because they did not get much support outside of Renewed. This user felt that aspects of Renewed such as progress monitoring, goal reviewing, and email prompts gave a sense of support and community, which encouraged them to revisit Renewed.

“I wasn’t really understood within my environment...when I told them [people within environment] that I had the cancer, they said no, it’s because I’ve put on weight. So I had to cope with them not accepting that I had the cancer... But the fact that actually I got that letter [Renewed study invitation] and people want to try and help me to get back into form, it’s really a help for me because I know that people actually do take an interest.” (*Participant 16, high-user, female, breast cancer, Renewed arm*)

### **3.4.5 Barriers to intervention use and performing behaviour changes**

Those with other health problems or with physical limitations to going outdoors experienced difficulty in actually performing the behaviours recommended by Renewed. Many participants often reported finding it difficult to perform some of the recommended behaviours alongside comorbidities, particularly those whose mobility was restricted or performance of a behaviour could cause immediate discomfort (e.g. trying to do exercise with an existing back problem). In one case, a participant who reported experiencing depression suggested that this interfered with his availability to use Renewed.

“I’ve not really sort of liked touched on it [Renewed], because of my own mental health problems [depression] I’ve not really sort of like got into it, really. I’ve been sort of preoccupied.” (*Participant 18, low-user, male, prostate cancer, Renewed with support arm*)

A few participants also reported adjusting to life changes (i.e. living with a stoma) after finishing treatment. These changes took priority over their motivation to make healthy



behaviour changes. These people were often preoccupied with adapting to specific changes as direct result of their cancer and its treatment, rather than to improve their overall health.

“Cause at the minute... the worst thing is the life change I get with the stoma bag. It [stoma] wasn't really covered on in the Renewed, is it?...the stomach bag is my biggest bugbear...it's just the stoma bag now is the thing that I've got to get over.” (*Participant 21, low-user, male, colon cancer, Renewed arm*)

For a few participants, the COVID-19 pandemic was a barrier to motivation to use Renewed. This was because the pandemic introduced new concerns that took priority over cancer and related health behaviour change.

“I think because of COVID the cancer has kind of taken a step back, it's not been the priority or the focus as much as what it was. I work full-time, I'm a key worker so I have to, have to do that. So my focus wasn't on my cancer.” (*Participant 25, low-user, female, breast cancer, Renewed arm*)

The COVID-19 pandemic was also a barrier to performing behaviour changes due to lockdown restrictions. This included physical limitations to going outside to exercise because of having to shield or being physically limited in their ability to carry about behaviour changes due to contracting COVID-19.

“When I had the COVID, when it first manifested itself, I was really very, very poorly. I couldn't even lift the phone up, never mind look at a computer.” (*Participant 33, high-user, male, colon cancer, Renewed with support arm*)

A minority of participants experienced technical issues such as navigation problems and error pages. This was reported when participants only had an iPad, with which Renewed was incompatible, or when certain technical bugs blocked participants' access to contents of Renewed. This only seemed to become a barrier to using Renewed in cases where the issue persisted to the extent that the individual could not effectively use the programme. For example, POWeR was a large stand-alone programme and could not be fully integrated into Renewed. This meant in order to access the POWeR intervention users would be taken outside of the Renewed intervention, and in a few cases participants experienced issues getting back into Renewed.

“I did find most of the navigation was really good but I did find sometimes that when you went to an external site, like the POWeR, it was quite difficult to get back because there's, there's the button that says 'take me back to Renewed' I was hoping it'd take me back to the login page of Renewed but it didn't. It took me back to the page I'd just

visited which was the POWeR website.” (*Participant 15, high-user, female, breast cancer, Renewed arm*)

Participants were warned that accessing POWeR would take them outside of Renewed, but very few participants expressed frustration in switching between Renewed and POWeR.

#### **3.4.6 Personal touch and added value of human support**

The majority of participants expressed a desire for some form of human support following their adjustment from finishing cancer treatment, whether from Renewed or elsewhere. In a few cases it was expressed that there was a lack of understanding from others of how such support would be useful.

“I’ve spoken to lots of people who do find that when they’re in remission after cancer, it’s almost as if everybody thinks, ‘Oh, that’s it’, you know, ‘You’re cured, you don’t need help anymore.’ but I do, I know a lot of people who do feel that people are not interested in how they’re getting on and whether they’re doing very well.” (*Participant 11, high-user, female, colon cancer, Renewed with support arm*)

Many participants in the Renewed with support arm appreciated that Supporter sessions were available, believing it would provide an extra level of support and be beneficial for their rehabilitation and recovery.

“It’s all very well doing something online, but if you’ve not got any support from anywhere else, I think it could be quite easy to go, “Oh yes, well I know this, I know this, and fine, I know what you’re getting at.” But it’s just about having that personal touch, I think. (*Participant 18, low-user, male, prostate cancer, Renewed with support arm*)

A few participants in the Renewed arm (without access to additional support) expressed a desire for healthcare professional support offered alongside Renewed. They believed this would have provided extra support and made Renewed more personal.

“You can’t pick up the phone and then talk to somebody about a specific problem...So I suppose that is where I fall down a bit with it...the ability perhaps to email somebody to discuss, might be something that ought to be considered added on.” (*Participant 12, high-user, male, colon cancer, Renewed arm*).

Indeed, a few participants who expressed satisfaction with their Supporter, often appreciated that they were able to offer tailored advice and provide extra resources.

“[I liked] the fact that she [Supporter] came up with some ideas. ‘Cause, as I say, she listened to me. But she came up with ideas in as much as things that she did, that I could implement. Which was to do with the, apart from walking for the papers, rather than getting all the fruit and veg when you do a main shop, getting it in-between time, and walking to the shop to get it.” (*Participant 18, low-user, male, prostate cancer, Renewed with support arm*).

However, the perceived value and perceived need for support appeared dependent on existing social support. For the majority of participants who did not access support, this often seemed to be because they reported strong existing social support outside of Renewed, such as other medical professionals (i.e. cancer nurses), community support groups, charities or family and friends. Consequently, they often did not feel the need for extra support from Renewed.

“I’m very lucky, I’ve got an excellent key, key worker at the hospital, yeah, and she’s been brilliant. So, she’s the one I’ve tended to go to.” (*Participant 11, high-user, female, colon cancer, Renewed with support arm*)

There did appear to be some differences in the reported availability of existing social support in participants’ networks dependent on cancer type. Prostate cancer survivors generally reported less pre-existing support outside of Renewed compared to breast and colon cancer survivors.

A few prostate cancer survivors reported a lack of availability of support for managing the consequences of cancer and its treatment.

“My absolutely perfect world would be to sit in a room with an oncologist, a cardiologist and some back specialist and for me just to talk to them for half an hour and say, “Look, these are all the things I want to do to feel better... And I feel like, okay, well that’s it. And there’s no place else to go. Which is quite frustrating.” (*Participant 31, low-user, male, prostate cancer, Renewed arm*)

Prostate cancer survivors in the Renewed (web-only intervention) arm sometimes expressed that while being in the study provided a greater sense of social support, they would have preferred additional human support.

“I feel that it [Renewed] can make you feel that you’re not completely on your own...it’s just having somewhere where some people who may be having this they don’t have any contact with other people...But also from that, I feel that it could be improved if somebody in the background within Renewed maybe should be contacting them [those using Renewed], maybe a health professional, because a lot of the time I find that I can

## Chapter 3

go to a, my GP or whatever and I can write all my concerns or my questions down, but sometimes there's no time to actually talk to them about problems." (*Participant 24, low-user, male, prostate cancer, Renewed arm*)

A few participants, across all cancer types, who started support sessions did not continue after their initial session because they were dissatisfied with their support. This was explored through deviant case analysis, finding that one participant disengaged from receiving support because he felt that the Supporter could not relate to, or understand his issues sufficiently to provide support. In this case, the participant spoke about sexual issues he was experiencing because of having had prostate cancer. The Supporter could not provide the support this participant needed and suggested that he speak to his GP or secondary care.

"I think he found it difficult to relate to somebody of my age, especially with some of the problems with the type of cancer that I've got a lot of them things that revolved around the sexual side of my life. And I don't think, he couldn't cope with it. So, I got frustrated with that, and you know, there's not a lot of point talking to him, 'cause he actually doesn't really understand what the problems are." (*Participant 6, high-user, male, prostate cancer, Renewed with support arm*).

Other reasons participants did not continue support included that they could not see any additional benefit. For example, one participant who was having technical issues accessing POWeR, raised this issue with her Supporter and was told they would contact the study team to help resolve this issue for her, but she did not hear back from Supporter or Renewed study team. This experience made the participant feel dismissed as their supporter was not able to follow through with the issues discussed, nor provide any encouragement or guidance.

"I did say to him [Supporter] about the problems that I was having [accessing into POWeR], and he said he'd email somebody [from the Renewed study team], but I haven't heard from anybody...I thought he might ask different questions about what would be helpful, or anything like that. But he didn't." (*Participant 4, high-user, female, breast cancer, Renewed with support arm*)

### 3.5 Discussion

This process study conducted qualitative interviews with cancer survivors who used Renewed to understand how and why they used Renewed as they did to allow a greater understanding of the Renewed RCT findings. the process study findings are discussed and triangulated with the RCT findings below.

A key aim of this study was to understand why some groups, like those with prostate cancer, might have benefitted more than those with breast and colorectal cancer in the Renewed RCT. Our findings suggest that the varying effectiveness of Renewed across cancer types may be at least in part due to differences in perceptions about the availability of, and perceived need for support in these individual's lives. These perceptions of the availability of support outside of Renewed also seemed to relate to the extent to which people engaged with the intervention. Prostate cancer survivors spoke less about having social support outside of Renewed compared to participants with other cancers, who often expressed having adequate support elsewhere and so not needing Renewed as much. Those with prostate cancer also often reported having other health-related problems for which they expressed a lack of access to support. Previous research has similarly suggested that prostate cancer survivors generally feel under-supported (Paterson, Jones, Rattray, & Lauder, 2013) and being male has been associated with lower perceived social support across various cancers (Eom et al., 2013). Furthermore, engagement with social networks can increase engagement in self-management among cancer survivors (Howard-Jones, Vassilev, Fenlon, Ewings, & Richardson, 2022). These findings suggest that the significant effect of Renewed in improving QoL compared to the control arm, particularly among prostate cancer survivors, may have been driven through Renewed providing the additional social support that this group felt they lacked outside of the intervention. In contrast, those with breast and bowel cancers generally seemed to feel sufficiently supported already. In this study prostate cancer survivors expressed a particular desire for professional advice and support, especially surrounding sexual health. Previous studies have suggested that prostate cancer survivors can find support through web-based interventions acceptable (Mehta et al., 2019), as they may consider group support embarrassing and fear stigma of being vulnerable and emotional (Weber et al., 2000). However, the human element offered by group support or peer support is valued for the informational and emotional exchange (Ihrig et al., 2020). Therefore, an intervention like Renewed may be particularly acceptable to this group as it offers the privacy of an online interventions while providing the emotional and informational support through the option of HCP support.

Another key aim of this study was to explore any perceived changes in participants' QoL and how these were experienced in relation to engagement with Renewed. This study was able to provide some understanding of the relationship between usage of Renewed and behaviour change, in as much that some participants reported not needing to access Renewed much before implementing behaviour changes, while others appeared to need to access Renewed more frequently before being able to implement behaviour changes. Many cancer survivors stopped using Renewed for various reasons whilst implying engagement with wider intervention goals, such as feeling as though they had received enough information to begin behaviour change or feeling sufficiently

supported. For those who only used Renewed a little, using just the Core Content may be sufficient engagement with Renewed (Yardley et al., 2016) for these individuals to provoke changes in behaviour. Those who did not use Renewed beyond the Core Content may not have perceived a need for more detailed and tailored support. This can potentially be understood through the concept of effective engagement (Yardley et al., 2016), which recognises that the extent to which an individual actively uses an online intervention is not necessarily a direct reflection of their performance of behaviour changes recommended by that intervention. Some individuals may need to use the intervention less, while some may need to use it more before they are able to perform behaviours. This is in line with literature which suggests that users disengage from digital interventions when they obtain positive results, making further engagement redundant (Schneider, Bolier, de Vries, & van Osch, 2016). If an intervention like Renewed were to be adopted in primary care, it might provide suitable support for those with less need for resource-intensive support.

Another key aim of the study was to understand what factors may have served as potential barriers and facilitators to cancer survivors' using Renewed and performing the recommended behaviours. One barrier identified was that many cancer survivors who disengaged early from Renewed did so due to an apparent lack of perceived need to use an intervention like Renewed. These cancer survivors expressed having access to sufficient support outside of Renewed, having finished treatment a while ago and thus not being focussed on their cancer symptoms anymore, or only participating for altruistic reasons connected with research participation, rather than because they wanted to make changes to improve their quality of life. Considering this finding in relation to the Health Belief Model (Rosenstock, 2000) might offer greater understanding of patients' decisions about whether or not to use Renewed. The Health Belief Model suggests that health-related behaviour change depends on several factors: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy. Especially relevant to these findings is the concept of perceived benefits. Perceived benefits refers to the belief in the efficacy of the recommended health behaviour in reducing the risk or seriousness of the condition – in this context beliefs about the extent to which engaging with Renewed and following its recommendations were likely to improve their quality of life. This may suggest that those individuals who discussed having other resources to support them may have believed that those resources were sufficient or more efficacious in helping them manage their side effects, and so didn't see the additional benefit of engaging with Renewed. It may also suggest that those who finished treatment a while ago or joined the study for altruistic reasons may not have perceived a benefit of using an intervention like Renewed because they had already built connections and knew how to manage their side effects, so an intervention like Renewed was not perceived as

being able to further help them reduce the risk or seriousness of their side effects. If Renewed were provided outside of a research study, it is likely that these cancer survivors would not have taken it up, as they did not perceive a need for it. The Renewed intervention development work and the wider literature suggest that a subgroup of cancer survivors who desire to feel better after treatment want support to improve their quality of life (Corbett, Cheetham, et al., 2018). However, others do not want to engage in behaviour change and are unlikely to become motivated to make changes, with or without access to resources like Renewed (Bradbury et al., 2019; Corbett, Cheetham, et al., 2018; Hardcastle et al., 2017).

Another barrier which hindered some cancer survivors' use of Renewed was a lack of perceived personal relevance. Many cancer survivors who did not access Renewed beyond the Core Content had already read widely about what they could do to help themselves and felt Renewed did not provide new information. Renewed was not considered relevant as it instructed them in things they already knew, instead of helping them learn new information. This is in line with findings from Kanera et al., (2016) which suggest perceived personal relevance is related to higher usage. Placing important and novel information early within an intervention may improve continued usage and exposure to behaviour change advice (Kelders & Van Gemert-Pijnen, 2013).

A few cancer survivors expressed not being able to engage in behaviour changes due to comorbidities. Despite this, the RCT results did not show less of an effect among those with comorbidities, which suggests that even if people are not able to follow all recommendations because of comorbidities, overall this does not seem to prevent them from having some benefit from Renewed. Renewed was designed to be easy to use for those with comorbidities, so as not to be a barrier to engagement. However, as occurred in this study, mobility issues are particularly commonly reported as a barrier to physical activity among cancer survivors (Fisher et al., 2016; Granger et al., 2017). Therefore, further work may be needed to develop content that can address concerns about engagement with physical activity whilst having mobility issues. It is noteworthy that COVID-19 often exacerbated these comorbid symptoms or introduced new illnesses within this sample. These illnesses due to COVID-19 reflect structural and psychological barriers to engagement. It may be that outside of the context of the pandemic cancer survivors may have had higher engagement.

### **3.5.1 Strengths and limitations**

This study provides useful insight into how an intervention like Renewed is experienced and may work to improve QoL among cancer survivors. There are a number of key strengths of this study. In line with guidance on conducting qualitative process studies alongside trials, data were

collected and analysed iteratively (Moore et al., 2015). This allowed issues underlying emerging themes to be explored further in later interviews. Furthermore, conducting interviews during the COVID-19 pandemic allowed unique experiences during that time to be identified, allowing data to consider contextual factors relating to users' experience, in accordance with guidance (Moore et al., 2015). Consideration should be given to limitations for example it would have been useful to collect data on participants' experiences over the duration of the study, rather than just during the first three months of being in the study. This might have allowed the identification of patterns over time and whether experiences changed (Saldaña, 2003). However, after piloting interviews at different time points since participants had started Renewed, it was clear that data were richer (and participants memories clearer) when conducted within the first three months of using Renewed, therefore the majority of the sample was interviewed at this time point. Additionally, it should be considered that there may have been other factors, other than level of Renewed usage, cancer type, age and gender, that may have influenced perceptions of Renewed and impact on outcomes, experience, and motivations to use the intervention. For example, research suggests those from minority ethnic groups and those from lower socio economic backgrounds are less likely to engage in cancer research and digital interventions (Delon et al., 2022; Western et al., 2021). However, those with a higher health literacy engage more with digital interventions have better outcomes (van der Hout et al., 2021a). However, despite attempts to do so, it was not possible to obtain as diverse a sample in socio-demographic characteristics. The experiences of using Renewed may have varied depending on these characteristics.

### **3.5.2 Conclusion**

This study has explored cancer survivors' experiences using a digital intervention in primary care designed to improve QoL and considered the findings alongside the results from the parallel RCT. These findings suggest that adding support alongside digital interventions may motivate engagement, particularly among those who lack this support outside of the intervention. Furthermore, these findings add to the literature regarding effective engagement with digital interventions, suggesting that even limited usage of online content may provide enough information to motivate behaviour change among those with less need for resource-intensive support. Novel information may need to be presented earlier in an intervention to motivate continued engagement with Renewed. This has implications for implementing Renewed and similar interventions into clinical practice as it suggests that with minor changes (e.g. addressing concerns about engagement with physical activity whilst having mobility issues), such as such an intervention may be able to provide support to many people with less need for intensive support and may be particularly helpful for those who lack support.



## Chapter 4 Usage of a healthcare professional-supported digital intervention for cancer survivors in primary care: A quantitative process evaluation (Paper 2)

### 4.1 Abstract

**Background:** A digital intervention, 'Renewed', was developed to improve the quality of life of cancer survivors through supporting healthy behaviour change (i.e. physical activity, healthy eating, weight management and managing psychological distress) with for some, optional brief support from a HCP. A randomised control trial (n= 2,736) evaluating Renewed found small improvements in the quality of life of cancer survivors in all arms, with the greatest effect found among those who also had access to support from healthcare professionals. This study aimed to explore the processes by which Renewed might have produced its effects by exploring how usage of the digital intervention and HCP support were related to improvements in quality of life.

**Methods:** This was a quantitative process evaluation of the use of Renewed. Usage was analysed among 1,760 cancer survivors randomised to the 1) Renewed and 2) Renewed with support arms, and who had completed trial follow-up measures. The digital intervention automatically collected usage data (overall number of times accessed the intervention and number of times across Renewed optional content). Whether or not a participant accessed support was logged by healthcare practitioners who provided support. The analysis examined the relationships between usage, accessing HCP support and quality of life.

**Results:** Usage of the introductory session (core content) of the intervention was high across both arms of the trial (84.4%), however, less than half of participants accessed the optional behaviour change support sections (optional content) of the intervention (45%). Greater usage of Renewed, specifically accessing the optional content, was associated with improved quality of life at 12 months. Only a third of participants (31%) in the Renewed plus support arm accessed HCP support, with a median of one support session when they did access it. Those who accessed support were three times more likely to access the optional content. However, accessing support was not directly related to greater QoL at 12 months.

**Conclusion:** This study suggests that higher usage of Renewed may lead to better quality of life. This has implications for the need to develop content that will motivate further engagement. The

brief support provided by health care professionals encouraged higher usage. However, accessing this support does not directly increase QoL. This suggests that human support has been useful to increase digital intervention usage, which may indirectly increase QoL.

### 4.2 Introduction

Treatment for cancer can cause multiple physical and psychological consequences (e.g. fatigue, anxiety and depression) (Macmillan Cancer Support, 2017). (Macmillan Cancer Support, 2017). Primary care is well placed to support cancer survivors to self-manage these problems (Gopal, 2020). Digital interventions offer a cost-effective way to support cancer survivors in managing these consequences, whilst providing accessible and individualised interventions to facilitate connections between healthcare professionals and cancer survivors (Furness et al., 2020). In particular, digital interventions which provide support about diet, weight management, physical activity and psychological wellbeing can directly support cancer survivors to self-manage the long-term consequences experienced and improve QoL (e.g. Bourke et al., 2016).

A digital intervention, “Renewed” (Bradbury et al., 2019; Corbett, Cheetham, et al., 2018; Corbett, Singh, et al., 2018; Krusche et al., 2019), was developed targeting multiple health behaviours to improve QoL of cancer survivors. Renewed was composed of a website, and for some the option of brief HCP support, and was designed with the aim to be implemented within NHS primary care services. A three-arm randomised controlled trial (Renewed, Renewed with support or control arm) showed substantial improvement in QoL across all three arms at 12 months. However, the largest effect was found among those in the Renewed with support arm.

A key aspect of evaluating behaviour change interventions is understanding how they produce change (Moore et al., 2015). A logic model was developed during the intervention development process to hypothesise how Renewed was expected to produce change (see [Figure 1](#)).

As represented in this logic model, the intervention targeted key health behaviours (e.g. physical activity) and mental health (e.g. managing distress) to improve QoL and mental health. To overcome barriers, maximise engagement and optimise implementation, the intervention was developed using the Taxonomy of Behaviour Change Techniques (BCTs) (Michie et al., 2013), which describes the ‘active ingredients’ of an intervention, the Behaviour Change Wheel (BCW: Michie, van Stralen, & West, 2011), a framework to identify intervention functions and policy categories that could bring about change, and Normalisation Process Theory (NPT: May & Finch, 2009), a theory that explains factors for successful implementation. As a result, Renewed contains BCTs (e.g. goal setting, increased information about health consequences) whilst targeting behavioural sources (e.g. psychological capability, physical opportunity), intervention functions

(e.g. education and persuasion), and constructs of NPT (e.g. coherence, understanding of a new intervention). Therefore, the Renewed logic model theorises that change will be produced through engagement with Renewed, and thereby the BCTs, behavioural sources and functions. For those in the website plus support arm, an additional theorised mechanism of change is through engagement with support sessions via a Supporter (a HCP). Engagement in this context is defined as usage of the intervention (the overall number of times participants accessed Renewed and its content). Higher usage of a digital intervention is often associated with better outcomes (Enrique et al., 2019), and human support has been found to boost engagement with, and outcomes of, digital interventions (Ozaki et al., 2019; Yardley et al., 2016). However, many engagement studies fail to utilise detailed and comprehensive usage data, which may reveal usage patterns regarding who used the intervention and how (Miller et al., 2019), which may in turn help explain how the intervention works (Whitton et al., 2015).

Quantitative usage process analyses can provide an understanding of which types and patterns of engagement effectively mediate positive outcomes (Yardley et al., 2016). 'Effective engagement' is defined as sufficient engagement with the intervention to achieve intended outcomes (Miller et al., 2019). Therefore, by examining the logic model's mechanisms of action and identifying how participants used Renewed, a clearer picture of what is required for effective behaviour change in this intervention is provided. Specifically, a description of how participants used Renewed, whether usage was related to outcomes in QoL, whether support was related to usage, and whether demographic and clinical variables were related to usage of Renewed. The research questions for this study were as follows:

1. A) How much did participants use Renewed? Which contents of Renewed were most used?  
B) Was there a difference in Renewed usage (i.e. frequency), based on participants' characteristics and whether participants accessed to support, chose not to access support or were randomised to the Renewed arm?
2. A) Did the use of Renewed relate to improvements in quality of life at 12 months follow-up?  
B) Did those who accessed support have greater improvements in quality of life at 12 months compared to those who did not access support or were randomised to the Renewed arm?

## **4.3 Methods**

### **4.3.1 Study design**

This design consisted of a quantitative process study nested within an RCT of the Renewed intervention (Krusche et al., 2019). Participants in the RCT were randomised to either: 1) Renewed: (web-only intervention arm), 2) Renewed with support (web-based intervention with additional guidance and support arm), or 3) Control: Generic advice and follow-up arm, where participants in this group received a link to the NHS LiveWell website which provided information on healthy living (NHS, 2022). Only data from participants in the Renewed and Renewed with support arms was used in this study. Participants' data and website usage were recorded via the LifeGuide intervention hosting platform (Yardley et al., 2009), and an extract of the 12-month follow up data was downloaded for analysis.

Ethical approval was granted by the University of Southampton (ERGO reference: 31000.A8) and NHS (reference: 18/NW/0013) ethics committees. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies (von Elm et al., 2014) was used to guide reporting (Appendix I).

### **4.3.2 Participant recruitment and procedure**

The full recruitment and procedure of the Renewed RCT is detailed elsewhere (Krusche et al., 2019). Briefly, cancer survivors were recruited from General Practitioner (GP) practices across England and Wales. Eligible participants were those who had finished treatment for breast, prostate, or colorectal cancer within the past ten years or were on active surveillance with prostate cancer. Participants also needed to demonstrate reduced quality of life (as defined by scores 85 or below on the European Organization for Research and Treatment of Cancer measure (EORTC QLQ-C30: Aaronson et al., 1993), be aged 18 years or older and have internet access. Participants completed questionnaires at baseline and 12 months post-randomisation, and were included in this analysis if they had completed the 12-month follow-up measures.

### **4.3.3 Intervention**

A detailed description of Renewed is provided in [Section 1.3](#). Briefly, Renewed is a web-based intervention designed to improve the quality of life of cancer survivors through supporting healthy lifestyle changes. It consisted of a website which begins with an introductory session (core content) that provided an overview of the intervention content, before providing users with tailored information on how Renewed could help them based on answers to a quality of life

measure (EORTC QLQ-C30: Aaronson et al., 1993), then reaching the Homepage. An extended version of the core content was shown to those on active surveillance with prostate cancer to provide reassurance about the safety and efficacy of active surveillance. From the Homepage, intervention users had a choice to use additional optional content within Renewed: 'Getting Active', 'Healthy Paths' (Geraghty et al., 2016), 'Eat for Health', and 'POWeR' (Dennison et al., 2014; Little et al., 2016, 2017; Smith et al., 2017; Yardley et al., 2012). Getting Active provided support with increasing physical activity. Healthy Paths provided support for improving psychological well-being, reducing stress and managing difficult feelings. Eat for Health provided support for healthy eating. POWeR was an evidence-based weight loss programme which provided support for weight management. Intervention users randomised to the website plus support arm were also given the option to have three brief (10-minute) support sessions with a healthcare professional. Support sessions were via either telephone or face-to-face and were based on the CARE approach (Bradbury et al., 2017).

#### **4.3.4 Measures**

The measures used in this study were demographic characteristics, intervention usage, and baseline and 12-month quality of life scores.

##### **4.3.4.1.1 *Demographic and clinical characteristics***

Participants were asked to self-report their age, gender, ethnicity and cancer type. In addition, participants reported the age they left full-time education and the month and year they finished cancer treatment.

##### **4.3.4.1.2 *Renewed usage***

Data on Renewed usage, including which pages were accessed and the number of times each page was accessed, were accessible to researchers from LifeGuide. Usage was defined as the overall number of times participants accessed Renewed and its optional content. Research suggests that engagement is multifaceted and usage should be measured at different levels, such as duration, depth and amount, thereby providing the breath of usage. However, access to many measures of usage was not feasible for this study as Renewed is a big intervention with behaviour change techniques contained across many pages, so the complexity of collating and analysing these variables would not be feasible for analysis in this particular study (Perski et al 2017). As a result, the overall number of times accessed was considered a good representation of usage because it provides an objective measure of the extent of usage over time (Perski et al., 2017).

#### **4.3.4.1.3 Quality of life**

Quality of life was measured with the EORTC QLQ-C30 scale (Aaronson et al., 1993). The EORTC QLQ-30 assessed functional domains (i.e. physical, emotional, role and cognitive and social) and common cancer symptoms (i.e. pain, fatigue, nausea/vomiting, dyspnoea, sleep problems, loss of appetite). The questionnaire included 30 items, each with a four-point response scale from 'not at all' to 'very much'. Scores were calculated using a linear conversion to create a score from 0 to 100. In this sample Cronbach's alpha was  $\alpha = 0.88$ , indicating high level of reliability (DeVellis, 1991). EORTC QLQ is a widely used questionnaire for health-related quality of life in cancer research (Giesinger et al., 2016).

#### **4.3.5 Statistical analysis**

Data were analysed using SPSS version 27. All data were examined for deviations from normality. The distributions of the measures for usage analysis were not normally distributed and were therefore analysed using non-parametric tests. The regression models and partial correlations controlled for baseline quality of life scores, baseline anxiety and depression scores, baseline fear or cancer relapse/recurrence, BMI, age, time since the end of treatment, age they left full time education, gender and cancer type. These variables were tested for multicollinearity with the variance inflation factor and was not significant (Mansfield & Helms, 1982).

Access to support was characterised in three ways: 1) participants who accessed support, 2) participants who chose not to access support (but had the option to access support) and 3) participants who were in the Renewed arm (without access to support).

#### **Usage outcome**

A linear regression was used to examine relationships between participants' characteristics, whether participants accessed support, did not access support (but had the option to access support) or were in the Renewed arm (without access to support) and usage of Renewed, controlling for potential confounding variables.

#### **12-month quality of life outcome**

Pearson's partial correlation was used to examine the relationship between overall usage of Renewed and 12 month QoL scores, controlling for potentially confounding variables. ANCOVA was also used to examine the differences in QoL based on whether participants accessed support, did not access support (but had the option to access support) or were in the Renewed arm (without access to support). The ANCOVA test does not directly allow the calculation of effect

sizes; standardised effect sizes may be converted from partial eta squared using the methods set out by Cohen (1988).

## **4.4 Results**

### **4.4.1 Participant characteristics**

The sample consisted of the 1,760 cancer survivors in the Renewed and Renewed with support arms who completed follow-up measures at 12 months. Of this sample, 58.5% were female, 52.0% had breast cancer, and 97.8% were White. The QoL scores ranged from 13-85 (cut off scores above 85), with a mean of 72.39, indicating a relatively high quality of life within this sample. See Table 5 for an overview of participant demographic characteristics.

Table 5 - Participant characteristics

<b>Baseline characteristics</b>		
<b>Age</b>		
Mean (S.D)		64 (10.88)
<b>Baseline EORTC QLQ-C30 score*</b>		
Mean (S.D)		72.39 (11.69)
<b>Cancer type</b>		
	<i>Colon</i>	281/1760 (16.0%)
	<i>Breast</i>	916/1760 (52.0%)
	<i>Prostate</i>	394/1760 (22.4%)
	<i>Prostate Active Surveillance</i>	169/1760 (9.6%)
<b>Renewed trial arm</b>		
	<i>Renewed</i>	877/1760 (49.8%)
	<i>Renewed with support</i>	883/1760 (50.2%)
<b>Gender</b>		
	<i>Male</i>	731/1760 (41.5%)
	<i>Female</i>	1029/1760 (58.5%)
<b>Time since last cancer treatment (years)**</b>		
Mean (S.D)		4 (2.67)
<b>Age they left full time education (years)</b>		
Mean (S.D)		18 (3.84)
<b>Ethnicity</b>		
	<i>Bangladeshi/South east Asian</i>	0/1760 (0%)
	<i>Indian</i>	4/1760 (0.2%)
	<i>Pakistani</i>	3/1760 (0.2%)
	<i>White</i>	1721/1760 (97.8%)
	<i>Black Caribbean</i>	3/1760 (0.2%)
	<i>Black African</i>	3/1760 (0.2%)
	<i>Black other</i>	1/1760 (0.1%)
	<i>Other</i>	24/1760 (1.4%)

\* European Organization for Research and Treatment of Cancer measure; \*\* N does not include those who were on active surveillance with prostate cancer

#### 4.4.2 Usage outcomes

##### 1. A) How much did participants use Renewed? Which optional content of Renewed was most used?

Participants accessed Renewed a median of 2 times, ranging from 0 - 268. Overall, the majority of participants (96.8%) accessed the core content of Renewed, with (84.4%) completing the core content and reaching the Homepage where they could access the other contents of Renewed. Slightly less than half (44.8%, n=790/1760) of participants continued to use Renewed past the Homepage to access the optional content of Renewed (Getting Active, Eat for Health, Healthy Paths, Power). After the core content, Getting Active was the most used optional content of



Renewed (30%), and Healthy Paths (10%) was least used. Of those who continued beyond the core content, the majority (56%) accessed just one additional content of Renewed, with 26% accessing two, 13% accessing three, and 5% participants accessing all four optional content. Amongst participants given the option to access support sessions (the website plus support arm), the majority (69%) of participants did not choose to access this support. An overview of the intervention usage data is provided in Table 6.

Table 6 - How participants used Renewed

<b>Contents of Renewed</b>	<b>n (%)</b>	<b>Median number of times accessed</b>	<b>Median quartiles (Lower, Upper)</b>	<b>Range number of times accessed</b>
<b>Overall number of times accessed</b>		2		0 - 268
<b>Core content</b>				
<i>Accessed core content</i>	1703/1760 (96.8%)			
<i>Did not access core content</i>	55/1760 (3.1%)			
<b>Homepage</b>				
<i>Accessed Homepage</i>	1487/1760 (84.4%)	2	1,3	0 – 268
<i>Did not access homepage</i>	273/1760 (15.5%)			
<b>Getting Active (Physical Activity)</b>				
<i>Accessed Getting Active</i>	524/1760 (29.7%)	0	0,1	0 – 106
<i>Did not access Getting Active</i>	1236/1760 (70.2%)			
<b>Eat for Health (Healthy Eating)</b>				
<i>Accessed Eat for Health</i>	485/1760 (27.5%)	0	0,1	0 – 103
<i>Did not access Eat for Health</i>	1275/1760 (72.4%)			
<b>Healthy Paths (Psychological well-being)</b>				
<i>Accessed Healthy Paths</i>	179/1760 (10.2%)	0	0,0	0 -123
<i>Did not access Healthy Paths</i>	1581/1760 (89.8%)			
<b>Power (Weight management)</b>				
<i>Accessed Power</i>	137/1231 (11.1%)*	0	0,0	0 -125
<i>Did not access Power</i>	1094/1231 (88.8%)			
<b>Accessed core content plus one content</b>	440/790 (55.7%)**			

<b>Accessed core content plus two optional content</b>	207/790 (26.2%)			
<b>Accessed core content plus three optional content</b>	103/790 (13.0%)			
<b>Accessed core content plus four optional content</b>	40/790 (5.1%)			
<b>Support Sessions</b>				
Accessed support	235/756 (31.1%)*	1	1,2	1-4
Did not access support	521/756 (68.9%)			

\*Participants were only offered access to Power if their BMI was >25. n=1231 reflects the number of participants who were offered access to Power.

\*\*n=790 reflects the number of participants who accessed the optional content.

\*\*\* n=756 reflects the number of participants for which support information was available (as some support data was not completed or returned). This is less than the 883 participants who were randomised to the Renewed with support arm as shown in Table 5.

**1. B) Was there a difference in Renewed usage (i.e. frequency), based on participants' characteristics and whether participants accessed support, chose not to access support or were randomised to the Renewed arm??**

The regression model explained 24% of the variance ( $R^2=0.24$ ,  $F_{15,1743} = 2.90$ ,  $p = <.001$ ) in usage of Renewed. Accessing to support significantly predicted usage of Renewed ( $\beta = .109$ ,  $p=.004$ ) see Table 7. There were no significant associations between the overall number of times participants accessed Renewed and any of their recorded characteristics (age, gender, and cancer type, age they left full time education and years since finishing treatment), those who chose not to access support and those in the Renewed arm (without access to support).

Table 7 - Usage of Renewed based on accessing support

	Renewed arm (n=877)	Chose not to access support (n=521)	Accessed support support (n=235)
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<b>Median number of times accessed (median quartiles) Renewed</b>	4 (2,9)	1 (1,3)	1 (1,3)
B	.076	-.983	3.750
Standard Error (95% CI)	1.105 (-2.091, 2.243)	1.151 (-3.241, 1.275)	1.285 (1.231, 6.269)
$\beta$	.003	-.038	.109
P Value	.945	.393	.004

In summary, most participants accessed the core content, but not the optional contents. A majority of those who did access the optional content, only accessed one optional content, with Getting Active being the most accessed content. Individual characteristics did not significantly affect how participants used Renewed. While the majority of participants did not access supporter sessions, those who chose to access support used Renewed the most compared to those who chose not to access support or were randomised to the Renewed arm. Furthermore, accessing support was a significant predictor of usage even after controlling for individual characteristics.

#### 4.4.3 12-month quality of life outcomes

##### 2. A) Did the use of Renewed relate to improvements in quality of life at 12 months follow-up?

There was a very small positive correlation of 0.08 (95% .039 to .123,  $p=.001$ ) between the number of times participants accessed Renewed and changes in quality of life scores at 12 months after adjusting for potentially confounding variables.

##### 2. B) Did those who accessed support have greater improvements in quality of life at 12 months compared to those who did not access support or were randomised to the Renewed arm?

As shown above, accessing support was significantly related to greater usage, here we explore whether accessing support lead to greater QoL at 12 months. At 12 months, there was no difference in QoL score between participants who accessed support, chose not to access support

(but had the option to access support) or were in the Renewed arm (without access to support) [ $F(2,1306)=.84, p=.43$ ], see Table 8.

Table 8 - Quality of life scores at 12 months for different access to support

	<b>Accessed support (n=235)</b>	<b>Chose not to access support (n= 521)</b>	<b>Renewed arm (n= 877)</b>
Mean EORTC QLQ-C30 score at 12 months (S.D)	77.5 (13.85)	77.09 (14.21)	77.15 (14.37)
Adjusted mean differences at 12 months (B(95% CI))*	REF	-1.21 (-3.07, .65)	-.94 (-2.65, .76)
Standardised effect size	REF	0.07	0.07
P-value	REF	.20	.28

\* *Adjusted for baseline quality of life scores, baseline anxiety and depression scores, baseline fear or cancer relapse/recurrence, BMI, age, time since the end of treatment, age they left full time education, gender and cancer type.*

In summary, more usage was related to better outcomes in quality of life.. However, accessing support was not associated with improvements in QoL.

## 4.5 Discussion

This study was a quantitative process study to examine how Renewed was used and whether the mechanisms hypothesised in the logic model were associated with the outcomes anticipated in quality of life. This study showed that greater usage of Renewed was associated with larger improvements in QoL at 12 months. Moreover, accessing the optional support led to increased use of additional content which in turn was related to higher QOL. However, accessing support was not directly related to greater QoL at 12 months. The complexity of this relationship is further discussed later in the discussion.

The findings of this study showed that there was high initial engagement with Renewed, as 84% of cancer survivors completed the core content. Total usage of Renewed did not differ between participants with different characteristics (e.g. age, gender, cancer type), which suggests that the intervention was of interest to participants taking part. This may have contributed to the high

usage of the core content and has practical implications for implementation as it suggests that Renewed can feasibly appeal to a wide range of cancer survivors in practice.

One hypothesis of Renewed's logic model that this study sought to examine was whether greater usage of Renewed would predict greater improvements in QoL. Results of this study showed a small positive correlation which suggested that greater usage of Renewed was associated with greater improvements in QoL. This is in line with literature which suggests that greater usage of web-based health interventions lead to better outcomes (Enrique et al., 2019). However, it has been argued that the relationship between usage and health related outcomes is complex (Morrison et al., 2018), as greater usage of digital interventions does not lead to better outcomes in all cases (e.g. Donkin et al., 2013). Therefore, there is a need to identify precisely what type and how much usage is required for effective behaviour change in this intervention (Yardley et al., 2016).

This study suggests using Renewed more may produce the greatest effect in QoL. As only 45% of participants accessed Renewed's optional content, consideration may be needed about how further engagement with the intervention can be improved. However, although using Renewed more may suggest greater engagement and outcomes, lower usage does not always imply disengagement with an intervention (Yardley et al., 2016). Despite only accessing the core content, the Renewed qualitative process evaluation (Paper one) showed that many participants stopped using Renewed for various reasons that may suggest positive engagement with wider intervention goals (e.g. enough information to begin behaviour change, sufficiently supported). For some, using just the core content may have provided the impetus they needed to manage the consequences of cancer treatments, making further use redundant (Schneider et al., 2016). For example, research has found that those who showed decreasing usage of a digital smoking cessation intervention still reported behaviour change (Castro et al., 2017). For other participants of Renewed in need of more support, effective engagement may only have been achieved with additional usage of optional content.

This study also examined whether engagement with support would be associated with greater usage of Renewed and improved QoL, as hypothesised in Renewed's logic model. The results suggest that accessing support significantly increased usage of Renewed, even after controlling for individual characteristics. This may suggest that support alongside a digital intervention may effectively promote engagement among cancer survivors of varying characteristics. However, accessing support did not significantly increase QoL at 12 months. While previous research has shown that that human support can boost engagement with digital interventions (e.g. Ozaki et al., 2019), review suggests that the relationship between accessing human support and boosts in

digital intervention engagement and outcomes is mixed (Renfrew, Morton, Morton, & Przybylko, 2021). Renfrew et al. (2021), suggest that human support is only sometimes associated with engagement and outcomes, and when it is, effects are small. This mixed relationship between support and outcomes was evidenced in this study in that support boosted use of Renewed, but not outcomes in QoL.

This study showed that accessing support was not associated with improvements in QoL. The Renewed qualitative process research (Paper one) and wider literature show that there are substantial variations in the reasons why people access healthcare support. In the context of Renewed, the Renewed qualitative process research suggests that some participants accessed HCP support to make Renewed more personal and receive more tailored behaviour change advice. However, the wider literature highlights other potential motivations for accessing support that may not necessarily have been beneficial for their quality of life. For example, a national survey in the United States of America found that information seekers were more likely to contact healthcare support, particularly if they were seeking support for specific health or medical conditions (Ybarra & Suman, 2006). Cancer survivors' information needs are quite complex (Ankem, 2006). As a result, during support sessions, cancer survivors may address topics or conditions not covered in the intervention (e.g. Ruland et al., 2013) and potentially unhelpful in improving their quality of life. It may be that after accessing support, for whatever reason, this may have produced accountability to use Renewed more. This is known as supportive accountability (Mohr, Cuijpers, & Lehman, 2011). While greater use can occur as a result of supportive accountability, supportive accountability does not always lead to significantly better outcomes (Boß et al., 2018; Mohr et al., 2012), and may account for why access to support boosted usage of Renewed but not quality of life outcomes.

### **4.5.1 Strengths and limitations**

The ability to consider the findings of this study in light of qualitative data of cancer survivors using Renewed added greater understanding of how the intervention was used, and strengthened the study in line with guidance (Moore et al., 2015). However, consideration should be given to the limitations of this study. Firstly, the inclusion of only those who completed follow-up measures may limit the generalisability of the results, as research suggests that those who engage less are less likely complete follow-up measures (Torous et al., 2020). Thus, levels of usage may have been lower for those who did not complete follow-up measures, introducing a risk of systematic bias in this study. Additionally, although this study derived from an RCT, it was observational and cannot draw causal conclusions about how specific usage or types of support

influenced outcomes in QoL. Future research is needed in order to determine the type of usage and support needed to effectively change QoL.

#### **4.5.2 Conclusion**

This was a process usage study of the Renewed intervention that sought to understand how Renewed improved QoL at 12 months as found in the RCT, and examined the proposed mechanisms of Renewed's logic model. This study suggests that more usage of Renewed was associated with better outcomes. Usage during the initial part of the intervention, the core content, was higher. This has implications for the need to provide the best support in the early stages of interventions or to develop content that will motivate further engagement.

Participants who accessed support sessions used Renewed more than those in the trial's Renewed arm, even after controlling for individual characteristics. However, accessing support was not related to outcomes in QoL at 12 months. Additional research is needed to test the extent that usage and outcomes of digital interventions are influenced by access to support to better understand how to implement support effectively.





## Chapter 5 Implementing a healthcare professional–supported digital intervention for survivors of cancer in primary care: Qualitative process evaluation of the Renewed intervention (Paper 3)

This paper was published in JMIR Cancer in April 2022.

### 5.1 Abstract

**Background:** Primary care plays an important role in supporting survivors of cancer; however, support is limited because of practitioners’ perceived lack of expertise and time. A digital intervention for survivors of cancer could provide an efficient way for primary care staff to support survivors of cancer without the need to accumulate expertise and skills to help cancer survivors make behaviour changes; providing very brief support alongside this could maximise adherence to digital interventions. “Renewed” is a digital intervention that combines web-based behaviour change advice with brief health care practitioner support from a nurse or health care assistant. Knowledge about the views and experiences of primary care staff providing support alongside a digital intervention for survivors of cancer is sparse, limiting the understanding of the acceptability and feasibility of this type of intervention.

**Objective:** This study aims to explore supporters’ experiences of providing support to survivors of cancer using Renewed, understand potential barriers to and facilitators of the implementation of *Renewed* in practice, and investigate the strengths and weaknesses of the intervention from the perspective of health care professionals.

**Methods:** This was a qualitative process evaluation nested within a large trial evaluating *Renewed*. A total of 28 semi-structured telephone interviews were conducted with nurses and health care assistants. Data were analysed using inductive thematic analysis.

**Results:** Four themes were developed during the analysis, which reflected the factors that supporters identified as hindering or enabling them to provide support alongside Renewed: Renewed as an acceptable digital tool with some improvements, confidence in enacting the supporter role, practicalities of delivering support alongside a digital intervention, and managing a patient-led approach. The analysis suggests that supporters perceived that a digital intervention such as Renewed would be beneficial in supporting survivors of cancer in primary care and fit

within current practices. However, barriers to providing support alongside the intervention were also identified, including concerns about how to facilitate rapport building and, in a minority, concerns about using a nondirective approach, in which most advice and support is provided through digital interventions, with brief additional support provided by primary care staff.

**Conclusions:** These findings add to the literature on how best to provide support alongside digital interventions, suggesting that although most practitioners cope well with a nondirective approach, a minority requires more training to feel confident in implementing this. This study suggests that the barriers to providing formal support to survivors of cancer in primary care could be successfully overcome with an approach such as Renewed, where a digital intervention provides most of the support and expertise, and health care practitioners provide additional brief support to maximise engagement. Strategies to maximise the chances of successful implementation for this type of intervention are also discussed.

## 5.2 Introduction

### 5.2.1 Background

In 2018, the total number of people alive within 5 years of a cancer diagnosis was estimated to be 43.8 million worldwide (Sung et al., 2019). Currently, there are 2.5 million survivors in the United Kingdom, which is estimated to increase to 4 million by 2030 (Macmillan Cancer Support, 2017). However, up to 86% of people who complete cancer treatment in the United Kingdom, Australia, and the United States of America experience enduring side effects (Macmillan Cancer Support, 2013a; Mahumud, Alam, Dunn, & Gow, 2020; Pearce et al., 2017), including fear of cancer recurrence, anxiety, depression, fatigue, and weight gain, contributing to a reduced QoL (Macmillan Cancer Support, 2013a).

The rising cancer burden places a strain on health systems worldwide (Prager et al., 2018). Health care professionals (HCPs) based in primary care are central to providing support for people who have had cancer after completion of their primary treatment (e.g., chemotherapy). However, these services are becoming overstretched and are increasingly unable to meet the needs of survivors of cancer (Adam & Watson, 2018). For instance, survivors of cancer have expressed a need for more support with the emotional effects of cancer and issues such as fatigue that can occur months or years after treatment (Khan et al., 2011). Primary care staff describe a lack of clear guidance on how survivors of cancer should be supported (Taylor et al., 2020). Patients and oncologists have expressed concerns that primary care staff are not experts, and their busy workloads lead to deficiencies in the continuity of care (Khan et al., 2011; Taylor et al., 2020), meaning that survivors of cancer may not receive access to appropriate support with their ongoing symptoms after cancer treatment. Therefore, there is a need for clearer, more effective,

and cost-efficient means of providing support. Digital interventions, such as websites or mobile apps, offer the potential to help survivors of cancer improve their QoL (Roberts, Fisher, Smith, Heinrich, & Potts, 2017). The addition of brief human support can boost engagement with digital interventions (Dennison et al., 2014; Yardley et al., 2016). Digital interventions combined with brief support from primary care staff may facilitate improved QoL after cancer treatment. It may provide efficient and low-cost models for delivering support without the need to accumulate expertise in the skills and knowledge needed to help cancer survivors make the behavioural changes needed to increase their QoL. However, the acceptability and feasibility of implementing digital interventions among survivors of cancer in primary care is still to be determined. An important aspect of this involves understanding the capability of HCPs to deliver brief support along with digital interventions.

Renewed (Bradbury et al., 2019; Corbett, Cheetham, et al., 2018; Corbett, Singh, et al., 2018; Krusche et al., 2019) is a complex intervention designed to improve the QoL of survivors of cancer. It combines a digital intervention focused on changing key behaviours that can improve the QoL of survivors of cancer with brief support from a nurse or health care assistant to maximise engagement. Renewed was designed for implementation in primary care within the United Kingdom's NHS. Renewed is currently being tested in a RCT to determine its effectiveness and cost-effectiveness. In addition to determining the effectiveness and cost-effectiveness of an RCT, it is critical to examine whether an intervention might be implemented well in practice. Understanding barriers to and facilitators of implementation could help optimise the implementation of Renewed and also provide helpful insights for others developing digital interventions that include human support.

### 5.2.2 Objectives

National guidance recommends conducting process evaluations to identify how new interventions are implemented in practice, the likely mechanisms through which they might produce an effect, or factors in the health care environment that might stop an intervention from producing an effect (Moore et al., 2015). This paper reports a process study exploring HCPs' perceptions of Renewed. Although the RCT of Renewed (Krusche et al., 2019) is ongoing, as recommended by the Medical Research Council guidelines, qualitative process data are reported here before obtaining knowledge of the RCT outcomes to avoid biased interpretation (Moore et al., 2015). This process study has been used to explore potential barriers to and facilitators of implementing *Renewed* in primary care and evaluate the acceptability of providing this type of support, which might contribute to the success (or not) of the intervention. Specifically, this study aims to explore (1) supporters' experiences of providing support to cancer survivors using the Renewed digital

intervention and (2) barriers to and enablers of the successful implementation of Renewed in practice.

## **5.3 Methods**

### **5.3.1 Study design**

The study design entailed a qualitative process evaluation of the Renewed intervention, which explored HCPs' perceptions of delivering support alongside Renewed. The COREQ (Consolidated criteria for Reporting Qualitative studies) checklist (Tong et al., 2007) guided the reporting (Appendix J). Participants in the RCT were randomised to: 1) Renewed: web-only intervention, 2) Renewed with support: web-based intervention with additional guidance and (HCP) support, or 3) Control: Generic advice and follow-up. For full details of the Renewed RCT, see the study by Krusche et al (2019). Briefly, survivors of cancer in the *Renewed* RCT (n=2712) had completed treatment for either colon (432/2712, 15.93%), breast (1216/2712, 44.84%), or prostate cancer (864/2712, 31.86%). Mean years since the completion of treatment was 4 (SD 3.1) years, mean age was 64.5 (SD 10.9) years, and mean baseline QoL score was 72.4 (SD 11.9; as defined by scores 85 or below on the European Organisation for Research and Treatment of Cancer measure (Aaronson et al., 1993)).

### **5.3.2 Ethics approval**

Ethical approval was granted by the University of Southampton (ERGO reference 31000.A8) and NHS (reference 18/NW/0013) ethics committees.

### **5.3.3 The Renewed intervention<sup>2</sup>**

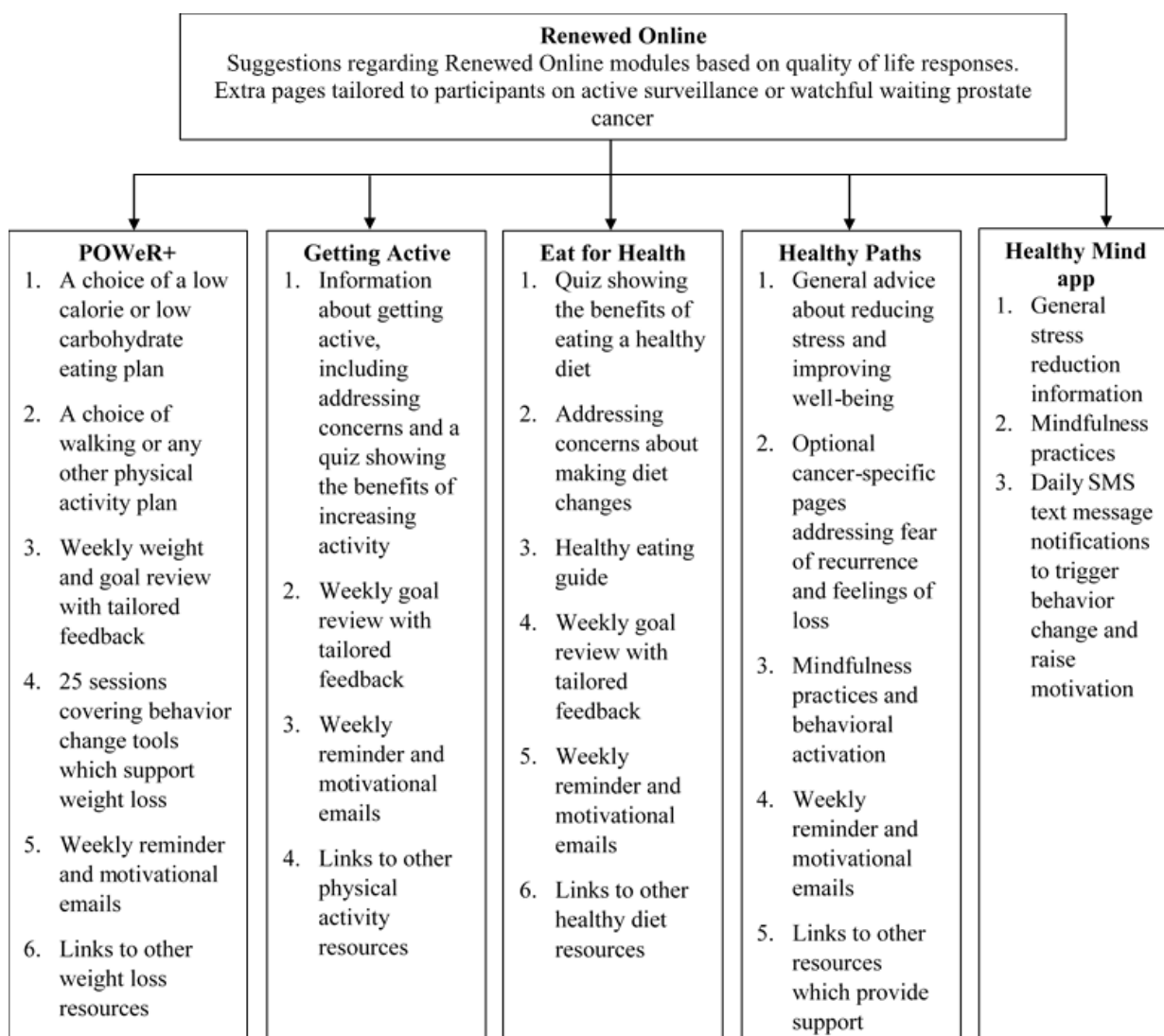
#### **5.3.3.1 Overview**

The full description of Renewed is provided in [Section 1.3](#). Briefly, a description of Renewed is provided in Figure 3 (Krusche et al., 2016), incorporating the TiDIER (Template for Intervention Description and Replication) guidelines (Hoffmann et al., 2014).

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<sup>2</sup>Parts of the description of the Renewed intervention has been changed or removed to avoid repetition throughout the thesis. In this way, the paper presented here is different to what has been published.

Figure 3 - Renewed intervention description



*Reproduced with permission from Krusche et al., (2019)*

### 5.3.3.2 HCP support

Participants who were randomised to the Renewed plus support arm also had the option of brief healthcare professional support. A full description of the HCP support is provided in [Section 1.3.7](#). Briefly, participants has the option of up the three 10-minute sessions with either a practice nurse, practice-based healthcare assistant or a clinical research nurse. Support sessions were delivered using the CARE approach and were provided via face-to-face, telephone or email.

### 5.3.4 Sampling and recruitment

Supporters were identified for interviews through the Renewed supporter database and the study team's records of HCPs providing support as part of the RCT. Emails or phone calls were used to invite supporters to participate in a telephone interview about their experience of supporting cancer survivors using Renewed (Appendix K.1). In the early stages of recruitment, supporters

## Chapter 5

were sampled purposively based on their job roles (practice nurse, practice-based health care assistant, or clinical research nurse); however, recruited supporters often had not undertaken any support sessions or only supported 1 cancer survivor. Supporters were then purposively sampled based on the number of cancer survivors they had supported to ensure the inclusion of those who had supported multiple cancer survivors to explore any variation in their experiences. Supporters were provided with a participant information sheet (Appendix K.2) and asked to confirm their informed consent on the web after consideration (Appendix K.3).

### **5.3.5 Procedure**

Interviews were conducted between September 2019 and January 2020, each lasting approximately 15 to 30 minutes, with a median of 21 minutes. A total of two (JS and JSB) researchers conducted the interviews. A semi-structured interview schedule was developed by a qualitative researcher (JS) and experienced health psychologist (KB) (Appendix L). The interview schedule explored supporters' experiences of providing support along with the digital intervention, perceptions of web-based supporter training, experiences of support appointments, perceptions of the CARE approach, and supporters' perceptions of the Renewed program.

### **5.3.6 Data analysis**

All interviews were audio recorded, transcribed verbatim, and then imported into NVivo 12 (QSR International Pty Ltd) (International, 2018). An inductive thematic analysis was performed based on aspects from the 6-step framework of Braun and Clark (2006) and (Joffe & Yardley, 2004). JS familiarised herself with the data before coding the interviews. A coding manual was created and continually updated to reflect the ongoing analysis (Appendix M). The identification and validation of the developing themes were achieved through an iterative data analysis process with frequent discussions with KB, RE, and AR. Deviant cases were considered to ensure that minority views were not overlooked (Seale, 1997). An audit trail (Appendix N) and reflective log (Appendix O) were completed to maintain rigor during the analysis. Constant comparison (a technique in which each interpretation and finding is compared with existing findings as it develops from data analysis (Lewis-Beck, Bryman, & Futing Liao, 2012) was used to examine potential similarities or differences in the reported experiences of different types of supporters (Glaser & Strauss, 1967).

## **5.4 Results**

### **5.4.1 Participant characteristics**

A total of 108 supporters were invited to participate in the interview, of whom 56 (51.9%) did not reply to invitations, 21 (19.4%) could not be interviewed as they had not undertaken any support sessions, 2 (1.9%) did not have the time to take part in an interview, and 1 (0.9%) could not

accurately recall supporting cancer survivors. The final sample included 28 HCPs comprising 16 (57%) practice nurses, 6 (21%) clinical research nurses, and 6 practice-based health care assistants (21%) who provided support for cancer survivors at 45 GP practices in total. Almost all participants were female (27/28, 96%).

## 5.4.2 Themes

### 5.4.2.1 Overview

A total of 4 themes were developed that provided insights into supporters' experiences of providing support along with digital interventions and factors that hindered or enabled them to support cancer survivors as intended. The themes were (1) Renewed as an acceptable digital tool with some improvements, (2) confidence in enacting the supporter role, (3) practicalities of delivering support alongside a digital intervention, and (4) managing a patient-led approach. Each theme is outlined in the following sections, including representative quotes to illustrate key points. Participants are referred to by their identification number, role, and the number of cancer survivors they supported.

### 5.4.2.2 Renewed as an acceptable digital tool with some improvements

Overall, supporters perceived Renewed as consistent with current practice, with the increasing use of web-based interventions. They could see how a digital tool such as Renewed would be useful for cancer survivors, especially as it allowed cancer survivors to work through rehabilitation at their own pace:

“They’re [GPs] signposting patients to online resources all the time more and more at the moment...So this [Renewed] is a similar thing. So I could see that it would be beneficial and would fit in.” (*Participant 10, practice nurse, 2 cancer survivors*)

Email support was also generally acceptable to supporters. However, a few worried that cancer survivors were not receiving emails from the supporter website; hence, they preferred to use their own email to contact cancer survivors.

A minority of supporters reported that their cancer survivors described the content of the information on the Renewed website as generic, not personal, and failing to provide anything new. These cancer survivors chose not to be part of the program:

“He felt that the website was very generic and wasn’t personal to him. He was like, “I already know all of that.” he felt that it couldn’t offer him any support at all...I couldn’t then offer him any support with anything because he didn’t want it. He said, “If you

could give me advice on specific areas,” which obviously we couldn’t do.” (*Participant 23, practice nurse, 1 cancer survivor*)

Approximately 7% (2/28) of supporters raised concerns over the timing of providing Renewed. They suggested that it was important for Renewed to be introduced to cancer survivors when they first finish treatment and support from the hospital ends. At that point, they felt that Renewed could better support them and be more of a teachable moment before cancer survivors form their own habits for managing side effects or returning to old ones:

“What would be brilliant, would be to get it in...very soon after they’ve finished their final treatment...because that’s when they’re perhaps the most vulnerable...giving them a tool where they can work out what’s gonna benefit them in their life at that point. I think two, three years down the line, however they’ve got there, they’ve got there on their own without that [Renewed] kind of support.” (*Participant 15, practice nurse, 4 cancer survivors*)

#### **5.4.2.3 Confidence in enacting the supporter role**

Supporters received web-based training at the start of the study on how to provide support alongside digital interventions ([Table 2](#)). This explained how to use the CARE approach to support cancer survivors’ engagement with Renewed and emphasised that the supporter did not need to be an expert in cancer. Most supporters reported that the length of training was adequate and provided clarity on what was needed for the role:

“It was thorough, it explained everything really well I wasn’t left with any questions. It was clear and easy to follow”. (*Participant 13, clinical research nurse, 1 cancer survivor*)

Some supporters possessed prior experience in cancer care and expressed confidence in their role supporting Renewed. Although not previously experienced in this area, others still expressed confidence but reported that this had grown as they gained experience in delivering the intervention. Although there appeared to be little substantive differences in the experiences of HCPs who supported multiple cancer survivors compared with 1 cancer survivor, the associated greater frequency of delivering support appeared to allow HCPs more opportunities to build confidence:

“The more you do the calls, or the email correspondence...the much easier I feel it’s become.” (*Participant 1, clinical research nurse, 3 cancer survivors*)

On the other hand, deviant case analysis highlighted that 33% (2/6) of health care assistants were the only supporters to report an initial lack of confidence based on pre-held perceptions that they were unqualified for the supporter role. The first (participant 5, 2 cancer survivors) reported that



the training did not prepare her for the role, expressing a lack of understanding of how to provide support and wanting to receive practical demonstrations of someone providing support. The second doubted her suitability for the role, initially being concerned that she was not an expert in cancer. However, these perceptions changed, and their confidence appeared to grow when actually delivering sessions, demonstrating that their initial concerns were perhaps unwarranted:

“I felt like a bit of a fraud at the beginning, thinking am I really qualified to do this, I feel like the patient’s phoning me up thinking I’m some sort of expert, but it wasn’t like that at all.” *(Participant 17, health care assistant, 2 cancer survivors)*

Differences in where the supporters were based (either practice based or remote in the case of clinical research nurses) appeared important to their experiences in supporting cancer survivors. In particular, a few clinical research nurses felt disadvantaged based on the assumption that practice staff were probably more familiar with cancer survivors. They felt that this would facilitate rapport with cancer survivors and improve the quality of the support sessions:

“It [Supporter role] would need to be somebody from the practice actually doing it who has access to their medical notes...just so that you’re aware when you’re listening to them, so you know what they’re going through rather than being completely blind.” *(Participant 8, clinical research nurse, 3 cancer survivors)*

#### **5.4.2.4 Practicalities of delivering support alongside a digital intervention**

Reflected in this theme is an exploration of the logistical problems supporters faced while delivering support to cancer survivors using Renewed.

Most of the current sample expressed difficulty in conducting sessions in the recommended 10 minutes, often reporting sessions of approximately 15 minutes. Sessions lasted >10 minutes for various reported reasons, including allowing time for introductions, the perception that cancer survivors felt lonely and were longing for someone to talk to, and not wanting the cancer survivor to feel rushed. In particular, the primary care staff expressed guilt about potentially rushing cancer survivors, considering that they had made an effort to come in for sessions. A clinical research nurse expressed difficulty in managing the 10-minute sessions as she was not used to working within this time limit:

“I’d given myself longer than what was suggested because I knew from experience that if somebody is opening up to you about how they’re feeling the worst possible thing that you can do is run out of time and have to end it.” *(Participant 24, practice nurse, 2 cancer survivors)*

A few supporters expressed a preference for lengthening sessions, particularly the first, to allow more time to get to know the cancer survivors and address any initial concerns. Relatedly, some clinical research nurses reported finding it challenging to build rapport with cancer survivors during the brief support sessions:

“The appointment seemed very short. Especially on your initial one. I think your initial appointment should be twenty. So you can get to know the patient a bit before you bang straight into the CARE approach. Otherwise there’s no real time to even introduce myself, introduce themselves.” (*Participant 23, practice nurse, 1 cancer survivor*)

HCPs viewed both face-to-face and telephone support as acceptable but with different benefits. Face-to-face sessions allowed them to read the patients’ body language, whereas phone support was better for cancer survivors who may have difficulty in coming into a GP surgery because of travel disruptions, weather conditions, and location. In addition, phone sessions provided greater flexibility to supporters as it was easier to slot into their schedules:

“That [phone sessions] works really well for me because it means that I can support patients when I’m not in the office...that’s given me a greater flexibility with the patients.” (*Participant 2, clinical research nurse, 5 cancer survivors*)

Furthermore, phone sessions reportedly helped some supporters manage the length of sessions by preventing them from performing health care checks unrelated to Renewed. Supporters also expressed less *guilt* of having cancer survivors make the journey into practice.

#### **5.4.2.5 Managing a patient-led approach**

Reflected in this theme were supporters’ perceptions and experiences of using a patient-led approach and what they saw as helpful and found difficult. In this context, a patient-led approach refers to one in which an autonomy-supportive relationship was facilitated using CARE to support the digital intervention rather than giving advice, which was instead provided through the digital intervention. Most supporters reported that they liked the CARE approach and believed that it provided a useful prompt and session guide:

“I liked that idea [CARE approach]. I thought that was really well planned and it’s easy to remember...a good thing to just prompt you.” (*Participant 26, practice nurse, 1 cancer survivor*)

During sessions, cancer survivors would often discuss their behaviour change goals and progress. Supporters expressed that it was initially a challenge not to give direct advice to cancer survivors during sessions. However, this reportedly became easier as they delivered more appointments.

One of the supporters expressed that it was nice to see cancer survivors who were actively interested in improving their health:

“It was refreshing to see them wanting to make life changes themselves rather than making lifestyle changes because they’d been advised to by a clinician.” (*Participant 24, practice nurse, 2 cancer survivors*)

In addition, some supporters expressed that not giving direct advice was a positive change and welcomed cancer survivors being more involved in their care:

“It’s all about them giving us the answers as opposed to the other way round, which I’m all for. I think that’s better.” (*Participant 23, practice nurse, 1 cancer survivor*)

A few supporters’ experiences portrayed a lack of understanding of the CARE approach and how to implement it, which caused some difficulty in delivering support alongside the digital intervention. For example, one of the supporters found it challenging to implement this approach when the cancer survivors went off on a tangent. She believed that this was because she viewed the CARE approach as a *script* to be followed strictly in a specific order, which made the conversation rigid:

“I think that’s why sometimes I didn’t manage to get the CARE aspects in the way I’d like because sometimes you would start at one element of it, and you think, “Okay, I must make sure I go back to the C element or the A element...” And then I’d be like, “Well, how do I sort of interject that in now? Now we’re kind of talking about something slightly different.” I wanted it to more fluid.” (*Participant 12, clinical research nurse, 1 cancer survivor*)

This supporter viewing CARE as a script may reflect a more traditional understanding of HCP–patient relationships in which HCPs provide systematic education and instruction. However, CARE encourages an approach that prompts supporters to help patients decide what works best for them, perhaps indicating the supporter’s misunderstanding or lack of familiarity with the CARE approach.

Relatedly, a practice nurse doubted the CARE approach as she perceived that cancer survivors wanted direct advice from her rather than just the website. Consequently, she felt quite limited in her supporter role.

Approximately 7% (2/28) of supporters highlighted that they would have liked to be able to review cancer survivors’ Renewed activity so that they could be aware of what cancer survivors were referring to during appointments:

“They would talk to me and I’m not completely sure I knew everything that they were covering [Renewed activity]...So that’s something that I found difficult because they would talk away as if I knew what they were talking about.” (*Participant 8, clinical research nurse, 3 cancer survivors*)

Other supporters printed off pages from the Renewed demo and brought them into support sessions to overcome this.

## 5.5 Discussion

### 5.5.1 Principal findings

This process evaluation used qualitative interviews to understand supporters’ experiences of providing support to survivors of cancer alongside a digital intervention in primary care. Exploring supporters’ experiences enabled the identification of possible factors that hindered or enabled support being delivered as intended alongside a digital intervention, highlighting lessons for future intervention development and implementation. Overall, supporters felt that they were able to follow the protocol and deliver support as needed; however, several issues were identified that might hamper implementation, and some minor alterations to Renewed would likely be required to ensure that the intervention is optimised for successful implementation in practice. Considering implementation theory in process evaluations can provide a framework for evaluating and explaining the success of implementation (Ross et al., 2018). Therefore, the findings will be discussed in relation to the NPT (C. May & Finch, 2009), an implementation theory that explains the processes through which new practices of thinking, enacting, and organising work are operationalised in health care (Huddleston et al., 2020). An outline of the NPT is provided in [Table 3](#).

The aspects of the intervention that supported implementation included the ease of training and the perceived similarity of Renewed to digital tools used in current practice. In relation to NPT, this demonstrates a high degree of *coherence* regarding the value of Renewed, which is needed for an intervention to be successfully implemented well in practice. Positive perceptions of the utility of an intervention have been shown to be key facilitators of implementation (Anrys et al., 2016), and implementation failure occurred when HCPs did not perceive intervention use as a legitimate activity for patients or providers (Kennedy et al., 2014). Previous literature has suggested that HCPs in primary care may not be well placed to provide support to survivors of cancer as they lack the expertise and time necessary to make these changes and desire clearer guidance on how to do so (Khan et al., 2011; Taylor et al., 2020). However, this study found that primary care staff felt that supporting survivors of cancer by using a digital intervention would be appropriate and beneficial. It is possible that this finding differs from previous literature as this is

the first study to explore the views of primary care staff providing support *alongside* a digital intervention. In most cases, this format seemed to overcome concerns about the lack of expertise and time, as the digital intervention provided specific advice, avoiding the need to develop expertise, and vastly reduced the amount of input needed to support survivors of cancer to make behavioural changes. A minority of supporters initially believed that their perceived lack of expertise would affect their ability to support cancer survivors. However, their confidence in this approach improved once they began to support the cancer survivors, suggesting that this was not a significant barrier to implementation.

Previous research on digital interventions for other conditions has shown that primary care staff have reservations about providing phone support, viewing it as less effective than face-to-face support (Smith et al., 2017). The acceptability of phone support seen in this study may reflect the fact that primary care is changing and is increasingly using phone appointments to manage increasing workloads (Baird, Charles, Honeyman, Maguire, & Das, 2016). This may normalise more rapidly in the current climate, as telemedicine is increasingly advocated for use in those with cancer during the COVID-19 pandemic to minimise the number of visits to health care settings and risk of exposure (Al-Shamsi et al., 2020). This increase in acceptability has implications for the implementation of future digital interventions using primary care staff to support digital intervention users, as phone support may provide similar effects and be more cost-effective (Little et al., 2016).

Most supporters successfully engaged with the CARE approach, with some noting that not giving direct advice was a positive change and welcomed cancer survivors being more involved in their care. This provided evidence of both *cognitive participation* and *collective action* and suggested that for most supporters, the CARE approach would likely normalise well in practice. However, a minority experienced difficulty adjusting to providing nondirective support and instead allowing the digital intervention to provide the advice. In terms of NPT, there was an apparent lack of *cognitive participation*, which suggests a potential challenge for successful implementation. In the wider literature, HCPs' difficulty in adjusting to not giving direct advice is a prevalent pattern. Encouraging health care workers to switch from a more traditional paternalistic approach, in which they hold all the knowledge and power and give it to the patient, to an equal relationship using nondirective support often requires intensive training, including reflective practices (Davies, Wood, Bullock, Wallace, & Edwards, 2018; Kulnik, Pöstges, Brimicombe, Hammond, & Jones, 2017). This is an issue that is pertinent to providing human support alongside many digital interventions, where health care workers are often employed to boost engagement but are not expected to be experts or to give advice (Bradbury et al., 2017; Little et al., 2016). It is possible that more intensive training might help the minority who struggle with the CARE approach. Alternatively, it may be that employing staff specifically to provide this support is more feasible

than implementing more intensive training to change the behaviour of health care workers whose daily work usually involves working in a directive way (e.g., giving advice). Such an approach has been adopted successfully in a digital diabetes prevention program in which a commercial company (Changing Health) provides telephone support to NHS patients using digital services (Changing Health, 2012).

Some clinical research nurses perceived that not being based in GP practices was a barrier to delivering support as intended, as they did not have a pre-existing relationship with cancer survivors or access to their medical records and consequently reported finding it challenging to build rapport during 10-minute sessions. NPT would see this as a challenge to *collective action*, which examines the work HCPs have to do to enact a process (May & Finch, 2009). This is an important issue, as the model of using research nurses adopted in this study is similar to that adopted within health care elsewhere, such as when private companies provide telephone support alongside digital interventions to patients in the United Kingdom's NHS (e.g., the NHS digital diabetes prevention program); these workers do not have prior relationships with patients or access to their medical records. It may be that within such a context, a longer (perhaps double) appointment is needed to provide time to build rapport, as rapport building is considered crucial to quality health care support (Baird et al., 2016).

Some supporters suggested that Renewed should be offered to cancer survivors sooner after finishing treatment as this may be when cancer survivors are most vulnerable and motivated for behaviour change. This demonstrates the NPT construct of *reflective monitoring*, whereby supporters' appraisal of Renewed considered the potential disadvantages and suggested how implementation may be improved in the future. In line with supporters' suggestions, previous research found that survivors of cancer described feeling the drive to adopt a healthier lifestyle to feel better and more empowered immediately after finishing treatment, and hence, it may be that this is the optimal *teachable moment* (Corbett, Cheetham, et al., 2018).

In light of the experiences of supporters and the barriers identified, several issues were identified, and potential plans for addressing these issues are presented in Table 9.

Table 9 - Plans for addressing challenges faced by supporters

Challenges faced by supporters	Plans for addressing those challenges
Many supporters were concerned that the 10-minute support sessions were too short.	Giving the option for the first session to be a double appointment should allow the time for initial introductions and addressing concerns.
Some clinical research nurses perceived that not knowing the cancer survivor before the first session was a disadvantage, as they had no existing rapport to build on.	Having the first session be an optional double appointment should allow time to build more rapport before beginning support.
Some HCPs <sup>a</sup> expressed a desire to see cancer survivors' activity on <i>Renewed</i> to enable easier and most salient conversations during sessions.	It may be useful to provide supporters with access to cancer survivors' <i>Renewed</i> activity.
Supporters suggested <i>Renewed</i> should be introduced at the point when cancer survivors are leaving cancer treatment as this is potentially when they are most in need of support.	Future implementation of <i>Renewed</i> may need to concentrate on cancer survivors who have finished treatment more recently instead of up to 10 years after treatment.
A few supporters were reluctant to use the CARE <sup>b</sup> approach as it was different from a traditional health care worker–patient relationship where the HCP is seen as having control and provides advice.	Training could be intensified for the minority who have concerns about not giving advice. This could include reflective practices, which have been shown to help people switch from a directive to nondirective approach (Davies et al., 2018; Kulnik et al., 2017).
A few supporters expressed a misunderstanding of how to use the CARE approach.	Update supporter training to include video demonstrations of how CARE can be delivered.
Some supporters expressed that delivering more support enabled them to build confidence.	Have fewer supporters so that they are able to support a greater number of cancer survivors, which could give them the opportunity to build confidence in delivering support.

<sup>a</sup>HCP: health care professional.

<sup>b</sup>CARE: congratulate, ask, reassure, encourage.

### **5.5.2 Strengths and limitations**

The variation in HCP roles included in the study allowed the nuanced experience of those in different job roles to be explored. This study has several limitations. First, the data could not be analysed iteratively during the interview period. This meant that the themes developed in early interviews could not be explored further in later ones, which can develop meaning and understanding (Srivastava & Hopwood, 2009). Second, most (401/557, 71.9%) logged support sessions in the Renewed RCT were reported as sticking to 10 minutes within support sessions; however, those who consented to the interview gave cancer survivors 15 minutes on average within support sessions. It is difficult to know why this study's sample differs from the overall trial sample in this way and whether it might limit the transferability of results. This difference may be because of the use of paper self-report measures to collect the duration of support sessions within the trial, possibly resulting in a social desirability bias (Grimm, 2010). However, given the opportunity in an interview to discuss this in more detail, HCPs may have been more inclined to mention if they went over 10 minutes and why. Third, we were unable to record consultations with supporters within this study; hence, we could not corroborate supporters' reports on how they implemented the CARE approach. Further research exploring the recorded consultations of supporters using CARE would be useful. Finally, there was a low response rate to the interview invitations. There may be various reasons for such a low response, one of which may be the capacity for HCPs to conduct interviews because of busy schedules. The perceptions and experiences of implementing support alongside Renewed may have differed for those who did not accept an invitation to interview.

### **5.5.3 Conclusions**

Our results suggest that HCPs generally found providing support alongside a digital intervention acceptable and were amenable to contributing to the delivery of support to survivors of cancer in primary care. Key factors that may support the successful implementation of this type of digital intervention in practice include the increasing acceptability of phone support and the utility and acceptability of non-directive support among most HCPs, such as the CARE approach. Challenges to implementing support alongside a digital intervention were also identified, including concerns about not having enough time during support sessions to build rapport and, in a minority, concerns about using a nondirective approach. This study shows that even when support for a digital intervention is designed to be brief, sufficient time needs to be allowed in the initial support sessions to allow practitioners to feel confident that rapport can be built. Further research is needed to explore whether additional training might be enough to support a minority



of health care practitioners who were concerned about giving nondirective support to adopt this approach. If not, then primary care could consider employing other staff, such as social prescribers of health coaches, who work in a less directive way than nurses and health care assistants and who are now becoming increasingly common in the United Kingdom's NHS (Drinkwater, Wildman, & Moffatt, 2019).

There is a clear need for primary care to provide support to survivors of cancer (Adam & Watson, 2018); however, previous research has suggested that lack of time and training on how to support this patient group are key barriers to providing this support (Khan et al., 2011; Taylor et al., 2020). This study showed that providing support alongside a digital intervention might be an acceptable way of overcoming these barriers, as only a small amount of support is required, and there is no need to develop cancer-specific expertise or behaviour change skills. This approach of mixing digital and human support will likely be useful to others in developing and implementing interventions to support other aspects of care for survivors of cancer, which are not targeted within Renewed, such as support for sexual dysfunction, smoking cessation, alcohol consumption, returning to work, and lack of social connection and support.



## **Chapter 6 General Discussion**

### **6.1 Overview of the chapter**

The aim of this thesis was to explore how a digital intervention for cancer survivors (Renewed) works and the barriers to implementation for cancer survivors and healthcare professionals. This chapter therefore first explores, describes and characterises the mechanisms through which Renewed achieves change in QoL and then considers their implications for Renewed's potential to be implemented in practice.

Three research studies were conducted to investigate these aims, reported via three papers. Paper one was a qualitative exploration of cancer survivors' experiences using Renewed. Paper two quantitatively examined how participants used Renewed and the relationships between their usage, personal characteristics, engagement with additional support, and QoL outcomes. Finally, Paper three qualitatively explored healthcare professionals' (HCPs) experiences supporting individuals using Renewed.

The first half of this chapter provides a summary of the key findings of each of these studies and then triangulates them in order to contribute insights relevant to the overarching aims of the chapter described above. The strengths and limitations of this research will be considered. The second half of the chapter then discusses the implications of these findings for implementation and directions for further research.

### **6.1 Summary of study findings**

#### **6.1.1 Paper 1: Experiences of using a supported digital intervention for cancer survivors in primary care: A qualitative process evaluation with cancer survivors**

Paper one (Chapter 3) was a qualitative process study that explored cancer survivors' experiences of using Renewed to understand how the intervention may have improved QoL in cancer survivors and why it provided the greatest benefit to prostate cancer survivors, as found in the Renewed RCT trial. Overall, this paper suggested that cancer survivors found Renewed easy and convenient to use. In relation to how Renewed achieved change in QoL, Paper one suggested that

for a few, minimal usage may have motivated behaviour change and promoted feelings of autonomy to perform behaviour changes. For example, participants who accessed Renewed and a small amount of the optional content reported gaining enough information to implement the recommended behaviours and not feeling a need to revisit the website. In contrast, many others appeared to need to access Renewed more frequently before being able to implement behaviour changes. This paper also provided possible insight into why those with prostate cancer had better outcomes in QoL than those with breast and colon cancers. Prostate cancer survivors spoke less about having social support outside of Renewed than participants with other cancers, who often expressed having adequate support elsewhere and so not needing Renewed as much. This implies that the greater benefit found among prostate cancer survivors in the RCT trial may have been due to this group lacking support elsewhere so perhaps needing the intervention more. This paper also identified barriers to cancer survivors engaging with Renewed including contextual (e.g. COVID-19), individual (e.g. comorbidities, perceived need and perceived relevance) and intervention-related factors (e.g. technical issues).

### **6.1.2 Paper 2: Usage of a healthcare professional-supported digital intervention for cancer survivors in primary care: A quantitative process evaluation**

Paper two (Chapter 4) involved a quantitative usage process evaluation study that examined the processes by which Renewed may have produced its effects. It did this by exploring how usage of the digital intervention and human support, as well as the characteristics of participants, were related to improvements in QoL. This paper demonstrated that most cancer survivors accessed the first part of the intervention (core content), but less than half accessed the optional content. Only a third of the support arm accessed the support sessions available to them. However, those who accessed support accessed Renewed a greater number of times in total. Greater usage of Renewed was related to greater improvements in QoL, but whether or not participants accessed support was not related to greater improvements in QoL. Finally, there were no apparent relationships between individual characteristics (e.g. age, gender, cancer type, time since completing treatment, age at which education was completed) and usage of Renewed.

### **6.1.3 Paper 3: Implementing a healthcare professional-supported digital intervention for cancer survivors in primary care: a qualitative process evaluation of Renewed**

Paper three (Chapter 5) was a qualitative exploration of HCP's experiences of supporting cancer survivors using Renewed. Findings were considered in relation to Normalisation Process Theory (NPT) (May & Finch, 2009) to understand the barriers and facilitators to HCPs providing support

identified by the paper and to help explain the work that may be needed to implement Renewed successfully in this context. Potential barriers to HCPs providing support and implementing Renewed were reported that could be mapped on to NPT constructs. Specifically, HCPs perceived value in Renewed and understood how it may be useful for cancer survivors (NPT construct: coherence). However, a minority experienced challenges adopting a patient-led approach (NPT construct: cognitive participation), like the CARE approach. HCPs' experiences of delivering brief support varied depending on their pre-existing job roles (NPT construct: collective action); for example, Research Nurses expressed challenges to delivering support within the 10-minute guidance. A minority of Healthcare Assistants initially lacked confidence in delivering support without cancer care expertise. HCPs suggested that offering Renewed sooner after cancer survivors finish treatment, when they might be most vulnerable and motivated for behaviour change, may improve the implementation of Renewed (NPT construct: reflective action).

Overall, the majority of HCPs found a non-directive approach to supporting cancer survivors, like the CARE approach, acceptable and feasible to implement, with a few HCPs desiring extra support. A minority of HCPs were less receptive to this approach because they believed cancer survivors would want direct advice and felt limited in providing non-directive support, often due to misunderstanding the CARE approach and how to deliver it.

## **6.2 Triangulation of key findings**

A triangulation protocol based on the methods proposed by Farmer et al., (2006) was applied to interpret and integrate key findings from the three studies and the Renewed RCT in order to identify the key processes involved in engaging with Renewed and QoL outcomes, as well potential processes for implementing Renewed everyday practice. Key findings across the three studies were coded according to their agreement with the other studies' findings using a convergence coding scheme as follows: 1) Agreement - finding has been identified in other studies; 2) Complementary (Partial agreement) – some, but not all aspects of the finding resonate with other studies; 3) Silence - finding does not appear in other studies; 4) Dissonance - finding is contradicted by other studies (Farmer et al., 2006). Table 10 shows the results of the triangulation process. These will be discussed in relation to the thesis aims and the wider literature in [Section 6.4](#).

Table 10 - Triangulation of key findings across studies and results of the Renewed RCT

Key findings	Related thesis aim*	Qualitative study with cancer survivors finding (Paper one)	Quantitative usage analysis finding (Paper two)	Qualitative study with healthcare professionals finding (Paper three)	Renewed RCT findings	Triangulation outcome
Using Renewed more may support greater improvements in quality of life	1	Silence	Greater use of Renewed was related to greater QoL at 12 months.	Silence	Those in Renewed and Renewed plus support arms had improved outcomes in QoL.	Agreement
Cancer survivors who did not perceive 'added value' of Renewed may not have been motivated to engage	1	Cancer survivors were less motivated to engage with Renewed if they already lived a healthy lifestyle, had existing support with the recommended behaviours outside of Renewed, or did not find the content on Renewed to be novel or address their needs.	Silence	Expressed that it was difficult to support cancer survivors who did not see Renewed as useful	Silence	Complementary (Partial agreement)
For some, moderate usage may be enough to motivate perceived behaviour change	1	A few of those who reported moderate use of Renewed expressed that they were able to take that information to implement behaviour changes.	Majority (86%) used the core content but less than half (45%) accessed the optional content.	Silence	Silence	Complementary (Partial agreement)
Those who lacked social support outside of Renewed may have received the most benefit most from the intervention	1	Prostate cancer survivors expressed lack of support outside of Renewed compared to breast and colon cancer survivors who often reported	Cancer type did not moderate usage of Renewed.	Silence	Prostate cancer survivors had greatest outcomes in QoL compared to breast and colon cancer survivors.	Complementary (Partial agreement)

		many other sources of external support.				
Accessing support may not necessarily improve outcomes in quality of life.	1	Silence	Choosing to access the additional human support available to those in the support arm was not related to better QoL.	Silence	Those in Renewed plus support arm had the best outcomes in QoL.	Dissonance
The majority of users chose not to access, or discontinued use of support.	2	<p>While the majority of participants expressed perceived value of the option of supporter sessions, many reported not accessing support. Reasons for not accessing support included having existing support outside of Renewed and lack of perceived need for support in this context.</p> <p>The majority of those who accessed support reported not completing all three support sessions. Reasons for not taking up support sessions included dissatisfaction with support offered (e.g. did not provide</p>	<p>Majority (69%) did not access support session.</p> <p>The median number of sessions was one.</p>	Silence	Silence	Complementary (Partial agreement)

		advice for personal needs unrelated to Renewed).				
The CARE approach was acceptable, feasible and appeared to support engagement	2	Some of those who accessed support expressed that the supporter motivated them to make behaviour changes and offered tailored advice on how to perform the recommended behaviour changes.	Those who accessed support used Renewed more.	Majority of HCPs liked the CARE approach and believed that it offered a new perspective and enabled cancer survivors to be more involved.	Silence	Complimentary (Partial agreement)
Implementing Renewed sooner after treatment may be more acceptable	2	A minority of cancer survivors reported that Renewed was offered too late after finishing treatment and was not useful for them, as they have already adjusted to life after cancer treatment.	There was no difference in usage of Renewed in relation to years since finishing treatment.	A few HCPs suggested that offering Renewed soon after finishing treatment may be more beneficial as this may be when cancer survivors are most vulnerable and motivated for behaviour change.	Silence	Complimentary (Partial agreement)

\*Thesis aims were to: 1) Explore, describe and characterise the mechanisms through which Renewed achieves change in quality of life in cancer survivors, and 2) Explore, describe and characterise Renewed's potential to implement in to practice.



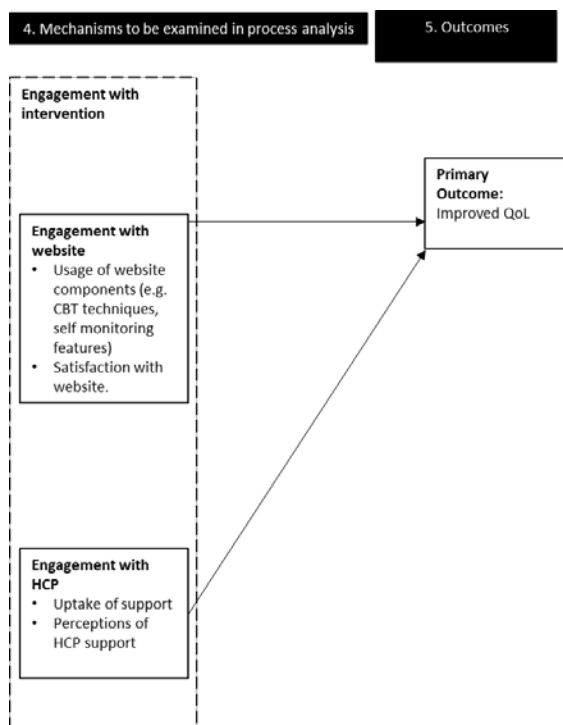
### 6.3 Contribution of findings to addressing aims

Returning to the overarching aims of the thesis, the contribution of triangulated findings to understanding Renewed and its implementation are discussed below.

#### 6.3.1 Aim 1: Explore, describe and characterise the mechanisms through which Renewed achieves change in quality of life in cancer survivors

Findings from all studies (Chapters 3 to 5) contribute important insights that address the first aim and enable investigation of the intervention’s proposed theory of change outlined in the logic model. The mechanisms investigated proposed to contribute to intervention outcomes are summarised in Figure 4.

Figure 4 - The mechanisms of Renewed investigated in the thesis



The findings pertaining to this aim and summarised in the triangulation table (Table 10) above are discussed below.

### **6.3.1.1 Key finding 1: Using Renewed more may support greater improvements in quality of life**

The findings from Paper two support the logic model's hypothesis that greater engagement with Renewed is associated with greater improvements in QoL. The paper found that accessing Renewed a greater number of times was correlated with greater improvements in QoL. This finding suggests that the improvements in QoL found in the RCT were due to cancer survivors using Renewed. Considering this finding in combination with the fact that most users (55%) did not access the optional content, this suggests that motivating greater use of Renewed's may be important for further improving QoL.

This is in line with systematic review evidence and previous studies, which suggest that greater usage of digital interventions is related to better health outcomes (Smith & Lui 2022; Enrique et al., 2019; Mattila et al., 2016). For example, a systematic review investigating the dose-response relationship between usage and outcomes of online physical activity weight-loss interventions found that an increase in digital intervention usage (e.g. total logins, login in frequency, login in duration) were related to greater improvements in physical activity and weight loss outcomes (Smith & Lui, 2020).

However, there is a lack of research on the relationship between usage and outcomes of digital interventions for cancer survivors. Instead, research has focused on identifying factors that influence usage of these interventions (Crafoord et al., 2020; Ruland et al., 2013; van der Hout 2021). Therefore, this thesis contributes novel findings on the overall usage of digital interventions in this context and how this may relate to QoL outcomes associated with digital interventions and suggests that greater usage is related to better outcomes.

Furthermore, Paper one suggested that cancer survivors were less likely to engage with Renewed if they reported availability of support outside of Renewed, perceived lack of novel insights gained from Renewed content, currently lived a healthy lifestyle, or had comorbidities. The interviews with HCPs added to this insight by suggesting that those who did not perceive the Renewed content as relevant to them, were not as receptive to support from HCPs during support sessions. Research has shown that perceived personal relevance is important to cancer survivors' engagement with digital interventions (Kanera et al., 2016). Further strategies could be developed to motivate greater usage of Renewed. As a way of motivating greater usage of Renewed, providing novel content earlier in the intervention may improve continued motivation to engage (Kelders & van Germert-Pijnen, 2013). Additionally, those who lacked support, most commonly

prostate cancer survivors, were more expressive of why an intervention like Renewed was beneficial for them and thus may have felt it was more relevant to their needs.

### **6.3.1.2 Key finding 2: Minimal usage may be enough to motivate perceived behaviour change**

Whilst Paper two demonstrated that greater improvements in QoL were achieved with higher usage of Renewed, Paper one suggests that some cancer survivors who used it only a little still reported behaviour changes. It may be that cancer survivors received enough information from minimally accessing the optional content to begin making perceived behaviour changes, and therefore future engagement became redundant (Schneider et al., 2016). Relatedly, studies have shown that the relationship between usage and outcomes is complex. Different types of usage can be related to outcomes in various ways. For example, an RCT investigating the relationship between usage and outcomes for an online intervention for depression found that while the total number of logins was not related to better outcomes in depression, the number of completed modules was significantly related to better outcomes (Donkin et al., 2013). This suggests that better outcomes are not always necessarily a result of 'how much' usage and should consider the nature of that usage. Research into a smoking cessation intervention indicates that although some individuals may use an intervention more, this does not always mean they have significantly better outcomes than those who use it less (e.g. Paz Castro et al., 2017). Providing insight into possible reasons why cancer survivors disengaged with Renewed, the qualitative data in Paper one revealed that usage of Renewed may have promoted autonomous motivation to engage with perceived behaviour change. The intervention incorporated many features (e.g. goal setting, health information, the CARE approach) underpinned by self-determination theory (Deci & Ryan, 2012) with the aim of promoting autonomous motivation. It may be that through using Renewed, participants felt more autonomy to engage in a behaviour over time as their motives for doing so became more internalised. It may be that those who used the intervention more needed more support and guidance, whereas those who used the intervention less may have obtained the same benefit with less use. Quantitatively exploring whether enablement was related to usage or outcomes would have added greater understanding to cancer survivors' experiences of using Renewed and whether perceived they were more able to perform behaviour changes. Although enablement is not a direct measure of taking on new behaviours, such insights might have provided a complementary understanding of whether cancer survivors felt more able to perform behaviour changes after using Renewed. However, due to the wide ranging content within the Renewed intervention and wide variety of possible research questions, the analysis of Paper two

had to focus on the most important and salient aspects of these data, the RCT findings and the Renewed logic model predominantly determined this. Enablement was not a hypothesised mediator between usage and outcomes in QoL in the intervention logic model and so was not considered in analysis.

### **6.3.1.3 Key finding 3: Those who lacked social support outside of Renewed may have received the most benefit from the intervention.**

Given the RCT finding that prostate cancer survivors had better QoL outcomes than breast or colon cancer survivors, an aim of the research was to try to understand why this may be the case. Paper two showed that cancer type (prostate, breast or colon) did not related to usage of Renewed, so the effect in QoL does not appear to be due to prostate cancer survivors using Renewed more than those with other cancers. Rather, the qualitative data in Paper one suggests that prostate cancer survivors more frequently reported a lack of support outside of Renewed than those with other cancers. As a result, prostate cancer survivors may have needed to rely on the intervention more for that support and therefore experienced more benefit from the same amount of use. Existing research suggests that social support is an important moderator of engagement and self-management among cancer survivors (Howard-Jones et al., 2022). The success of web-based interventions is influenced by the extent to which intervention users garner social support for making changes (Anderson-Bill et al., 2011). Individuals who lack social support outside of the intervention may have received the greatest boost in perceived social support and therefore engaged with behaviour change more. For example, findings from Paper 1 suggest that some cancer survivors were able to seek advice from HCPs for issues which they previously had no access to supportive resources, or they reported feeling that they were being looked after, when they had previously felt unsupported by those in their social networks. These factors may have motivated greater engagement in perceived behaviour changes. This finding has implications for the design of digital interventions as it suggests greater effects may be achieved through tailoring interventions so that the option of additional support is targeted towards those who lack social support outside of the intervention. Furthermore, this finding adds understanding of how digital intervention experiences and needs may vary among different cancer groups (Van der Hout et al., 2020) and suggests that prostate cancer survivors may be particularly in need of access to support, and possibly have different experiences and outcomes when using digital interventions compared to breast and colon cancer survivors. More research is needed to qualitatively explore the needs across different cancer types and how these may vary and possibly shape their experiences and outcomes with digital interventions. This could inform the design of more effective and engaging digital interventions for these populations.

#### **6.3.1.4 Key finding 4: Accessing support may not necessarily improve outcomes in quality of life**

Paper two found that whilst accessing support was related to greater usage of Renewed, it was not related to improved outcomes in QoL. This appears to be contrary to the logic model's hypothesis that engaging with support would be related to better outcomes in QoL, and contrary to the RCT findings, which demonstrated that those in the support arm had greatest outcomes in QoL. However, while actually choosing to access support was not related to outcomes, it may have been that simply providing access to support led to increased perceived social support amongst this group - an important factor for improving QoL (Culbertson et al., 2020). On the other hand, it's also possible that accessing support may have led to greater engagement and adherence to perceived behaviour changes without having had an impact on QoL outcomes (Renfrew et al., 2020; Renfrew et al., 2021). This finding contributes understanding to the literature about support alongside digital interventions for cancer survivors and suggests that accessing support does not always directly improve outcomes. The findings from this thesis are unable to fully explain why accessing support was associated with greater usage, that greater usage was associated with greater QoL, but that accessing support was not associated with greater QoL. It is possible that accessing support promoted supportive accountability, which may have led those who accessed support to feel more motivated to use the intervention. However, supportive accountability does not necessarily lead to better outcomes (e.g. Mohr et al., 2012). For example, if an individual who is primarily extrinsically motivated accesses support and subsequently accesses Renewed more frequently or engages in behaviour changes due to external rewards (such as praise from the support provider). In that case, this may not necessarily lead to long-term behaviour change, particularly if the support sessions only last for a short period of time (e.g. three sessions). In contrast, if an individual is intrinsically motivated to change their behaviour, they may be more likely to continue engaging in behaviour change regardless of the supportive accountability provided during the support sessions. These findings have implications for considering whether providing support alongside digital interventions for cancer survivors is beneficial. Greater understanding is needed of how best to offer support alongside digital intervention for cancer survivors and a greater exploration of the effect support has on cancer survivors' experiences and outcomes in digital interventions. Future research could explore ways to best implement support by examining how varying types of support (e.g. the number of sessions, mode of communication) relate to usage, perceived behaviour change and outcomes in cancer survivors. In doing so, it may be possible to tailor interventions to optimise support to

boost outcomes and improve satisfaction among cancer survivors. Furthermore, exploring engagement with various behaviour changes (e.g. physical activity) more directly will allow a greater understanding of the relationship between support and perceived behaviour change and the relationship between perceived behaviour change and outcomes. This is important for gaining a deeper understanding of the role and impact of support alongside digital interventions for this population.

#### **6.3.1.5 Summary of findings that contributed to aim 1**

Findings were used to explore, describe and characterise some of the mechanisms through which Renewed achieves change in QoL in cancer survivors. Findings suggest that use of Renewed may support improvements in QoL. Accessing support was related to increase use of Renewed. However, the relationship between usage and outcomes within Renewed was complex and may depend on the nature of the usage, rather than just the amount as minimal usage may also be enough to motivate perceived behaviour change as such usage may promote autonomous motivation to engage with perceived behaviour change. Those who perceive a lack of support outside of the intervention may particularly benefit from access to Renewed.

Overall, the findings largely supported the theory of change for the Renewed intervention ([Figure 1](#)). However, the findings in this thesis suggest some aspects of the logic that did not work as theorised. In the logic model, it was hypothesised that the uptake of support would be related to improvements in QoL. However, this thesis did not find evidence for this direct relationship. Rather, results showed that accessing support did not relate to improvements in QoL, but related to higher usage of Renewed. The current logic model did not account for any relationship between support and usage of Renewed. Furthermore, qualitative findings with cancer survivors (Chapter 3) suggest that the option of support may relate to improvements in QoL among those who lacked support outside of the intervention. The current intervention logic model does not theorise the potential role of perceived social support. This suggests that there may be a need to revise the depiction of mechanisms to better reflect the potential relationship between support and usage of Renewed and the potential relationships between perceived social support and QoL. However, further quantitative research is needed to explore the relationship between perceived social support, usage of Renewed and outcomes in QoL before specific revisions to the logic model can be finalised. Suggested revisions to the logic model are presented in Figure 5.

Figure 5 - Suggested revisions to Renewed's logic model

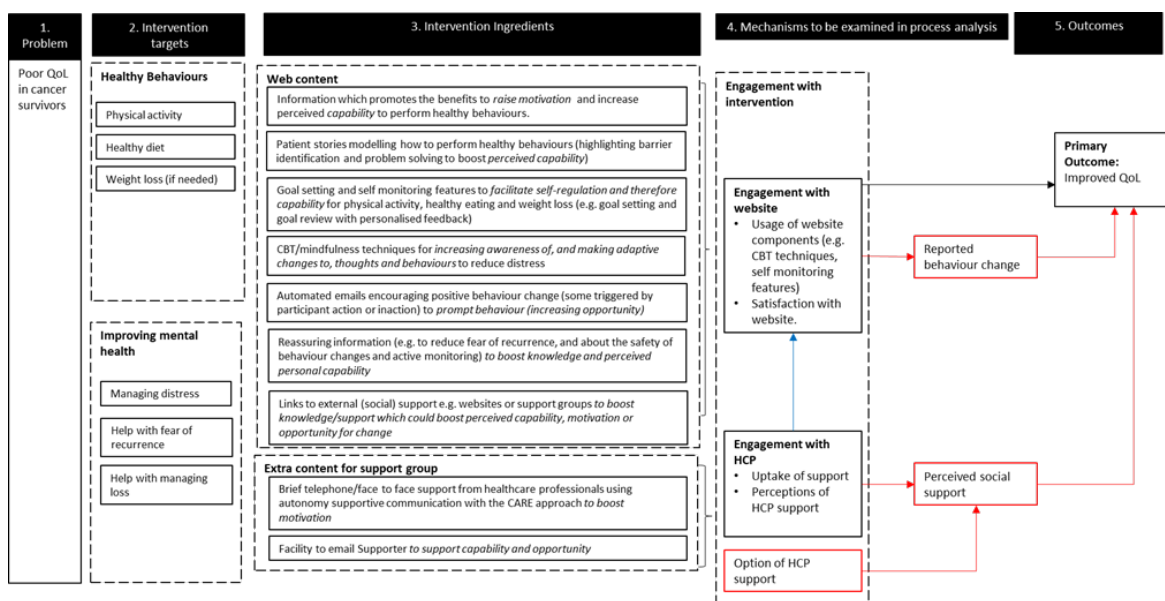


Figure 5 presents suggested changes to the logic model based on findings from this thesis. Changes suggested by the quantitative work are indicated in blue lining, while changes suggested by the qualitative work are indicated in red lining. Specifically, the quantitative data in Paper 2 found that accessing support was related to greater use of Renewed. The other additions of 'option of HCP support', 'perceived social support' and 'reported behaviour changes' are largely drawn from the findings from the qualitative studies, so are somewhat speculative and would need further quantitative investigation of these relationships before permanent changes to the logic model can be applied. One of these suggested revisions is a possible relationship between usage of Renewed and engagement in behaviour changes reported by the participants. The findings suggest that using Renewed may motivate engagement with recommended behaviour changes, thus improving QoL. Future work that measured engagement and adherence to specific behaviours could explore this finding quantitatively to determine whether this supported the qualitative findings. This suggested future research is discussed more fully in [Section 6.6](#). Another suggested change is the addition of the option of support and perceived social support. Qualitative findings in Chapter 3 suggested that those who lacked support outside of the intervention might have greater benefits from using Renewed. Therefore the revised logic model suggests that improvements in perceptions of one's social support, either from accessing support or simply knowing they have the option to access support, may be a mechanism through which improvements in QoL occur.

### **6.3.2 Aim 2: To explore, describe and characterise Renewed’s potential to implement in to practice**

Findings from all studies contributed important understandings that addressed the second aim of and will be discussed further in this section.

#### **6.3.2.1 Key finding 5: The majority of users chose not to access, or to discontinue use of, support**

Although in Paper one many participants expressed perceived value in the support offered, Paper two found that the majority did not use it, or discontinued support sessions before using the full number available to them. This raises questions regarding the extent to which additional human support is wanted or needed. One possible reason cancer survivors did not take up support at all despite acknowledging its potential value may have been that the support was a ‘pulled’ model of support rather than ‘pushed’ model. ‘Pulled’ support refers to a model in which action is required from the patient to initiate support, whereas ‘pushed’ support refers to actions from the Supporter to initiate support (Schueller, 2017). Relying on pulled support alone alongside digital interventions may be problematic in this specific context because research suggests that there is a lack of support-seeking behaviour among post-treatment cancer survivors in primary care. Research suggests that reasons for this may include: cancer survivors often do not see a role for primary care staff in their care (Hudson et al., 2012), believe that primary care staff are not skilled or possess expertise in their care (Taylor et al. 2020), or because they take discharge as an indication that they are clear of cancer and not in need of follow up support (Taylor et al 2020; Khan et al 2011). If the responsibility is on cancer survivors to reach out for support they may underutilise this and miss out on active elements contained in digital interventions. This is particularly relevant considering that Paper two suggested that accessing support was related to more usage of Renewed. Under-utilising support could have implications for how a digital intervention like Renewed is experienced. To increase the uptake of support alongside digital interventions for cancer survivors, a pushed or mixed (pushed and pulled) model of support may be beneficial.

#### **6.3.2.2 Key finding 6: The CARE approach was acceptable among healthcare professionals**

Qualitative data from HCPs in Paper three suggested that while the majority of HCPs found the CARE approach acceptable, a few had misunderstandings and were hesitant about delivering a non-directive approach like CARE and desired additional support to implement it. This is mirrored in the wider literature where the majority of HCPs outside of cancer care express uncertainty with



regard to delivering non-directive support (Davies et al., 2018; Kulnik et al., 2017; Mudge et al., 2015). This thesis adds understanding to this wider literature in this regard because it suggests the majority actually are receptive to non-directive support, but a minority may have uncertainties due to misconceptions of what non-directive support involves as well as facing challenges in switching from a traditional patient and provider relationship. More research is needed to explore strategies to help HCPs overcome misconceptions about non-directive support to further uptake and improve implementation efforts for digital interventions among cancer survivors. For example, it was suggested in Paper three that opportunities for optional reflective practice where HCPs are able to challenge their assumptions and highlight successful examples of self-management may be helpful in overcoming misconceptions (Mudge et al., 2015; Kulnik et al., 2017). It may be that such practices increase self-efficacy to deliver this type of support by enhancing a sense of mastery by recalling past successful experiences (Bandura, 1994), and therefore motivate HCPs to continue doing it (Davies et al., 2018). Alternatively, it may be helpful to employ other staff, such as social prescribers or health coaches, who often work in a less directive way than nurses.

#### **6.3.2.3 Key finding 7: Implementing Renewed sooner after treatment may be more acceptable**

Data from both Papers one and two suggested that implementing Renewed sooner after cancer survivors finish treatment might provide greater benefit. A few cancer survivors reported that it had been a while since they finished treatment, so did not find Renewed useful as they had been able to adjust to life after treatment and implement changes since then. Similarly, a few HCPs expressed that cancer survivors may be most vulnerable and motivated for behaviour change sooner after finishing treatment. However, usage data from Paper two did not find a relationship between time since completing treatment and usage of the intervention. This suggests that while a minority may not be motivated to engage due to a perception the intervention is no longer relevant or as helpful, such interventions are used similarly across the years after treatment. There is inconclusive research regarding whether cancer survivors who engage with a digital intervention, have greater engagement in behaviour change or outcomes in QoL more than those who finished treatment sooner rather than later (Ryan et al., 2018; Tollosa et al., 2019).

#### **6.3.2.4 Summary of findings contributing to aim 2**

The thesis has explored, described and characterised Renewed's potential to implement in to practice. The findings suggest that Renewed has the potential to be implemented successfully into practice with minor changes. In particular, a "pulled" model of support (where patients initiate support) may not be effective in this context, rather a "pushed" model of support (where the HCPs initiate support) may be more beneficial. While the CARE approach was generally acceptable, upon implementation on a wider scale, there may some misconceptions or challenges among a minority of HCPs to implementing this kind of approach. Therefore, identifying effective strategies to overcome these misconceptions is crucial. Finally, while usage of Renewed did not differ based on the amount of years since cancer survivors finished treatment, both cancer survivors and HCPs suggested that implementing Renewed sooner after treatment may be more beneficial. As evidence of the varying effects of years since treatment on outcomes and engagement are inconclusive, more work needs to be done to increase the perceived relevance of an intervention like Renewed for cancer survivors across different years post-treatment to potentially increase uptake among cancer survivors and HCPs.

### **6.4 Implications for intervention development, theory and practice**

#### **6.4.1 Cancer survivorship care in primary care**

These findings provide important understanding about how to best support cancer survivors' QoL in primary care. Previous research has highlighted barriers to healthcare professionals in primary care being able to successfully support cancer survivors, such as lack of time and expertise. However, this thesis' findings suggest that an acceptable way of overcoming these barriers is to provide the majority of support through a digital intervention, with staff providing additional brief support to maximise engagement. The findings demonstrate that most healthcare professionals may be able to support cancer survivors with a non-directive approach like CARE successfully. However, a small minority of HCPs may need extra support to implement this.

#### **6.4.2 Understanding cancer survivors' engagement**

As outlined in Chapter 1, the primary mechanism of interest was engagement with Renewed and support sessions. A distinction was made between maximum engagement and effective engagement, arguing that promoting effective engagement may ultimately be more important for outcomes than maximum engagement. Participants' accounts of their experiences using Renewed

provide support for the strategy of promoting effective engagement rather than maximum engagement. This thesis also demonstrates that it is important to use both qualitative and quantitative methods to explore effective engagement with digital interventions.

Cancer survivors appeared to gain improvements in QoL from accessing the intervention, but continued to gain greater improvements from increased usage. This has implications for the design and implementation of interventions like Renewed as it suggests that having core and optional content is acceptable among cancer survivors in primary care as it allows individuals the flexibility to engage in as much as suits their needs. Renewed may be able to provide cost-effective support to a large number of cancer survivors with less need for resource intensive and tailored support. Cancer survivors with more complex needs may benefit from having the option to access additional, more specialised supportive information.

#### **6.4.3 Support alongside digital interventions for cancer survivors**

The findings of this thesis suggest that accessing support may be important to motivate greater engagement, but not a critical factor in improving QoL. Furthermore, the majority of users did not access support. It appeared that support alongside a digital intervention is a personal preference, with some desiring support, possibly because they lack this outside of the context of the intervention (e.g. prostate cancer survivors), while others choose not to engage with a support offer. Therefore there may need to be more flexibility in the nature of support s offered. For example, allowing participants to select their personal preferences for customising support and other discretionary features (e.g. the number of sessions, mode of communication), may enhance users' experience and allow individuals to tailor the level of support to reflect their needs (Renfrew et al., 2021). While the thesis suggests that both cancer survivors and HCPs are receptive to phone and face-to-face support, participants were not offered a choice over the support mode. Further research could explore whether the option to customise mode of support would lead to greater uptake of support and usage of the intervention.

It may also be important to consider whether it is more effective for support to be pushed rather than pulled amongst cancer survivors. As cancer survivors are less likely to pull support (e.g. Meiklejohn et al., 2016), pushing the support alongside digital interventions for this population may increase the uptake of support sessions once the onus is removed from cancer survivors. However, whether support should be pushed or pulled must be considered in light of whether there is a benefit of accessing support on experiences of outcomes.

Additionally, the findings suggested that a perceived lack of support outside of the intervention appeared to be particularly important to outcomes and experiences of using Renewed. Therefore, it may be beneficial to target the option of support particularly towards those individuals who report a lack of support.

#### **6.4.4 The use of Normalisation Process Theory to aid implementation evaluation**

Paper three drew on NPT to aid understanding of the barriers and facilitators HCPs faced in providing support to cancer survivors using Renewed. It was possible to map some potential barriers and facilitators reported by HCPs onto the four constructs, supporting reviews which suggest NPT is useful in examining implementation (May et al., 2022). While most studies utilising NPT apply it during the phases of data analysis or data collection (Huddleston et al., 2020), Paper three used it following data analysis to aid interpretation of barriers and facilitators to implementation. It has been argued that applying NPT during analysis and data collection may influence the focus of data collected and, ultimately, the findings, meaning that the exploration of themes and topics outside of the scope of NPT constructs are overlooked (Morden et al., 2015). Indeed, Paper three found that HCPs had difficulty delivering support when cancer survivors did not find Renewed relevant to their needs. It has been argued NPT has an overemphasis on the experiences and perceptions of those delivering the intervention and not enough consideration as to who is receiving the intervention (Kennedy et al., 2014; Segrott et al., 2016). The finding in Paper three may have been overlooked if NPT had been applied as a framework during analysis. This has important implications for the application of NPT in this context as it suggests that additional aspects are needed to extend NPT to better understand the experiences of intervention recipients to gain a more holistic examination of the barriers and facilitators to implementation. It has been suggested that using a patient-focused theory, such as PBA (Yardley et al., 2015), alongside NPT can provide a helpful way of addressing this gap in NPT (Huddleston et al., 2020).

### **6.5 Strengths and limitations**

This thesis provided insight into how a digital intervention for cancer survivors worked, for whom, and examined how such an intervention could be implemented in primary care successfully. This understanding is important in order for researchers and intervention developers in this field to identify intervention features and functions that are effective, and learn how to improve those that are not (Moore et al., 2015). In addition, the findings also contribute to the limited literature on how digital interventions for cancer survivors that target multiple behaviours are

experienced and processes that relate to outcomes. Furthermore, it contributes novel understanding about healthcare professionals' views of providing support alongside a digital intervention for cancer survivors and insight into barriers and facilitators of implementing this type of intervention.

A strength of the process evaluation was the mixed methods approach as it facilitated the development of a holistic understanding of engagement and implementation of Renewed in relation to improving cancer survivors' QoL in primary care. Using both quantitative and qualitative approaches has allowed deeper insights into what motivates cancer survivors to engage with the intervention in the ways they do. Using one method alone may have limited insight and understanding. Triangulating quantitative and qualitative data enabled each method's limitations to be counteracted and generate complementary insights.

Whilst the process evaluation has contributed understanding as to how an intervention like Renewed works, and how it may be implemented, several potential limitations should be acknowledged. Firstly, while the qualitative work with cancer survivors (Chapter 3) suggested using Renewed promoted engagement with perceived behaviour change, as there were no measures incorporated into the RCT of the behaviours which the intervention was attempting to change, it was not possible to test this quantitatively. This meant that we could not quantitatively examine whether actual changes in the relevant behaviours (e.g. physical activity) were a mechanism through which QoL improved or examine whether there was a relationship between support and perceived behaviour change.

Not having a measure for actual behaviour change may limit the validity of the research and the ability to draw conclusions about some of the possible mechanisms through which QoL improved in this sample. With physical activity (PA) in particular, the trial initially attempted to collect some objective data about PA (specifically number of daily steps) through pedometers, but issues with mail out prevented successful data collection so collection of data via this method was not possible. Other gold standard methods of objective measurement of physical activity such as indirect calorimetry are expensive and not feasible for a trial of Renewed's size (Strath et al., 2013). Self-report measures of physical activity such as questionnaires, activity logs, and diaries may have been more feasible for a sample of this size. However, there are several limitations with these types of methods. Self-report measures such as these are criticised for relying on recall, potentially influenced by memory and bias (Falck et al., 2015) and lack content validity for comprehensive assessment (Murray et al., 2016). This is especially important as there are already

many self-report measures in the trial (see Krusche et al., 2019), to avoid overburdening participants with questionnaires.

Using qualitative research and triangulation may provide complimentary insight into behaviour change (Yardley et al., 2015) which may help to partially overcome the lack of a direct behaviour change measure. In this thesis, while using a combination of methods did not give a measure of actual behaviour change, it did shed light on how participants perceived any possible behaviour change and how this was experienced in relation to using Renewed. In this way, the findings do not speak to a direct relationship between behaviour change and QoL, but they do indicate a relationship at least between perceived behaviour change and QoL.

Second, interviews with cancer survivors and HCPs were conducted at one single time point (Chapter 5), so could not account for individuals' experiences of using and engaging with Renewed over time. In relation to cancer survivors (Chapter 2), using longitudinal interviews to explore their engagement with Renewed over time may have provided further insight into how engagement evolved with Renewed and uncovered additional barriers or facilitator's that might be important to continued motivation to engage with Renewed in the longer term. In relation to HCPs, longitudinal interviews may have provided further exploration of the finding that HCPs' confidence grew over time as HCPs delivered a growing number of support sessions, allowing a deeper understanding of their experiences in providing support. Understanding HCPs experiences in this way could have shed greater light on the potential for Renewed to be implemented successfully long-term. This suggests that the barriers that some of the HCPs experienced are something that would resolve over time with experience, they may be less of an issue to be addressed.

Third, due to the timing of the wider RCT, findings from one Paper were not always able to inform the next in the series. For example, qualitative interviews (Chapters 3 and 5) were conducted in parallel to the RCT, whereas usage data (Chapter 4) had to be collected and analysed months after the RCT so that enough follow-up data was available. This meant that the interviews were not able to explore some of the novel insights that arose from the analysis of the usage data or trial findings that were potentially important to QoL outcomes or engagement with Renewed. For example, as mentioned previously, qualitative data from cancer survivors suggests that using Renewed may have supported autonomous motivation. Quantitative usage data analysis of exploring the relationships between enablement, Renewed usage and outcomes in QoL could have provided complementary insights into cancer's reported experiences. This made identifying key insights during triangulation difficult, as key findings from all the studies could not always be mapped onto the findings from across the studies to allow comparison.

Fourth, Paper two (Chapter 4) showed that most participants who accessed the optional content, only accessed one extra section of content, with increasingly fewer people accessing multiple sections of content. However, data collected did not allow full exploration of why (or why not) and how participants engaged in multiple behaviours. Understanding this may have provided better understanding of cancer survivors' experiences and evaluation of how Renewed may have worked and how perceptions and motivations might have related to maintaining multiple behavioural changes.

Fifth, the analysis in Paper two (Chapter 4) excluded 46 participants due to missing QoL data. While the data from the 46 participants are unlikely to impact the results (Jakobsen et al., 2017), the lack of a full sample was a limitation in this study as the current sample does not reflect everyone who used Renewed. Having a full sample would have further minimised the risk of bias (Altman & Bland, 2007).

Sixth, the Renewed trial sample as a whole lacked ethnic diversity, meaning that it was not possible to achieve fully diverse samples in the process studies. This limited the generalisability of the findings and limited understanding of how the experiences of using Renewed and outcomes in QoL may have differed across ethnicities. For example, research has shown that ethnicity has been related to incidence, diagnosis, experience and outcomes among cancer survivors (Cancer Research UK., 2022; Delon et al., 2022). As Renewed targeted those who had prostate cancer, it would have been particularly useful for the sample to include a higher number of Black men, as prostate cancer in the UK is highest among this group (Delon et al., 2022). Understanding Black men's outcomes and experiences of using Renewed would have better reflected the barriers and facilitators to engagement among prostate cancer survivors and more accurately explored the intervention's potential to implement successfully. As Black and minority ethnic groups are less likely to participate in cancer clinical trials than their White counterparts (Smart, 2021), there are calls for clinical trials and interventions to be more inclusive and accessible to the needs of people from a variety of ethnic and cultural backgrounds to overcome digital inequalities and ensure interventions can be scalable and effective for a wide population of cancer survivors (Smart, 2021).

Additionally, diversity in other factors such as health literacy, digital literacy and socio-economic status (SES) were not explored within this thesis. Health literacy and digital literacy were not measured in the wider RCT trial so there were no data available to explore the potential impact of these factors. Whilst postcode data were collected and could have been used to identify index of multiple deprivation, this was not examined in this thesis because the potential moderators that

were examined were determined by hypothesised mechanisms of action from the logic model or main trial, which did not highlight SES.

However, research indicates that these are factors that may impact cancer survivors' experiences using a digital intervention. For example, as mentioned in Chapter 3, those with higher health literacy are more likely to engage with digital interventions and have better outcomes (Van der Hout et al., 2021a), whilst those with lower digital literacy and from lower socio economic backgrounds are less likely to engage in cancer research and digital interventions (Western et al., 2021), likely due to lack of resources and various accessibility needs (e.g. language barriers, lack of digital devices (Mistry & Jabbal, 2023)). The failure to measure and examine diversity of these factors means that it is not possible to determine whether these factors were important moderators through which Renewed worked. Going forward, it is important for research to measure digital literacy, health literacy and SES so that there is greater understanding on the impact of these factors on engagement with digital interventions. This is because without such research, we do not know what the experiences of people who are different in terms of these types of factors are in relation to an intervention like Renewed in practice. To avoid exacerbating inequalities through issues connected to accessibility of these types of interventions it is important that future research intentionally seeks to understand this. However, exploring the impact of diverse characteristics on engagement and experience with digital interventions may require novel ways of inviting and recruiting such people into studies and collecting their data (Ellard-Grey et al., 2015).

Lastly, while digital health is becoming more widespread, there is growing concern about the ability for everyone to use and benefit from these digital services. The growing trend in digital health is in some part being driven by its potential to reach hard-to-reach communities (Furness et al., 2020). This digital trend has grown drastically during the COVID-19 pandemic (De et al., 2020). However, some groups are at greater risk than others of digital exclusion, which is the lack of access, skills and capabilities needed to engage with devices or digital services that help people take part in their health care (Mistry & Jabaal, 2023). As more services are delivered online through websites, apps, email and SMS, and online becomes the preferred means of contact, digitally excluded people are in danger of being left behind (UK Parliament, 2023). People have different needs and ideas about what to expect from digital technology. A range of personal, situational and environmental factors can influence digital inclusion. For example, survey data suggest that for adults who do not use the internet, some of the main reasons include a lack of interest or perceived need, privacy and security concerns, lack of ability to use it, and cost of access (UK Parliament, 2020). This means that while primary care becomes more digital, many steps are still needed to digitally transform healthcare in a way that is inclusive so that these



types of interventions can be accessible to the wider population (Mistry & Jabbal, 2023). The most frequently reported reason for not being online is motivation, or a lack of willingness to engage with and use digital technology (NHS, 2022). There is an argument that digital services need to be structured around people's needs, for instance by identifying people capabilities and preferences, offering services with different levels of digitalisation and working with communities to develop more inclusive services (Mistry & Jabbal, 2023). This suggests that to maximise the reach of the Renewed intervention and its ability to best serve cancer survivors, there is a need to keep these factors at the forefront of decisions about how to implement, disseminate and, where necessary, adapt the intervention in order to minimise the risk of digital exclusion.

## **6.6 Implications and future directions for research**

### **6.6.1 Measuring adherence to behaviour change**

As mentioned in the limitations, as there was no measure for behaviour change, it was not possible to quantitatively examine whether actual changes in the relevant behaviours (e.g. physical activity) were a mechanism through which QoL improved. It would be valuable to address this limitation, as this would provide further understanding as to how Renewed worked. Future research could explore whether adherence to target behaviours improved cancer survivors' QoL. This may add further evidence about mechanisms of change in behavioural health interventions for cancer survivors and allow greater exploration on how digital interventions work in this population.

### **6.6.2 Usage**

The current thesis only examined usage of Renewed by frequency of logins. Future research should examine usage of Renewed (and similar interventions), especially optional content, using a variety of different usage metrics (e.g. time spent, goals set and obtained, which BCTs underpinned the features that individuals used most and found most helpful). The application of a wider variety of usage metrics may have provided a better understanding of why accessing the intervention a greater number of times further improved QoL and precisely which contents, features or information would have been beneficial to include in the earlier content to boost outcomes with even minimal usage. Identifying and applying meaningful usage metrics that capture interactions with specific content is important to gain a greater understanding of how an

intervention works. For example, Donkin et al. (2013) found that only one usage metric (number of completed modules) was associated with significantly better improvements in depression in web-based intervention. Whereas the other three usage metrics (number of log-ins, time spent online, and activities completed), were not related to significant improvements in depression. Therefore, looking at usage with only one metric may overlook insights into which type of engagement is most effective in producing outcomes. New and evolving usage frameworks are being developed to support the analysis of usage in digital interventions (e.g. Miller et al., 2019). Applying a usage framework to future research may support identifying and examining meaningful usage metrics in digital interventions for cancer survivors.

### **6.6.3 Understanding engagement with multiple behaviours**

As mentioned in the limitations section, most cancer survivors who accessed the optional content only accessed one section of content. Unfortunately, the thesis did not explore why, or how, participants engaged with multiple behaviours. This finding raises an important question that should be explored with further research. To better understand how change is produced as a result of digital interventions that target multiple behaviours, future research could explore why and how people choose to make multiple behaviour changes and the barriers and facilitators to this. A mix of quantitative and qualitative methods could explore this. Qualitative interviews could be used to explore reasons for engagement in various behaviours and qualitative responses on baseline questionnaires that asked participants about their behaviour change goals. These could be compared with quantitative data of behaviour changes and optional content accessed on Renewed, as well as examining whether the behaviours engaged with related to the behaviours recommended by the intervention and the self-reported goals to understand the mechanisms in multiple behaviour change. More complex statistical modelling than that used in the current thesis would be needed to explore these interrelationships.

### **6.6.4 Examining the utility of health behaviour change theories in Renewed**

One of the aims of a process evaluation is to understand how an intervention works. Part of this involves understanding how the behaviour was changed. Health behaviour theories evaluate or explain how individuals make behaviour changes and suggest strategies for promoting behaviour change. As behaviour change theories underpinned Renewed it would have been beneficial for part of this process evaluation to include an in-depth evaluation of the utility of the underlying theories for promoting behaviour change.

Some of the theories of behaviour change that informed the Renewed intervention included self-determination theory (Deci & Ryan, 2012), and social cognitive theory (Bandura, 2003). As Renewed contained a wide-ranging content within and this process evaluation was nested within a wider RCT, research questions had to focus on the most important and salient aspects of the data, which the RCT findings or intervention logic model predominantly determined. While this thesis could not fully evaluate the utility of the various theories, some findings may support the utility of social determination theory and social cognitive theory in understanding behaviour changes in this context.

For example, self-determination theory explains how social environments can influence the motivational dynamics behind the regulation of health behaviours and suggests that individuals become more autonomous in engaging in a behaviour over time as their motives become more internalised (Deci & Ryan., 2012). Data from cancer survivors' experiences' using Renewed (Chapter 3) suggested that usage of Renewed may have promoted autonomous motivation to engage with behaviour change, potentially through the use of the intervention features underpinned by self-determination theory (e.g. CARE approach). For instance, one way CARE support promotes an autonomy-supportive relationship is by providing non-controlling feedback. Creating autonomy-supportive relationships between physicians and patients has been shown to lead to weight management and physical activity behaviour change (Fortier, Duda, Guerin, & Teixeira, 2012). Further quantitative research examining the relationship between autonomy-supportive structures in Renewed and their relation to behaviour change would have provided insight into the utility of self-determination theory.

Social cognitive theory suggests that interpersonal influences, environment and behaviour all interact and influence motivation to engage in behaviours. One key motivational process within Social cognitive theory is self-efficacy (Bandura, 1994). HCPs reported that their confidence in delivering support grew as they gained more experience delivering support. It may be that HCPs were growing a sense of mastery in delivering support, which may have enhanced their self-efficacy. Quantitative self-reported measures of self-efficacy could have added complementary insight into this finding and given a better understanding of the utility of social cognitive theory in this context.

### **6.6.5 Other approaches to process evaluation research**

As outlined in [Section 1.5](#), process evaluation includes examining implementation, mechanisms of action and context. This process evaluation was able to examine some of the mechanisms of

action through quantitative usage analysis, which allowed testing of some of the assumption of the intervention's logic model about how change was produced, and provided insight into how cancer survivors and HCPs interacted with Renewed. Qualitative interviews with cancer survivors complimented usage analysis to provide in-depth accounts of how users engaged with and experienced the intervention. The role of context was considered through qualitatively exploring barriers and facilitators to cancer survivors' engagement with Renewed and quantitatively examining moderators of intervention usage. This process evaluation only partially examined implementation. As section 1.5 details, implementation considers both 'how' delivery is achieved and 'what' is actually delivered (Moore et al., 2015). This thesis only examined how delivery of Renewed was achieved, considering how the intervention may achieve its effects in everyday practice. It did not examine what was actually delivered – examining factors such as fidelity, reach and dose. The Medical Research Council (2015, p.8) defines these terms as: “fidelity – the consistency of what is implemented with the planned intervention; dose – how much intervention is delivered; reach – the extent to which a target audience comes into contact with the intervention.” Examining which aspects of Renewed were actually received by participants could allow outcomes to be understood in light of what was delivered, providing greater understanding of what parts of the intervention were most important for achieving outcomes (Moore et al., 2015). For example, conducting a fidelity assessment on how Supporters delivered the CARE approach would have allowed exploration of whether this differed substantially between HCPs or regions, and further research could have examined whether higher fidelity of the delivery of CARE produced better outcomes in QoL or if it seemed to impact on participants' experiences of using Renewed. By not examining the 'what' of implementation, this thesis is not able to offer a detailed understanding to what extent the Renewed intervention was delivered as intended, and if this deviated from protocol, what the impact of this was for outcomes.

One way of overcoming this limitation in similar future work is through the incorporation of an evaluation framework. Evaluation frameworks have been successfully applied to process evaluation research and can ensure through understanding of the intervention through the consideration of many factors (Fynn et al., 2020). One example of a widely used framework in process evaluation research is The Re-Aim framework (Glasgow et al., 1999). The Re-Aim framework assists in understanding the implementation of an intervention and its potential to reach a broader population. This includes the examination of five factors: 1) Reach (extent to which the intervention reaches the intended target audience), 2) Effectiveness (the impact of the intervention on relevant outcomes), 3) Adoption (the degree to which organisations or providers successfully integrate the intervention into their practice), 4) Implementation (the extent to which the intervention is delivered as planned and adheres to the original protocol or guidelines), and 5)

Maintenance (the long-term sustainability of the intervention's effects over time) (Glasgow et al., 1999). Use of this framework in previous studies has provided a structure for evaluating interventions and their impact (Kwan et al., 2019). In a similar manner, if the Re-Aim framework had been applied to the Renewed process evaluation, its use may have ensured that all aspects of evaluation were considered and the interventions' impact more fully examined. For example in regards to the 'reach' factor, by examining the proportion and characteristics of individuals who participated in the intervention compared to those eligible to receive but declined may have shown the level of interest in the intervention and potentially added more insight on cost-benefit evaluations. However, even with use of such a framework it may still have been necessary to prioritise which factors of the framework to explore given time constraints.

## **6.7 Conclusion**

This mixed method process evaluation of Renewed was conducted to explore how the intervention worked, for whom, and under what circumstances. The findings suggest that greater usage of Renewed may improve QoL among cancer survivors and that accessing HCP support may increase use of Renewed. These findings have implications for intervention developers as they suggest that developing strategies to motivate further engagement may be beneficial for improving QoL. Further research is needed to examine the usage of Renewed's optional content with various usage metrics (e.g. time spent, goals set and obtained, which BCTs may have underpinned the features that individuals used most and found most helpful). Additionally, future research could explore why and how people choose to make multiple behaviour changes and the barriers and facilitators to this.

While there was evidence suggesting that greater usage of Renewed may improve QoL, it appeared that for some, minimal usage may have been enough to motivate perceived behaviour change. This suggests that promoting effective engagement may be better than promoting maximum engagement in this context. This finding has implications for the design of future digital interventions for cancer survivors because it suggests that having both core and optional content in digital interventions may allow cancer survivors the flexibility to engage in the intervention as much or as little as suits their needs. In this way, it may provide a cost-effective form of support for a large number of individuals, with less need for resource-intensive and tailored support. Further quantitative research is needed to explore the relationships between usage, accessing HCP support and engagement with behaviour changes.

Those who lacked support without the intervention may benefit more from an intervention like Renewed. This is because the intervention may provide a perceived source of social support and a sense of a social network, which may motivate greater engagement with the intervention and potentially increase QoL. This finding suggests that digital interventions for cancer survivors should incorporate an option of support, particularly those individuals who report a lack of support. However, although accessing support may improve the usage of Renewed, it may not directly improve QoL. Further research is needed to determine how the option of support alongside digital interventions may relate to experiences or outcomes in QoL. Research is also needed to explore whether offering individuals the opportunity to customise their support and other discretionary features may enhance their experience and allow them to gain the appropriate level of support for their needs.

# Appendix A Systematic search details

## Inclusion criteria

1. Type of studies:
  - i) RCTs
  - ii) Observational cohort studies
  - iii) Longitudinal
  - iv) Qualitative studies
  
2. Type of participants:
  - i) Cancer survivor: Can be either active treatment or post-treatment cancer survivors
  - ii) Adults

### 3. Type of intervention

#### Multi-domain digital interventions

- i) Included if targeted two or more healthy behaviour changes (e.g. diet and physical activity)
- ii) Included if used alongside other types of interventions
- iii) Included if evaluated as a standard intervention alone (i.e. before and after studies)

### 4. Type of outcome measures

#### Primary outcome:

- i) Quality of life by any measure. Preferably a standardised measure such as EORTC or (name)

#### Secondary outcome:

- i) Behaviour changes:
  - Lifestyle behaviour changes: a range of behaviour changes were accepted (i.e. physical activity, diet, self-monitoring, smoking cessation)
  - Various methods of measurement were accepted (e.g. either objective or self-report measures).

## **Exclusion Criteria**

- i) Studies not available in English.
- ii) Non-human studies.
- iii) Non-intervention trials (e.g. surveys).

**Example MeSH terms:**

***Multi-domain digital interventions terms:***

Multi-domain interventions; multi-target intervention

***Digital behaviour change interventions terms:***

Digital interventions OR, e-health, OR, m-health, OR, website, OR, app, OR, smartphone

***Behaviour change terms:***

Health behaviour, OR, behaviour change

***Cancer Survivor terms:***

Cancer survivors, OR, neoplasm, OR, living with and beyond cancer

***Quality of life terms:***

Quality of life, OR, health related quality of life



## Appendix B Key materials for Renewed RCT trial

### B.1 Participant invite letter

<patient name and address>

Study ID

GP surgery code/initials

<insert date>

Dear <insert patient name>

#### **The Renewed Online Study**

We are writing to ask if you would like to take part in a study led by the University of Southampton. Our surgery has decided to take part in this study and will support all of our patients who choose to take part.

Researchers at the University of Southampton have made **a website which supports people who have finished treatment for breast cancer, bowel cancer or prostate cancer, or people on active surveillance** (people monitoring prostate cancer symptoms). There is advice on improving physical health and help with feelings of tiredness, worry or stress and concerns about cancer.

**If you would like to take part**, you can read more about the study and how to take part take part in the leaflet with this letter. Once you had read the leaflet, you can go to the study website to answer a few questions to make sure the study is right for you and see more about what will happen next.

**If you do not want to take part** then you don't need to do anything else, there's no need to call us or the study team to let us know.

The study team would like to know why people don't want to take part so if you like, you can let them know why by filling out the reply slip with this letter and returning it to them in the freepost envelope.

Thank you very much for taking the time to read this letter,

Yours sincerely

Dr <insert GP name>

## B.2 Participant information sheet

<b>Who is paying for and running the study?</b>	<b>Has anyone else reviewed the study?</b>
The study is being funded by the National Institute for Health Research (NIHR), which is funded by the government to carry out research in the NHS. Renewed has been written by a team of leading doctors and scientists from the University of Southampton.	The study has been reviewed and approved by the Greater Manchester West NHS Research Ethics Committee (Ref 18/NW/0013).
<b>If you want to make a complaint</b>	<b>Contact Details</b>
If you wish to make a complaint regarding this study, please contact the Research Governance office at the University of Southampton on 02380 595058 or by email: <a href="mailto:rgoinfo@soton.ac.uk">rgoinfo@soton.ac.uk</a> .  If you remain unhappy and wish to complain formally you can do this through the NHS complaints procedure. Details are available from your own practice.	For more information about this study please see our website, email us or call and ask to speak to the Renewed study team.  Website: <a href="http://www.renewedstudy.org">www.renewedstudy.org</a>  Tel: 023 80 591752  Email: [renewed study email]
<b>What if there's a problem?</b>	<b>What do I do now?</b>
If there is a problem or you have any concerns, you can contact your practice nurse or a member of the research team.	<b>If you are interested in taking part, please go to <a href="http://www.renewedstudy.org">www.renewedstudy.org</a> to see if you can take part in the study and sign-up.</b>  Please contact us if you have any questions.  <b>Thank you very much for your time.</b>

## A study of online support for people who have had cancer Can you help?

### We invite you to take part in a study

It is up to you to decide whether or not to take part. Saying no will not affect the care you receive from your GP. This booklet tells you why the study is being done and what it will involve. After you read it you can choose whether or not you want to take part. Please contact us if anything is unclear or you would like to ask any questions.

#### A quick summary of the study

- **This study is testing an online programme (Renewed) for people who have finished treatment for cancer or are on *active surveillance*. Renewed aims to help people improve their wellbeing and physical health.**
- If you take part, the study will last for 12 months.
- We ask everyone who takes part to complete some questions about how they are three times, with the last time being a year after they start taking part.
- About two thirds of people will be in a group with access to Renewed straight away and one third of people will wait and carry on with their usual care.
- Which group you are in will be decided by chance.
- Everyone in the study will continue to receive their usual NHS care.
- The study is being run by the University of Southampton and is funded by the National Institute for Health Research, the main funder of research in the NHS.
- You will be given a £10 voucher to thank you for your time.

#### What do I do next?

If you are interested, please see our website or contact the research team.

- **See more or sign-up to take part on our website at [www.renewedstudy.org](http://www.renewedstudy.org).** If you have any trouble, try <https://renewed.lifeguidewebsites.org> instead.
- **Email us at [renewed@soton.ac.uk](mailto:renewed@soton.ac.uk) or phone us on 023 80 591752**

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The Renewed study is funded by the National Institute for Health Research

<b>Why are we doing this study?</b>	<p><b>2.</b> You will be asked some questions online to see how you are and check if you can take part in the study. You will be told straight away if the study is right for you.</p>
<b>We want to see whether using the Renewed online programme can help people who have had cancer improve their well-being and physical health.</b>	
<b>Why am I being asked to take part?</b>	

<p>You are invited to take part because you <b>have had breast, colon or prostate cancer</b> in the past 10 years and are not having any more treatment for it (e.g. surgery, chemotherapy). You can take part if you think the website might be helpful for you.</p> <p><b>You need to have finished treatment more than a month ago</b>, but you can take part if you are having hormone therapy. If you have prostate cancer you can take part if you are <u>not</u> being treated (if you are on <b>watchful waiting/active surveillance</b>).</p> <p>You'll need access to an online computer or tablet to be able to take part.</p> <p>If you feel fine right now and don't think the website would be helpful at all then the study isn't right for you as we're looking at how it can help people.</p>	<p><b>3.</b> Then, you will be put into one of three groups by chance (the same as flipping a coin), so:</p> <ul style="list-style-type: none"> <li>• You will be in the group using Renewed online for up to a year.</li> <li>• <b>Or</b>, you will be in the group using Renewed plus support from someone at a charity, such as Macmillan, or your GP Practice or a specially trained research nurse.</li> <li>• <b>Or</b>, you will have your usual care and given access to Renewed after a year.</li> </ul> <p><b>4. If you are in one of the two groups using the Renewed programme:</b></p> <p>You can use the Renewed programme to help you to improve your wellbeing.</p> <p>You can choose which bits of the website you want to use. You can use as little or as much as you like. We will log which parts of the website people see for the study.</p> <p><b>Renewed can give you support with being more active, reducing feelings of tiredness or stress, losing weight and eating a healthy diet.</b></p>
<p><b>What will I do if I take part?</b></p>	
<p><b>1.</b> The first step is to sign-up on our website or get in touch. We will be happy to answer any questions about the study.</p>	<p><b>5.</b> We'll get in touch with everyone in 6 months and a year to ask you to complete some more questions online to see how you are.</p>
<p><b>Possible benefits and disadvantages of taking part</b></p>	<p><b>More information about taking part</b></p>
<p>There is no direct benefit but taking part in the study may have a positive impact on your health and general well-being. Renewed might also help to maintain and improve your physical health. You will be given a £10 voucher to thank you for taking part.</p> <p>The main disadvantage is that it will take up some of your time, about 30 minutes to fill-out the questionnaires online. You will be asked to complete the questionnaires online</p>	<p><b>What happens if I change my mind?</b></p> <p>You can withdraw any time by contacting the research team. You don't need to give us a reason. This will not affect your current or future NHS treatment. Information you have given us up to that point would be used in study results (with no personal details, e.g. your name).</p> <p><b>Will my information be confidential?</b></p> <p>The online Renewed programme is secure. Only members of the research team will be able to see your data from this study. The research team will also</p>

<p>three times: at the start of the study, after 6 months and after 12 months. Using the website might cause distress because it can remind you about your time going through cancer but the questions are designed to minimise distress and you will be given lots of advice about where you can get more support if you need it.</p>	<p>have your name and contact details which will be used to stay in touch with you during the study. Your GP will be told you are taking part in the study. At the end of the study, relevant parts of your medical records will be checked by the research team. Study data will be used without personal details like your name. This information will be stored securely and privately. Personal details will be destroyed after the study has finished. You can find out more at <a href="https://renewedpis.lifeguidewebsites.org">https://renewedpis.lifeguidewebsites.org</a>.</p>
<p><b>Optional study</b></p>	
<p>There will also be the option to talk about your experience of Renewed later in the study.</p> <p>We will be in touch to ask if you would like to talk to us about how you found using Renewed and what you think of the study (usually over the phone). This would last about 30 minutes, depending on how much feedback you have. This conversation would be recorded and written-up with your personal details (e.g. your name) removed. You would be given another £10 voucher as a thank you for this extra study.</p>	<p><b>What will happen to the study results?</b></p> <p>The results will be presented at medical conferences, published in medical journals, used to educate students and further develop the website. A summary of the findings and the full report can be made available on request. The results will not contain names or personal details.</p>

### B.3 Participant consent form

Renewed Online: A study of online support for people who have had cancer

**If you are happy to take part in this research then please read all of the statements below and tick all of the boxes if you agree with them.**

1. I confirm that I have read the Participant Information Sheet (PIS version number and date) and understand what I will be doing in this study.

I understand that I do not have to take part and that I can withdraw at any time without giving a reason, and this will not affect my medical care or legal rights.

2. I understand that if I withdraw from the study then the information collected up to that point may still be used to complete the study.

3. I understand that data collected during the study may be looked at by researchers from the University of Southampton and by regulatory authorities and that personal information about me, such as my name or where I live, will not be shared outside of the study team.
4. I understand that information that could identify me as an individual is removed and anonymized data may be used for any research, clinical or teaching purposes.
5. I understand that what I look at on the website or on an app will be recorded securely and the researchers will look at the data to see how people use them.
6. I consent to my GP being made aware that I am taking part in this study.
7. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the research team, from regulatory authorities or from an NHS Trust where it is relevant to me taking part in this research. I give permission for these people to have access to these records.
8. I understand that I may be contacted later by the research team to ask if I would like to take part in an interview about my experiences of the study.
9. I agree to take part in the above study and for my data to be used for the study.

Name of Participant

Date

Signature (please tick)

## Appendix C Consolidated criteria for reporting qualitative research guidelines

No. Item	Guide questions/description	Reported on Page #
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	47
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	25-27
3. Occupation	What was their occupation at the time of the study?	25-27
4. Gender	Was the researcher male or female?	N/A
5. Experience and training	What experience or training did the researcher have?	47
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	47
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	47
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	47
<b>Domain 2: study design</b>		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	47
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g.	46

## Appendix C

	purposive, convenience, consecutive, snowball	
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	46
12. Sample size	How many participants were in the study?	48
13. Non-participation	How many people refused to participate or dropped out? Reasons?	48
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	47
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	47
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	47
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	47, Appendix E
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	47
20. Field notes	Were field notes made during and/or after the inter view or focus group?	47
21. Duration	What was the duration of the interviews or focus group?	47
22. Data saturation	Was data saturation discussed?	41, 42
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
<b>Domain 3: analysis and findings</b>		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	47
25. Description of the coding tree	Did authors provide a description of the coding tree?	Appendix F
26. Derivation of themes	Were themes identified in advance or derived from the data?	47
27. Software	What software, if applicable, was used to manage the data?	47



28. Participant checking	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	49-57
30. Data and findings consistent	Was there consistency between the data presented and the findings?	47-57, Appendix F - H
31. Clarity of major themes	Were major themes clearly presented in the findings?	49-57
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	49-57



## Appendix D Participant materials for qualitative study with cancer survivors

### D.1 Participant email invitation

Dear [First and last name],

My name is Jazzine Smith and I am doing a project with the Renewed study team at the University of Southampton

I am sending you this email to ask if you would be able to help with my project and speak to me on the phone about what you thought of the Renewed website? If you can spare the time, it should take about 30-60 minutes.

It doesn't matter if you used the website much or not at all or if you liked it or not; all feedback is really valuable. If you would be able to speak to me over the phone, I would be happy to give you a £10 voucher to thank you for your time.

I have an information sheet with further details about the study that I can send to you if you would like to know more. If you would like to take part or have any questions, please get back to me at [researchers email] or call [researcher's number]. If you'd like to sign-up then please go to [link to online consent form].

Thank you very much for your time and effort with the Renewed study. I know it is very much appreciated.

I hope to hear back from you soon.

Many thanks,

Jazzine

### D.2 Participant information sheet

A study of online support for people who have had cancer  
**Feedback study**

**We invite you to take part in an extra part of the Renewed study**

It is up to you to decide whether or not to take part. Saying no will not affect the care you receive from your GP or your involvement in the Renewed study you are already in. This booklet tells you why the study is being done and what it will involve. After you read it you can choose whether or not you want to take part. Please contact us if anything is unclear or you would like to ask any questions.

#### **A quick summary of the study**

- **This study is asking people what they think about the Renewed programme and study.**
- **If you take part, we will talk to you on the phone for 30 – 60 minutes. We will ask you some questions about the Renewed study and Renewed online and what you think about it.**
- **It doesn't matter if you like the programme or not or if you used it or not. We are interested in hearing all sorts of feedback to help make the best programme we can.**
- **The study is being run by the University of Southampton and is funded by the National Institute for Health Research, the main funder of research in the NHS.**
- **You will be given a £10 voucher to thank you for your time.**

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#### **What do I do next?**

**If you are interested, please get in touch with us or sign-up on our website: [link to online consent form]**

**Email us at [renewed study email] or Phone us on [researchers number]**

#### **What is the aim of the study?**

The aim of this study is to find out what people think of the 'Renewed' study and programme. The study has been running for a few months and now we would like to hear your opinions on it. It doesn't matter if you have looked at all of the programme or none of it, or whether you liked it or not. All feedback is valuable and we try to get lots of different comments to help us to make the programme as good as possible. This will ensure the programme is easy and useful for people to use.

#### **Why have I been invited?**

You have been invited because you have been taking part in the Renewed Study for at least couple of months. We hope that about 36 people will take part in this study.

#### **What will happen to me if I take part and what do I have to do?**

We will arrange a telephone call to talk to you about what you thought of the programme.

#### **What are the possible pros and cons of taking part?**

There is no direct benefit to you but your feedback is very valuable and will help us to create a programme that people can use for support. In our other studies, people have expressed interest and satisfaction in taking part, enjoyed learning new things and liked having their views listened to. We will give you a £10 gift voucher to thank you for your time.

The main disadvantage of taking part is that it will take up some of your time: about 30-60 minutes for the interview, depending on how much you would like to talk about.

### **What will happen if I don't want to carry on with the study?**

If you choose to take part in this part of the study you are free to change your mind and withdraw at any time without giving a reason. This will not affect the medical care you receive in any way. If you decide to stop taking part then we would still like to use the anonymous information you have given us for the research study, unless you tell us not to.

### **Will my taking part in this study be kept confidential?**

Your GP will know that you are taking part in the Renewed study. We will get in touch with them if you tell us something which sounds like you are at any risk. With your permission, the interview will be audio-recorded to make an accurate record of what is said. These recordings will be typed up and your name or any other details that can identify you will be removed, to ensure your privacy. The people who type up the interviews will have signed agreements to keep everything private. These anonymised transcripts (which don't include information which identifies who you are) will be stored on a password protected file on secure University of Southampton computers. The recordings will be kept securely on the computer system at the University of Southampton which only the research team can access. The recordings will be destroyed when the study is complete. The findings from this study will be used in research reports and the programme, but no names will be included in the report or programme so any quotes from the interview will be anonymous.

### **What will happen to the results of the research study?**

The results will be shared as widely as possible with everyone interested in improving quality of life for people who have had cancer in the past, including doctors, nurses and the general public. We will send you a summary of the findings if you would like one.

### **Who has reviewed the study?**

The study has been reviewed and given approval by North West- Greater Manchester West NHS Research Ethics Committee (Ref 18/NW/0013).

### **What if there is a problem?**

If you have any concerns or feel that you have been placed at risk you can contact the Head of Research Governance at the University of Southampton at [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk) or telephone 023 8059 5058. If you remain unhappy and wish to complain formally you can do this through the NHS complaints procedure. Details are available from your own practice.

### **How can I find out more?**

For more information about this study or if you would like to take part please email us at [renewed study email] [or call us on](#) [researcher's number] and ask to speak to the Renewed study team. If you take part or decide not to, nothing will change about the Renewed study you are already taking part in.

**THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION**

### **D.3 Online consent form**

**Renewed Study: A study of online support for people who have had cancer. Feedback study.**

**If you are happy to take part in this research then please read all 6 statements below and initial all the boxes if you agree with them.**

1. I confirm that I have read the Participant Information Sheet (PIS version number and date) and understand what I will be doing in this study.
2. I understand that I do not have to take part and that I can withdraw at any time without giving a reason, and this will not affect my medical care or legal rights.
3. I understand that data collected during the study may be looked at by researchers from the University of Southampton and by regulatory authorities.
4. I am happy for a voice recording to be made of this interview (including phone interviews), with possible use of anonymous quotations in reports and publications.
5. I understand that the voice recording made in this interview will be typed up and anonymized (all information that could identify you as an individual is removed) and this anonymized data may be used for any research, clinical or teaching purposes.
6. I agree to take part in the above study.

## Appendix E Interview schedules for qualitative study with cancer survivors

### E.1 Those in the Renewed with human support arm

#### Patient (Support) Interview Schedule

##### *Patient introductions and set-up:*

- Introduce myself to the participant
- The purpose of this interview is to find out how you have found taking part in the Renewed study.

Do you have any questions at this point?

- I just want to check that you are still happy to take part (patient has already given written consent).
- Most interviews last between 20 minutes and 1 hour, this will be up to you depending on how much you have to say. We can do the interview in 2 parts if you prefer, so just let me know if you want to stop at any point and we can always arrange another day to finish. You will get a £10 high street voucher at the end to thank you.
- There are no right or wrong answers, so please say any thoughts which spring to mind, even if you think they might not be important. Your experiences of using the programme are really important so the more you can tell us about it the better.
- If you have any questions while we are going through, I will be very happy to answer them but it's probably best if I answer them at the end.
- If you are happy, I will record the interview, so I can listen again to what is being said. We will not keep anything on record that identifies you, or where you live or anyone else that you mention, so it will all be anonymous. Also, everything we talk about here will be confidential.
- We can take a break at any time you like, please just let know and I can pause the recording, or I can always call back to finish the interview another time if that is better for you. I might be quite quiet and that's because I'm just listening to what you are saying so please don't feel put-off, I am still here.

## Appendix E

- I did not help to develop the Renewed website myself so I'm just interested in anything you tell me about it.
- You can choose not to take part at any time.
- Is there anything you would like to ask me at the moment?
- If you are happy, I will start recording now.

### **Inductive opening questions**

1. Can you tell me why you decided to sign up for the Renewed study?
2. Can you tell me what life was like for you back when you were deciding to sign up for Renewed? (how did you feel, how was your health?) / How were you when you signed-up to Renewed, if you remember?
3. I'm really interested in hearing all about your experiences of using the Renewed programme, can you tell me all about it?
4. Can you tell me about anything that you liked about the Renewed programme?
5. Can you tell me about anything that you have disliked about the Renewed programme?
6. Thinking a bit more about the parts of Renewed that were available to you, I can see that you looked at (describe each part in turn, starting with session 1, then any other additional bits they looked at – Getting Active, Healthy Paths for help with coping with feelings of loss or fear of cancer coming back (or stress), Eat for Health or POWeR). What did you think of X (ask about each one in turn). What did you like about X? What did you dislike about X?
7. How did you choose which parts of Renewed to use? *Possible prompts for elaboration: Renewed gives a choice of a variety of things that you can try including help with increasing physical activity, improving diet and managing difficult feelings like stress or fear of cancer coming back (add in weight loss if the person was eligible). How did you feel about being offered a choice of these different things to try?*
8. **If they did not go past session 1:** I can see online that you completed the first session but did not go on to try any of the other bits of Renewed can you tell me a bit about that? *Possible prompts: In session 1 you were given advice about how Renewed could possibly help you personally based on your answers to the questionnaire, what did you think about this?*
9. Renewed gives some support with making healthy changes like changing your diet, physical activity, losing weight or managing difficult feelings. Can you tell me about any of these changes that you might have tried?
10. **If they tried one or more change:** What was that like? Why did you choose (insert name of change). How did it make you feel to try (insert name of change)? (ASK THESE QUESTIONS FOR EACH CHANGE THEY MENTION).
11. **If they didn't try out any of these changes:** Can you tell me why you decided not to make any changes?
12. Can you tell me about the contact you have had with your Supporter so far in the Renewed study? (if needed to prompt the patient to remember: the supporter will be a nurse/healthcare assistant or someone similar, they may have gotten in touch by email or phone or you might have seen them in person at your GP surgery - NOTE INTERVIEWER TO CHECK IF PRIMARY CARE OR CRN SUPPORT IN ADVANCE TO ASK RIGHT QUESTION HERE (only primary care supporters will provide in person support)). Possible prompts to use if the patient needs to elaborate: What was the support like? Can you tell me about anything you liked about this support? Can you tell me about anything you disliked about this support?
13. **If they did not have any contact with their Supporter:** Can you tell me if you thought about contacting your supporter?
14. Overall, can you tell me about any advantages that you can see in using Renewed?
15. And overall, can you tell me about any disadvantages that you can see of using Renewed?



16. Has anything changed as a result of you using Renewed?

17. Can you tell me what life is like for you now, since you've been using Renewed for a while? (how are you feeling, how is your health? Discuss any issues that they mentioned in question 2)

*If the patient didn't opt to have any telephone/face to face support:* Can you tell me what you thought about receiving emails from your Supporter about Renewed?

18. Can you tell me about how you have found the emails from Renewed?

19. Is there anything else you would like to tell me about the Renewed study that we haven't already talked about?

OK I'm going to stop the recording now.

**End of interview:** Explain about £10 voucher – check address to post it to and ask them to send confirmation email when they receive it, and option to receive report of findings.

Nice to talk to you.

**Key follow-up prompts:**

Can you tell me a bit more about that?

**Can you tell me what that was like for you?**

You mentioned xxxxxx/ You said about xyz.... (use their words). What does 'xxxxx' mean to you?

## **E.2 Those in the Renewed (web-intervention only) arm**

### **Patient (Intervention) Interview Schedule**

***Patient introductions and set-up:***

- Introduce myself to the participant
- The purpose of this interview is to find out how you have found taking part in the Renewed study.

## Appendix E

Do you have any questions at this point?

- I just want to check that you are still happy to take part (patient has already given written consent).
- Most interviews last between 20 minutes and 1 hour, this will be up to you depending on how much you have to say. We can do the interview in 2 parts if you prefer, so just let me know if you want to stop at any point and we can always arrange another day to finish. You will get a £10 high street voucher at the end to thank you.
- There are no right or wrong answers, so please say any thoughts which spring to mind, even if you think they might not be important. Your experiences of using the programme are really important so the more you can tell us about it the better.
- If you have any questions while we are going through, I will be very happy to answer them but it's probably best if I answer them at the end.
- If you are happy, I will record the interview, so I can listen again to what is being said. We will not keep anything on record that identifies you, or where you live or anyone else that you mention, so it will all be anonymous. Also, everything we talk about here will be confidential.
- We can take a break at any time you like, please just let know and I can pause the recording, or I can always call back to finish the interview another time if that is better for you. I might be quite quiet and that's because I'm just listening to what you are saying so please don't feel put-off, I am still here.
- I did not help to develop the Renewed website myself so I'm just interested in anything you tell me about it.
- You can choose not to take part at any time.
- Is there anything you would like to ask me at the moment?
- If you are happy, I will start recording now.

### **Inductive opening questions**

20. Can you tell me why you decided to sign up for the Renewed study?
21. Can you tell me what life was like for you back when you were deciding to sign up for Renewed? (how did you feel, how was your health?) / How were you when you signed-up to Renewed, if you remember?
22. I'm really interested in hearing all about your experiences of using the Renewed programme, can you tell me all about it?
23. Can you tell me about anything that you liked about the Renewed programme?
24. Can you tell me about anything that you have disliked about the Renewed programme?
25. Thinking a bit more about the parts of Renewed that were available to you, I can see that you looked at (describe each part in turn, starting with session 1, then any other additional bits they looked at – Getting

Active, Healthy Paths for help with coping with feelings of loss or fear of cancer coming back (or stress), Eat for Health or POWeR). What did you think of X (ask about each one in turn). What did you like about X? What did you dislike about X?

26. How did you choose which parts of Renewed to use? *Possible prompts for elaboration: Renewed gives a choice of a variety of things that you can try including help with increasing physical activity, improving diet and managing difficult feelings like stress or fear of cancer coming back (add in weight loss if the person was eligible). How did you feel about being offered a choice of these different things to try?*
- 27. If they did not go past session 1:** I can see online that you completed the first session but did not go on to try any of the other bits of Renewed can you tell me a bit about that? *Possible prompts: In session 1 you were given advice about how Renewed could possibly help you personally based on your answers to the questionnaire, what did you think about this?*
28. Renewed gives some support with making healthy changes like changing your diet, physical activity, losing weight or managing difficult feelings. Can you tell me about any of these changes that you might have tried?
- 29. If they tried one or more change:** What was that like? Why did you choose (insert name of change). How did it make you feel to try (insert name of change)? (ASK THESE QUESTIONS FOR EACH CHANGE THEY MENTION).
- 30. If they didn't try out any of these changes:** Can you tell me why you decided not to make any changes?
31. Can you tell me about the contact you have had with your GP or nurse so far in the Renewed study?
- 32. If they have had any contact:** Can you tell me about how you have found the support from your GP or nurse while you were taking part in the Renewed study?
33. Overall, can you tell me about any advantages that you can see in using Renewed?
34. And overall, can you tell me about any disadvantages that you can see of using Renewed?
35. Has anything changed as a result of you using Renewed?
36. Can you tell me what life is like for you now, since you've been using Renewed for a while? (how are you feeling, how is your health? Discuss any issues that they mentioned in question 2)

*If the patient didn't opt to have any telephone/face to face support:* Can you tell me what you thought about receiving emails from your Supporter about Renewed?

37. Can you tell me about how you have found the emails from Renewed?
38. Is there anything else you would like to tell me about the Renewed study that we haven't already talked about?

OK I'm going to stop the recording now.

**End of interview:** Explain about £10 voucher – check address to post it to and ask them to send confirmation email when they receive it, and option to receive report of findings.

Nice to talk to you.

## Appendix E

### **Key follow-up prompts:**

Can you tell me a bit more about that?

**Can you tell me what that was like for you?**

You mentioned xxxxxx/ You said about xyz.... (use their words). What does 'xxxxx' mean to you?

## Appendix F Excerpt from coding manual for qualitative study with cancer survivors

Initial themes	Codes	Description	Examples
<b>Support</b>	Expectations of supporter	Mentions what support they expected to receive from the supporter	<p>“I did request a chat with her [Supporter] right at the very beginning, and she said, “Oh, you know, you’re doing everything right”, and I thought, ‘Yeah, but I just wanted a bit of reassurance from someone’, you know?”</p> <p><i>(Participant 11, 79, female, colon cancer, Renewed with human support group).</i></p>
	Supporter satisfaction	Discusses ways in which they were, or were not, satisfied with the support they received from their supporter.	<p>“And, the, the idea was good, but in practice it wasn’t very good...for instance on one occasion I, I’d, I’d was talking to him [Supporter] about em the lack of sexual activity for me, which was important in our, my married life...he said “well probably I should</p>

			<p>talk to the doctor about it". And he made an appointment for the doctor to ring me. And then when I spoke to the doctor, on the phone, he said "oh well it's to do with the cancer, so, you really ought to talk to the hospital...So I felt that I was being, you know, pushed around from pillar to post. So it, the idea is good."</p> <p><i>(Participant 6, 72, male, prostate cancer, Renewed with human support group).</i></p>
	<p>Supporter providing new resources</p>	<p>Mentions the Supporter suggesting or providing new materials, behaviours or websites tailored to the individual needs.</p>	<p>"And she [Supporter] sent me to, I had a referral to Slimming World, which is a bit outside of your study."</p> <p><i>(Participant 10, 65, male, prostate cancer, Renewed with human support group).</i></p>
	<p>The need for support</p>	<p>Discusses whether or not they believe they need support.</p>	<p>"I haven't had any other contact with her. And then she said she'd, I could email her or go up and see her if I want to, but I don't think I need to now.</p>

			<p><b><i>Okay, and why would you say that you don't need to?</i></b></p> <p>Well, I... I suppose I just don't need to. I mean, I... I don't know, I just suppose I'm "I don't think I need any help, as such, and I know I'm overweight and don't do exercises, so..."</p> <p><i>(Participant 1, 64, female, breast cancer, Renewed with human support group).</i></p>
	The need for face-to-face support	Discusses whether they would like to receive physical support.	<p>"I know that you could speak to somebody over the phone, and you could do the live chat. But I found that I wanted to see somebody face-to-face. So I think that's the only disadvantage...it's about time and interaction, sort of personal time. So I found that I really enjoyed that interaction...With a person, to get that feedback. So I think that I would prefer the practice nurse one-to-one, because it's about time."</p>

			<p><i>(Participant 18, 60, male, prostate cancer, Renewed with human support group).</i></p>
	<p>Social support outside of Renewed (i.e. Friends, Family, Medical professionals, Community groups, Courses, Online resources).</p>	<p>Mentions support they received outside of Renewed.</p>	<p>“I put the positive changes down to conversations with the people I mentioned before, just a counsellor and the nurses. As it was more tailored advice, and they were people I interacted with on a more regular basis.”</p> <p><i>(Participant 3, 36, female, breast cancer, Renewed group).</i></p>



## **Appendix G      Excerpt from audit trial for qualitative study with cancer survivors**

25/04/2019 09:44

Had a supervision meeting yesterday where we discussed the coding manual. It was advised to rethink a few codes such as 'usefulness of renewed' and 'use of additional resources'. The usefulness one was agreed to be too vague and the additional resources one was not a correct reflection what was trying to be portrayed.

29/04/2019 12:03

Received 3 more transcripts and will begin coding on them. All interviews have been postponed until analysis has caught up. Following the meeting on 24th and reading the paper by Sekhon et al (2017) on acceptability new codes will be added and some codes split across these new codes. The following codes will be broken down: Usefulness of renewed; use of additional resources and implementing behaviour. The codes adjusting to life after cancer; impact of cancer on behaviour; the work to do to use the intervention digitally, the work to do to implement the behaviour will be added.

24/07/2019 09:31

Had taken a break from coding to focus on preparing for my progression review in August. I now have more free time and will continue coding. When preparing for the progression review I continue to collect interviews. I will code and soon meet with Kat to discuss current data. Have 3 more transcripts coming.

05/08/2019 14:23

After coding transcript S028N1411 4 new initial codes have been created: 'Session 1', 'Choosing components', 'Behavioural goals', 'Personal characteristics'. These codes are likely to be merged or changed, especially the latter 2.

05/08/2019 19:15

After coding S029N1430 a new initial code has been created 'Reasons for behaviour change'. I am considering whether it would be appropriate to merge this into the 'motivation' code.

06/08/2019 11:09

Participant X025N2002 transcript will be excluded. After initial reading it has become apparent that the participant has no recollection of using Renewed of what it even is. He answers the questions very generally and just says what he assumes must be the case. He gives detailed responses in relation to his medication of gym activities but has not made any changes as a result of Renewed because as far as he can remember he hasn't interacted with it.

## Appendix H Excerpt from reflective log for qualitative study with cancer survivors

W104N3008 12/08/19 @ 16:30

Participant did have experience of using renewed. Gave detailed answers in what he liked about each component. He particularly liked getting active. Found the navigation difficult overall but especially with Healthy paths. Had difficulty obtaining support from NHS aftercare cancer services and as a result was very appreciative of Renewed. Said he felt less alone and more motivated because he felt as if someone care. Has started walking more and set himself a goal to walk 10,000 steps a day.

I felt that this was a very good interview except for the fact that he cannot remember session 1 much at all. This seems to be a persistent problem and may need to sample within 1 month of starting Renewed.

X018N2112 13/08/2019 @11:00

Participant used Renewed quite bit. Used every component except HPs. Said that HP was not something she was concerned about atm, just weight loss and exercise. E4H was very useful for her, had lost 3 pounds, made eating goals and liked the links to other websites. Wished there could have been an opportunity to monitor progress in E4H. did not used GA and Power as much because was not motivated but knew she needed to do it. Didn't like the technical issues on Renewed, most prominent in Power. She expressed that she liked the fact that it was online = 24/7 access and is more convenient then going to her GP. Suggested that older people may prefer to see someone in person but she liked the online aspect.

Maybe try not to be as emotive, i.e. "that's really good!" [in response to weight loss] because can bias future responses and may make participant think I only want to hear good feedback. Luckily, this participant still shared when she wasn't successful (not using GA and Power).

F\_Breast\_S, 28/07/2020 14:00

This patient did not use Renewed much and did not take up any support sessions. She expressed that she found that Renewed did not tell her anything new and that she did not need the support sessions. She mostly said this was down to the fact she has been 10 yrs free of cancer and since reaching 5 years post treatment, the cancer is not at the forefront of her mind. She is a carer for her husband who is a stroke survivor and she feels she does not have much time to go on Renewed. Neither does she spend much time at the doctor already because her husband's physio is who she addresses her concerns with in the first instance so she was unlikely to contact the supporter.

S056C1262\_F\_Breast\_S, 30/07/2020, 14:00

This participant used the intervention past session 1 and had contacted the supporter. She spoke about the healthy paths and expressed that she found it frightening. She explained that the man's voice was scary to her and the bell and the end was as if she was being brought out of a trance. She used all 3 support sessions. She liked the support sessions and said she had nothing negative to say about it. She expressed that she was computer illiterate and struggled to get onto the websites at first, she said the supporter helped her with this and her to order a pedometer.

## Appendix I      Strengthening the reporting of observational studies in epidemiology guidelines

	Item No	Recommendation	Page No
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	63
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	63,64
<b>Introduction</b>			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	64,65
Objectives	3	State specific objectives, including any prespecified hypotheses	65,66
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	66
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	66
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up  <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls  <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	66

		<p>(b) <i>Cohort study</i>—For matched studies, give matching criteria and number of exposed and unexposed</p> <p><i>Case-control study</i>—For matched studies, give matching criteria and the number of controls per case</p>	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	67,68
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	67,68
Bias	9	Describe any efforts to address potential sources of bias	-
Study size	10	Explain how the study size was arrived at	37
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	68
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	68
		(b) Describe any methods used to examine subgroups and interactions	68
		(c) Explain how missing data were addressed	118
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed	
		<i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	
		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	
		(e) Describe any sensitivity analyses	

Continued on next page

<b>Results</b>			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	69
		(b) Give reasons for non-participation at each stage	-
		(c) Consider use of a flow diagram	-
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	69,70
		(b) Indicate number of participants with missing data for each variable of interest	118
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	-
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	-
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	-
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	-
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	73-76
		(b) Report category boundaries when continuous variables were categorized	-
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
<b>Discussion</b>			
Key results	18	Summarise key results with reference to study objectives	76-78

Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	78,79
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	76-79
Generalisability	21	Discuss the generalisability (external validity) of the study results	78,79
<b>Other information</b>			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	-



## Appendix J Consolidated criteria for reporting qualitative research guidelines

No. Item	Guide questions/description	Reported on Page #
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	86
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	25-27
3. Occupation	What was their occupation at the time of the study?	25-27
4. Gender	Was the researcher male or female?	N/A
5. Experience and training	What experience or training did the researcher have?	86
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	86
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	86
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	86
<b>Domain 2: study design</b>		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	86
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g.	85, 86

	purposive, convenience, consecutive, snowball	
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	85, 86
12. Sample size	How many participants were in the study?	86, 87
13. Non-participation	How many people refused to participate or dropped out? Reasons?	86,87
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	86
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	86
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	85, 86
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	86, Appendix L
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	86
20. Field notes	Were field notes made during and/or after the inter view or focus group?	86
21. Duration	What was the duration of the interviews or focus group?	86
22. Data saturation	Was data saturation discussed?	41, 42
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
<b>Domain 3: analysis and findings</b>		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	86
25. Description of the coding tree	Did authors provide a description of the coding tree?	Appendix F
26. Derivation of themes	Were themes identified in advance or derived from the data?	86
27. Software	What software, if applicable, was used to manage the data?	86

28. Participant checking	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	87-92
30. Data and findings consistent	Was there consistency between the data presented and the findings?	87-92, Appendix M-O
31. Clarity of major themes	Were major themes clearly presented in the findings?	86-92
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	87-92



## Appendix K Participant materials for qualitative study with healthcare professionals

### K.1 Participant invitation email

Dear [First name],

Thanks so much for taking part in the Renewed study as a 'Supporter' of patients who are using the Renewed website to improve their quality of life after finishing primary treatment.

The study is going really well and its now time for us to interview you about your experiences of providing support in this study. Interviews are over the phone and usually quite short (often 20 mins, the longest has been 30 mins), we just want to know what it was like to provide support to patients in this study to help us understand what its like being a Supporter. I'm happy to fit in around your schedule and can speak in the daytime, or in evenings if that is more convenient. When would be best for you?

I've attached the study information sheet which has further details about the study. If you have any questions then feel free to give me an email or call me [researcher's number]. Look forward to speaking to you soon and thanks again for all your help with this study, we really appreciate it.

With many thanks,

Jazzine on behalf of the Renewed team

### K.2 Participant information sheet

A study of care-provider feedback for an online support for people who have had cancer  
**Supporter Feedback study**

**We invite you to take part in an extra part of the Renewed study**

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It is up to you to decide whether or not to take part. This booklet tells you why the study is being done and what it will involve. After you read it you can choose whether or not you want to take part. Please contact us if anything is unclear or you would like to ask any questions.

### **A quick summary of the study**

- **This study is asking healthcare and cancer charity workers what they think about the Renewed website and study.**
- **If you take part, we will talk to you on the phone for 30 – 60 minutes or if you are available, we will invite you to take part in a focus group. We will ask you questions about what you think of the Renewed study.**
- **We are interested in hearing all sorts of feedback to help make the study the best we can.**
- **The study is being run by the University of Southampton and is funded by the National Institute for Health Research, the main funder of research in the NHS.**
- **Research costs will be paid for your time.**

---

### **What do I do next?**

If you are interested, please get in touch with us.

- **Email us at [renewed study email] or**
- **Phone us on [researcher's number]**

### **What is the aim of the study?**

The aim of this study is to find out what people think of the 'Renewed' study and support website. Patients have been able to try out the Renewed website for a couple of months and have been getting support if they are in the support group of the study and now we would like to hear your opinions about it. It doesn't matter if you have had support sessions with many people or not. All feedback is valuable and we try to get lots of different comments to help us to make the study and support as good as possible.

### **Why have I been invited?**

You have been invited because you have been taking part in the Renewed Study as a healthcare worker or supporter. We hope that about 36 people will take part in this study.

### **What will happen to me if I take part and what do I have to do?**

We will arrange a telephone call to talk to you about what you thought of the website. We may invite you to take part in a focus group, but you do not have to attend if you are not available.

### **What are the possible pros and cons of taking part?**

There is no direct benefit to you taking part but your feedback is very valuable and will help us to create an intervention that works well and support sessions that can help people. In our other studies, people have expressed interest and satisfaction in taking part, enjoyed learning new things and liked having their views listened to. We will pay research costs for your time.

The main disadvantage of taking part is that it will take up some of your time: about 30-60 minutes for the interview, depending on how much you would like to talk about.

### **What will happen if I don't want to carry on with the study?**

If you choose to take part in this part of the study you are free to change your mind and withdraw at any time without giving a reason. If you decide to stop taking part then we would still like to use the anonymous information you have given us for the research study, unless you tell us not to.

### **Will my taking part in this study be kept confidential?**

With your permission, the interview will be audio-recorded to make an accurate record of what is said. These recordings will be typed up and your name or any other details that can identify you will be removed, to ensure your privacy. These anonymised transcripts (which don't include information which identifies who you are) will be stored on a password protected file on secure University of Southampton computers. The recordings will be kept securely on the computer system at the University of Southampton which only the research team can access. The recordings will be destroyed when the study is complete. The findings from this study will be used in research reports and the website, but no names will be included in the report or website so any quotes from the interview will be anonymous.

### **What will happen to the results of the research study?**

The results will be shared as widely as possible with everyone interested in improving quality of life for people who have had cancer in the past, including doctors, nurses and the general public. We will send you a summary of the findings if you would like one.

### **Who has reviewed the study?**

The study has been reviewed and given approval by North West- Greater Manchester West NHS Research Ethics Committee Ref 18/NW/0013 (IRAS Ref 238636).

### **What if there is a problem?**

If you have any concerns or feel that you have been placed at risk you can contact the Head of Research Governance at the University of Southampton at [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk) or telephone 023 8059 5058.

### **How can I find out more?**

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For more information about this study or **if you would like to take part** please email us at [renewed study email] call us on [researcher's number] and ask to speak to the Renewed study team.

Whether or not you take part, nothing will change about the Renewed study you are already taking part in.

**THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION**

### **K.3 Online consent form**

**Renewed Online Feasibility Study: A study of care-provider feedback for online support for people who have had cancer (Health Professionals interviews)**

**If you are happy to take part in this research then please read all 6 statements below and initial all the boxes if you agree with them.**

1. I confirm that I have read the Participant Information Sheet (version 2.1, dated 08.03.19) and understand what I will be doing in this study.
2. I understand that I do not have to take part and that I can withdraw at any time without giving a reason, and this will not affect my legal rights.
3. I understand that audio recordings collected during the study may be studied by researchers from the University of Southampton and by regulatory authorities.
4. I am happy for a voice recording to be made of any interviews or focus groups, with possible use of anonymous quotations in reports and publications
5. I understand that any voice recordings made will be typed up and anonymized (all information that could identify you as an individual is removed) and this anonymized data may be used for any research, clinical or teaching purposes.
6. I agree to take part in the above study.



## Appendix L Interview schedule for qualitative study with healthcare professionals

### Telephone Interviews

- Introduce yourself to the participant, remind them about the purpose of the interview (to find out how they found being Support in the Renewed study), ask if they have any questions.
- 
- State that you will be recording the conversation to check they are happy with this.
  - Most interviews last between 30-60 minutes, depending on how much you have to say.
- Notify participant you will start recording. Remind them that they can take a break at any point or stop without giving a reason if they would like to.

### Introduction

Before recording, explain outline of phone call.

- Firstly, **thank you very much for agreeing to be a Supporter** in the study. This is a study to find out more about your experience of being a supporter for the 'Renewed Online' Study. Renewed Online was designed for people to use at home and provides online support for people after cancer treatment.
- Today, I will asking you about your experience of offering support to patients using the programme
- There are **no right or wrong answers**, so please say any thoughts which spring to mind, even if you think they might not be important.
- We can **take a break** at any time you like, please just let know and I can pause the recording. We can also stop the interview at any time if you want to.
- If you are happy, **we will record the interview**, so we can listen again to what is being said.
- We will not keep anything on record that identifies you, or which practice you work for or anyone else that you mention, so it will all be anonymous. Also, everything we talk about here will be **confidential**.
- Do you have any questions before we start? If you have any questions during the interview I can answer them at the end once we've finished recording.

### Interview schedule:

#### 1. Opening questions

To start, I have a few short **questions to ask you about your experience of working with cancer patients.**

- Before the start of the Renewed study, how did you support patients who had had cancer and finished treatment?
  - What was your usual practice?

## **2. Supporting patients using renewed**

I'm really interested to hear all about what it was like to support patients in the Renewed study, please can you tell me all about it?

Probe anything interesting that the supporter says.

### **Then ask:**

- Can you tell me about anything you liked about supporting patients?
- Can you tell me about anything you disliked about supporting patients?
- Can you tell me about anything that you think should be changed?
- Can you tell me about any benefits you feel you've gotten by being a Supporter in the Renewed study?
- What do you think patients thought of the support you provided alongside Renewed?

## **3. Supporter Training**

- Can you tell me what you thought of the online supporter training that you completed at the start of the study?
- Can you tell me about anything you liked about this training?
- What was useful about this training?
- Can you tell me about anything you disliked about this training?
- Can you tell me about anything else that you thought could have been useful to include in this training?

## **4. Support appointments**

- Can you tell me about what happened during the support appointments that you had with participants? (Probe: what did you do during these appointments? What kinds of topics were discussed?)
- How did you find following the support outlined in the Supporter's guide?
- Can you tell me about anything you liked about the appointments?
- Can you tell me about anything you disliked about the appointments?
- Can you tell me about any benefits of these appointments?
- How did you feel during the appointments?
- Can you tell me about any problems that you encountered during support appointments?
  - IF they raise barriers to use ask: Can you tell me about any suggestions that you have of how we might overcome this problem?
- Can you tell me about your experiences of providing support appointments by telephone? (what was this like? How did phone appointments compare to face-to-face)?

## **5. Questions about emails**

**Check online if the supporter sent emails to patients through the supporter website, if yes ask:**

- How did you find sending emails to patients?

**If no ask:**

- Did you need to provide any email support to patients at any point during the study? (if yes: Can you tell me a bit about that? Probe, how they sent the emails and what it was like).
- Can you tell me about any emails you received from patients? (How did you find getting these emails?)

**6. The CARE Approach**

What did you think of the CARE approach that - Congratulate, ask, reassure and encourage?

- Can you tell me about anything that you liked about the CARE approach?
  - Can you tell me about anything that you disliked about it?
  - IF they raise barriers to use ask: Can you tell me about any suggestions for how you might overcome that problem?
- Thinking about what you do within your role on a day to day basis, how did supporting patients who were using Renewed fit in with your usual role? ***If they raise any concerns:*** You mentioned (re-state the problem they discussed), can you tell me about any ways that you might overcome that?

It would be good to hear your thoughts about implementing the intervention in everyday practice:

- Can you tell me about any benefits you can see in implementing the intervention in usual practice?
- Can you tell me about the any problems you can see in implementing it?
- Could you tell me about any suggestions you have to overcome these problems?

**7. Questions about the overall intervention:**

- Overall, how do you feel about being a supporter on the Renewed study?
- Can you tell me about anything else that we've not discussed that you felt you'd like to mention about the programme?

Other prompts

Can you tell me a bit more about why you think that?

What is it you like about that?

That's really interesting.....



### Appendix M Excerpt of coding manual for qualitative study with healthcare professionals

<b>Practicalities of managing supporter role</b>	How supporting patient fit into workload	Mentions how their workload or schedules may affect how they are able to carry out the role.	<p>“I overran massively with that patient when he was having the conversation with me, obviously, with the feedback about the Renewed. So I think... So in that way, that makes it a bit tricky with the—your normal day-to-day clinic because then obviously you’re running late for all your other patients.”</p> <p><i>(Participant 23, practice nurse)</i></p>
	Keeping appointments to 10 minutes	Discusses whether or not they managed to keep appointments to 10 minutes	<p>“I think timing was quite tight to do that in the ten minutes that we, you know, I think we were meant to be doing our support in ten minutes, which is quite hard, I think.”</p> <p><i>(Participant 9, practice nurse)</i></p>

	Arranging sessions	Discusses how sessions were arranged.	<p>“I always said that the door was open if they needed to come back to just explain to the girls on reception that you were part of the trial and to book the nearest appointment I had available...And they all understood that and, and that’s what they did.”</p> <p><i>(Participant 11, practice nurse)</i></p>
	Phone sessions vs. face-to-face sessions	Discusses the differences between phone and face-to-face sessions.	<p>“It [phone sessions] was good in that you were able to keep to time...it is different because I do it face-to-face [<i>in other studies, not in Renewed</i>] and I think, yeah, it’s, from a time management perspective, doing it over the phone was much better. However, it would have been nice to meet these people as well face-to-face, but I don’t think you could have kept of track as well as you would’ve if you can on the phone.”</p> <p><i>(Participant 3, CRN nurse)</i></p>

## **Appendix N      Excerpt from audit trial for qualitative study with healthcare professionals**

18/02/2020 12:29

Currently coding transcript n1438 and this has highlighted in this idea of building rapport/familiarity with patients. This participant mentioned that emailing a patient who you have never met or spoke to invite them to have a support session with you seemed unnatural, especially given the unprofessional tone of the email templates which implied a more friendly tone...yet the patient does not know the HCP. Suggested that if the templates were written as if you were sending them to your mate, whereas in this context you've never met each other. She suggested an initial f2f meeting would be best before any email of correspondence, after this meeting the email and so forth could begin as such. Similarly, transcript c1725, suggested that to start speaking to someone you've don't know and have never met is a something for which you need confidence, suggesting that if the patient was instead speaking to someone who they knew (i.e. a practice nurse) they may have been more interested in having support sessions. She said if they roles were reversed she'd she this person trying to contact her and be apprehensive about who this person may be.

19/02/2020 12:15

CARE approach restrictive and does not facilitate fluid conversation: C2220 and N3801.

26/02/2020 11:50

Codes 'confidence in providing support' and 'supporter's perception in the support they provided' reflect that: HCA's seems to be less confidence and more likely to believe the haven't done much when supporting patients compared with nurses. Also, it appears HCA would prefer a more thorough and detailed training provided practical examples and workshops/shadowing. (refer to transcript N2227). HCA may med more aids during sessions, posters, leaflets, goals etc...to support and guide conversations (N2227 code expectations of providing support).

Code The setup process for supporters; reoccurred that hard to make contact with patients because they name would be in one list but their emails and contact information in other, which was not always accessible in every practice. And then there's too many emails coming through from Renewed and they sometimes are delayed/referring to something that has already happened or no longer relevant.

27/02/2020 11:29

The second patient this HCP supported had relapsed. Raises concern of the suitability of allowing those who relapse to continue with the study as some of the information is irrelevant and can be triggering (i.e. FCR). If they continue suggests better provision be made for them. = Transcript C1628.

Bridges on the idea that those who are not computer literate need extra support with using Renewed. suggests it have be useful to have a f2f sessions which focuses on how to access and use Renewed. Also mentions the issues with arranging appointments through email and the patient saying he never received an email.

27/02/2020 12:03

N1342, C1628 and N1042 all have or had a strong background with supporting cancer patients. It will be necessary to compare their codes against those that did not have any previous experience with those who have had cancer treatment. On surface reflection N1042 appears to have a depth of understanding of how practice nurse may be best suited to Support such a study and speaks on the necessary time needed in an appointment of this nature.

27/02/2020 12:22

Preliminary theme 'Role of supporter':

Subtheme: 'Skills to preform role': Confidence providing support, fit within role, familiarity with patients, burden, supporter training.



Subtheme: 'Understand the role of supporter': perceived role of supporter, adjusting to supporter role, patients guiding appointments, patients perceptions of support received, supporter's perception of the support the provided, supporters expectations.



## **Appendix O      Excerpt from reflective log for qualitative study with healthcare professionals**

N3021 08/10/2019 @ 17:30

Was a HCA at practice, only had one support phone conversation over the phone which lasted 30 minutes. Did not have much to prompt outside of long appointment and contradictory to get patients. Was told they must contact patients but was also told patients must contact them. The patient she did end up seeing she met because they came into the surgery asking for the supporter. Liked the CARE approach and training, but couldn't elaborate on how it fits into her role or how implementing may or may not help.

Prompts may have been suggestive as she was really struggling to think of what to say. Need to be more mindful and probably ignore answers to these in analysis. In future do not interview HCPs with only 1 support appointment experience, does not provide much rich data.

N2227 09/10/2019 @16:00

Participant was a HCA who had supported 2 patients. She did not particularly enjoy her experience being a supporter and would get confused with the load of emails sent from renewed. Like that patients were offered extra support after finishing treatment, but felt as if they support she was giving was of no benefit. Struggled supporting one of her patients who she believed had anxiety and was not engaging much, she did signpost him on for further help. Could not remember much from the training but remembers that she felt it was not so good and did not prepare her for being a supporter.

I was a little distracted during this interview. In future, do not respond to email at least 30 minutes before interview. Prompts were good at some parts, other missed due to distraction. Need to sound more friendly and engaging.

N1257 Interview 30/10/2019 @ 17:00

Interview with nurse who had support 1 patient and had 1 appointment. Patient visited her before even using the renewed website, wanted to know what it is all about and how she should be using it. (interesting about a lot of patients expect their supporter to know a lot about

renewed and advise them on how they should be using it, whereas supporter often don't understand renewed and cannot see what they are doing...shifts the balance then so that it has to be patient driven, but are patients accepting on this balance? Do they prefer nurse lead?). suggested that other patient maybe did not meet with her because patient was a worker so practice opening hours made appointments inaccessible. (interesting, maybe online support sessions may have overcome this?). Said implementation would be beneficial if there were enough resources (particularly staff levels and long appointment times, 10 not enough to make the patient feel as if you want to help them).

Prompts okay, missed a few opportunities.

N3801 Interview 31/10/2019 @ 12:00

Interview with practice nurse turned research nurse. Had supported 4 patients, all supports sessions via phone. Support was done a while ago so could not remember every detail, especially about training. Remembers 2 patients, one who had a follow up and one who didn't. Spoke about many things, renewed needing modernising, cs needing more support, and interesting such an intervention needing to be offered right at the point of finishing treatment.

Was a long interview but prompts were good and showed interest. Be careful how you word questions.

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