

# The Role of Connected Health Technologies in Supporting the Psychosocial Wellbeing and Quality of Life of People Living with and Beyond Cancer

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#### **Abstract**

The number of people living with and beyond cancer (PLWBC) has been steadily increasing in recent years. This growth brings a parallel rise in the demand for ongoing care for the physical and psychosocial challenges associated with cancer diagnosis and treatment. However, access to care and support is limited. Connected Health (CH), defined as the use of technology to gather, analyse, and interpret user data to improve health outcomes, offers a promising solution for bridging healthcare gaps and expanding access to vital support services. While CH holds potential for improving cancer survivorship care, limited evidence exists on how CH interventions are experienced and adopted by PLWBC in Ireland. This thesis examines the potential of CH to support the psychosocial wellbeing and Quality of Life (QoL) of PLWBC, guided by three key objectives namely (i) to examine the role of CH in supporting psychosocial well-being and QoL of PLWBC, (ii) to identify the factors influencing the adoption and utilization of CH technologies among PLWBC and (iii) to explore the barriers and facilitators to CH implementation within the Irish context of cancer survivorship.

This research comprises six interconnected studies to achieve these objectives. Study 1, a systematic literature review and meta-analysis (n = 33 studies), establishes the positive but mixed impact of CH interventions on psychosocial outcomes, in particular anxiety and depression symptoms, and QoL in PLWBC. Study 2, a secondary data analysis of the US-based, population level Health Information National Trends Survey, focused on individuals who self-identified as having has a cancer diagnosis (n = 626). This study identified factors associated with CH use among PLWBC, offering a broad population-level snapshot of access, usage and potential digital disparities, and provided a macro-context for more focused Irish-based studies that followed. The subsequent empirical studies (studies 3a, 3b, and 4) utilised the setting of the Cancer Thriving and Surviving (CTS) programme, a nationwide cancer survivorship programme in Ireland, to explore the PLWBC's experiences with its online delivery. Study 3a (n = 44) utilised a mixed methods cross sectional design and demonstrated high usability and user satisfaction with CH technologies to deliver the programme in its online format, while also highlighting varying motivations for CH, and the need for tailored approaches. A further analysis of this dataset (Study 3b) revealed that unmet needs may remain among PLWBC even after participating in the programme, highlighting the importance of providing ongoing care and support to this cohort. Study 4 (n = 43) utilising a cross sectional post-test design compared post programme outcomes and experiences between participants who completed the CTS programme online versus in-person, examining modality preference and associated psychosocial outcomes. Results showed that both modalities are well received and could be utilised in supporting psychosocial wellbeing QoL in PLWBC. This study also highlighted the influence of individual, contextual and geographical factors on delivery mode selection and experience, rather than treating CH as a neutral or uniform medium. Finally, drawing upon insights from the preceding quantitative studies, the fifth study, a qualitative descriptive study, uses in-depth interviews with PLWBC (n=15) to provide richer insights into their lived experiences, challenges and enablers of CH, adding depth and personal context to the preceding studies. Findings showed that, while convenience and improved access to support are highly valued, digital divide concerns and the impersonal nature of virtual interactions are notable barriers to CH use.

Taken together, this research demonstrates the potential of CH technologies in expanding access to survivorship support while also acknowledging the limitations, complexities and contextual factors that influence their adoption and impact in practice. This research underscores the need for personalised, patient-centric CH services that directly address the identified barriers while leveraging facilitating factors. These findings offer valuable insights into improving the adoption and utilisation of CH technologies, ultimately enhancing the accessibility of care and support for PLWBC. This is particularly crucial in the Irish context, where rapid digitalization presents a significant opportunity to improve patient outcomes.

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#### List of abbreviations

AI Artificial Intelligence

Apps Applications

ARC Cancer Support Centres BFI Brief Fatigue Inventory

CAU Care as Usual

CBT Cognitive Behavioural Therapy

CH Connected Health

CTS Cancer Thriving and Surviving

DT Distress Thermometer eHealth Electronic Health

EHRs Electronic Health Records

EORTC QLQ- European Organization for Research and Treatment of Cancer

C30 Quality of Life Questionnaire-Core 30

FACT-G Functional Assessment of Cancer Therapy-General

GLOBOCAN Global Cancer Observatory

GP General Practitioner

HADS Hospital Anxiety and Depression Scale

HCPs Healthcare Providers

HINTS Health Information National Trends Survey

HRQoL Health-Related Quality of Life
HSE Health Service Executive

IACR Irish Association for Cancer Research

IARC International Agency for Research on Cancer

ICS Irish Cancer Society

IHCA Interactive Healthcare Communicative Applications

IPSON Irish Psycho-Social Oncology Network
IPOS International Psycho-Oncology Society
LACES Life and Cancer- Enhancing Survivorship

MMAT Mixed Methods Appraisal Tool

mHealth Mobile Health

NCCN National Comprehensive Cancer Network
NCCP National Cancer Control Programme
NCCS National Cancer Survivorship Service

NCI National Cancer Institute

NEHR National Electronic Health Record
NIHR National Institute for Health Research

PA Physical Activity

PHQ-9 Patient Health Questionnaire-9

PLWBC People Living With and Beyond Cancer
PPI Public and Patient Involvement (in Research)

Preferred Reporting Items for Systematic Reviews and Meta-

PRISMA Analyses

PSS Perceived Stress Scale

PTGI Post-Traumatic Growth Inventory

QoL Quality of Life

RCT Randomised Control Trial

SC Standard Care

SCNS-SF34 Supportive Care Needs Survey-Short Form 34

SE Standard Error

SIG Special Interest Group SMD Standard Mean Difference

Sláintecare Ireland's Healthcare Reform Programme SPSS Statistical Package for Social Sciences TUQ Telehealth Usability Questionnaire

WHO World Health Organisation

#### **Publications arising from the thesis**

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# Chapter 1 General Introduction

#### 1.1. Cancer and the Shifting Burden

Cancer, which encompasses a diverse group of diseases characterized by uncontrolled cell growth and spread (Weinberg, 1996), poses a global challenge. This abnormal proliferation, driven by transformed cells subject to evolutionary pressures, can invade surrounding tissues and metastasize to distant sites (Brown et al., 2023). The World Health Organization (WHO), through its cancer research arm, the International Agency for Research on Cancer (IARC), recognizes cancer as a leading cause of death globally, with nearly 10 million deaths attributed to the disease in 2020 (WHO, 2024). In 2022 alone, an estimated 20 million people received a cancer diagnosis, with approximately 9.7 million dying from the disease, according to the Global Cancer Observatory (GLOBOCAN). This already substantial burden is projected to escalate dramatically, with predictions forecasting a surge to 35 million new cases by 2050 (Bray et al., 2024).

While cancer incidence rates vary significantly across geographic regions and populations, some cancers, including breast, lung, colorectal, prostate, skin (non-melanoma), and stomach cancers, consistently rank among the most prevalent globally (Bray et al., 2024). The rising incidence of cancer and its profound impact on individuals, families, and healthcare systems globally underscore the need for innovative approaches to prevention, early detection, and treatment strategies, as well as comprehensive support for people living with and beyond cancer (PLWBC) (Debela et al., 2021; Levit et al., 2013).

Like the rest of the world, cancer presents a significant health challenge in Ireland. According to a report from the National Cancer Registry of Ireland (National Cancer Registry Ireland, 2023), an average of over 43,470 new cancer cases were diagnosed annually between 2018 and 2020. Moreover, the same report indicates that cancer accounts for approximately 30% of all deaths annually, with an average of 9,493 deaths from invasive cancers each year between 2018 and 2020 (National Cancer Registry Ireland, 2023).

On a positive note, continued advancements in cancer treatment, early detection, and supportive care have led to a steady increase in the number of PLWBC worldwide (Bray et al., 2024). This situation has been described as a 'pandemic of treatment success' (Wolff, 2007). Increasing survival rates have been attributed to, among other things, breakthroughs in medical technology (Bray et al., 2024). This includes the development of novel chemotherapeutic agents, targeted therapies, and

immunotherapies (Markham et al., 2020; Raghani et al., 2024). Furthermore, advancements in diagnostic imaging and screening techniques allow for earlier detection, often at more treatable stages, further bolstering survival outcomes (Hoskin et al., 2021). Concurrent with these medical advancements is the demographic trend of an aging global population (Martini et al., 2007). As individuals age, their susceptibility to developing disease, including cancer, increases (White et al., 2014), making age a significant risk factor. This demographic shift, coupled with improved survival rates, translates to a growing number of people living with cancer who require ongoing care and support.

Globally, it is estimated that that there are over 50 million people who were alive within five years following cancer diagnosis in 2022, a figure projected to grow significantly in the coming decades (WHO, 2024a). Reflecting international trends, Ireland has also witnessed encouraging improvements in cancer survival rates in recent years. The National Cancer Registry reported that five-year net survival for patients diagnosed with cancer between 2014 and 2018 improved considerably. However, survival rates depend on the type of cancer. For example, the five-year net survival rates for breast and prostate cancer are among the highest (above 80%), while those for pancreatic and liver cancer are substantially lower (below 20%). By the end of 2020, over 207,000 people in Ireland were living well after a cancer diagnosis, representing approximately 4.2% of the population, or about 1 in 24 people (National Cancer Registry Ireland, 2023).

The rising population of PLWBC, both globally and Ireland alike, presents a need for comprehensive support services and interventions tailored to patient needs, with a growing focus on cancer survivorship. As a result, the landscape of cancer care has been dramatically altered in recent decades, shifting from a focus on mortality to one of survivorship (Emery et al., 2022; Shapiro, 2018). This shift presents both opportunities and challenges for healthcare systems worldwide (R. J. Chan, Hollingdrake, et al., 2021; Shapiro, 2018). One such challenge is the growing pressures on healthcare systems (Prager et al., 2018; Wolff, 2007). PLWBC often require long-term follow-up, management of late and long-term effects, ongoing psychological support, and coordination across services (Shapiro, 2018a; WHO, 2024d). These demographic changes place considerable strain on health systems that are already stretched, particularly in terms of specialist oncology staffing, access to community-based survivorship services, and continuity of care. This strain is exacerbated by chronic

healthcare workforce shortages (Trapani et al., 2021; WHO, 2024b) and fragmented care pathways. Meeting the sometimes complex and long-term needs of PLWBC, which extend beyond medical treatment, necessitates a similar paradigm shift in healthcare delivery models. Even more critical is, while cancer may present with broadly similar symptoms and treatment protocols, each individual's experience is unique (Emery et al., 2022; Han et al., 2020), particularly regarding the impact of the disease on the individual and its associated treatments. Therefore, personalised support framed around patient needs is paramount, and has in the recent past become the loci in design and delivery of supportive care and research (Clauser et al., 2015; C. Taylor, 2024). Moreover, the longterm effects of cancer and its treatments can persist for months, years, or even a lifetime after treatment ends (Shapiro, 2018; Stein et al., 2008). These effects can include physical challenges like chronic pain, fatigue, lymphedema, and increased risk of other health conditions (Stein et al., 2008). Psychosocial challenges including anxiety, depression, fear of recurrence or fear of progression, and relationship and financial difficulties, can also persist long-term. Addressing these needs in PLWBC is essential for improving their overall quality of life (QoL), and long-term health outcomes (Essue et al., 2020).

#### 1.2. Cancer Survivorship

The concept of cancer survivorship has evolved significantly since its introduction in the early 1980s by Dr. Fitzhugh Mullan, an American physician and person living with cancer. His impactful 1985 article (Mullan, 1985) detailing his personal cancer journey helped shift the perception of survivorship from a single outcome to an ongoing process. Initially defined as the phase following the completion of primary treatment (Institute of Medicine and National Research Council., 2005), survivorship now encompasses a broader understanding, recognising the end of treatment marks the beginning of rehabilitation.

It is now widely accepted that survivorship includes the health and well-being of individuals from the point of diagnosis onward, recognising that cancer's impact is felt throughout the person's life (NCI, 2024). This perspective is further echoed by the National Coalition for Cancer Survivorship (NCCS, 2024). Thus, survivorship encompasses the physical, mental, emotional, social, and financial effects that begin at diagnosis and continue beyond treatment. It also includes follow-up care, addressing late effects of treatment, the potential for recurrence or second cancers, and importantly,

impacts on QoL. Furthermore, survivorship experience involves not only the individual diagnosed but also their family, friends, and caregivers (NCI, 2024). While survival rates have improved globally, a substantial proportion PLWBC continue to experience enduring challenges such as fatigue, cognitive decline, altered self-identity, financial toxicity, and fear of recurrence, among others, many of which fall within the domain of psychosocial wellbeing and QoL (C. Kumar, 2020; Pitman et al., 2018), the two main outcomes of interest in this research.

Psychosocial wellbeing aligns with the multidimensional construct in personcentred models of survivorship care, and captures both internal and external influences on wellbeing following a cancer diagnosis (Benedict et al., 2022). Notably, psychosocial wellbeing is closely related to, but distinct from three other constructs extensively used in this thesis. These are (i) psychological wellbeing, which refers to internal emotional states and personal functioning (for example life satisfaction, self-worth) (Ryff, 2013; Ryff & Singer, 1996; Speight et al., 2009) (ii) depression and anxiety, which represent clinical or subclinical symptoms of distress (APA, 2025; WHO, 2025a); and (iii) QoL. A common trend identified in a previous review is the measurement of psychological well-being primarily through negative constructs (e.g., depression, anxiety), with less emphasis on indicators of positive mental health (Speight et al., 2009).

Quality of life, often subjective, is influenced by factors such as physical health, psychological state, social relationships, level of independence, and personal beliefs (Barofsky, 2012; Fayers et al., 2002; Testa & Simonson, 1996). Essentially, QoL reflects an 'individual's perception of their position in life in the context of the culture and value systems in why they live in relation to their goals, expectations, and standards' (WHO, 2025b). While early conceptualisations of QoL focused predominantly on health status, contemporary definitions recognise its dynamic and subjective nature, influenced by evolving experiences across the cancer continuum (European Cancer Organisation, 2024; Fayers et al., 2002).

In the context of cancer survivorship, QoL includes physical health, psychological state, level of independence, social relationships, and relationship to salient features of the environment (Fayers & Bottomley, 2002). Most recent survivorship-specific frameworks often extend this conceptualisation to include concerns about recurrence, financial toxicity, altered body image, and long-term treatment effects. This expansion is reflected in the recently developed QoL in survivorship questionnaires by the Survivorship and QoL network within the *European* 

Cancer Organisation (Marieke et al., 2023), whose validation across different contexts is still ongoing. QoL's importance in survivorship has been evident in its prominence within cancer research literature (Fayers et al., 2002). For instance, a review of papers published in the Journal of Cancer Survivorship (JCS) since its inception in 2007 found "quality of life" to be the most frequently used keyword (R. J. Chan, Hollingdrake, et al., 2021). Similarly, a review of presentations at the International Psycho Oncology Society (IPOS) World Congress over a four-year period (2017 to 2021) identified QoL as the most common topic of interest (Gitonga et al., 2023). Psychological well-being was the second most common.

Psychosocial wellbeing and QoL are often interrelated in PLWBC. For example, cancer-related fatigue or pain can lower QoL (Muthanna et al., 2023), while reduced social support may contribute to anxiety or depressive symptoms (S. Cohen & Wills, 1985). However, while these overlaps may exist (Eiroa-Orosa, 2020), psychosocial wellbeing is used as the umbrella concept, encompassing both emotional and social support dimensions (C. Kumar, 2020). Broadly speaking, while QoL encompasses a broader view of functioning, psychosocial wellbeing focuses more narrowly on emotional and interpersonal domains. Both are important to understand the cancer survivorship experience and are thus examined accordingly across the studies in this thesis. Where relevant, more specific outcomes such as anxiety, depression, self-efficacy, or QoL are explicitly named. These terms, alongside others used in the thesis, are operationalised later in this chapter.

# 1.2.1 Cancer Survivorship Landscape in Ireland.

Ireland's healthcare is organised in a two-tiered system, offering both public services, managed by the Health Service Executive (HSE), and private healthcare options (Turner, 2018). Cancer care is provided through this mixed system, with the HSE coordinating the majority of publicly funded services. Cancer treatment is centred around specialized cancer centres which offer comprehensive care pathways from diagnosis, as well as various therapies. General Practitioners (GP) play a key role in early detection and referrals. While publicly funded care is available for eligible individuals, those with private insurance often experience quicker access to services, a situation that has been viewed as undermining the fundamental principle of equity and universal access (Johnston et al., 2019). Current reforms under the Sláintecare programme, a 10-year plan which commenced in 2017, aim to transition Ireland towards

a single-tier healthcare system, thereby improving access to cancer care, reducing wait times, and enhancing community-based support for a more holistic approach (Burke et al., 2018). However, progress evaluations have noted a slow implementation of this programme (Thomas et al., 2021). As Thomas et al., (2021) note in their implementation status report, expanding entitlements under Sláintecare has been 'slower than initially anticipated' due to several interconnected factors, ranging from financial constraints, changing political realities, shifting policy focus, and the complex, adaptive nature of health system reform, which has prioritized organisational change over entitlement expansion.

The Irish healthcare system also prioritizes community-based support for cancer patients, including psychosocial care and survivorship programmes. The HSE's National Cancer Control Programme (NCCP), often working in conjunction with charitable organizations like the Irish Cancer Society (ICS), provides comprehensive support and resources for patients and their families (NCCP, ICS, 2024). Recognising the importance of holistic cancer care, Ireland has prioritised psycho-oncological care within the recent National Cancer Strategy 2017-2026 (Department of Health, 2017). More specifically, recommendation 43 of the strategy designated NCCP to work with cancer centres to develop and implement survivorship programmes in order to enhance the support for PLWBC. The strategy provides a roadmap for improvements in cancer prevention, diagnosis, treatment, and survivorship. A key emphasis is placed on a patient-centred approach, recognising the need to address the holistic needs of individuals affected by cancer.

As part of ongoing efforts, a 2019 scoping review conducted by the Irish Cancer Society, the NCCP, and the National Cancer Registry Ireland revealed significant gaps in understanding the unmet needs of PLWBC in Ireland (O'Connor et al., 2019). The review also noted that, while existing research primarily focused on common cancers (e.g., prostate, colorectal, and breast cancer), there was limited understanding of the needs of those living with rarer or more aggressive cancers. The review further highlighted shared unmet needs among PLWBC, including physical and psychological challenges and lack of information. While highlighting psychological wellbeing as one of the top unmet needs, the review recommended regular and direct collection of data from PLWBC to ensure their evolving needs are met effectively. Given the shifting and rising burden in survivorship care, especially post-treatment and in the community setting, innovative models are imperative to provide scalable, person-centred support.

# 1.3. Healthcare Digitalisation

Increasing healthcare digitalisation presents new frontiers and opportunities in healthcare delivery (Shaffer et al., 2023), with the WHO leading the way in developing relevant strategies for its adoption globally (WHO, 2021a). Digital health, encompassing the use of technology to improve health outcomes and healthcare delivery, has witnessed substantial growth in recent years (Awad et al., 2021; Bhatia, 2021). For instance, Electronic Health Records (EHR) have become increasingly common, replacing paperbased systems and facilitating seamless information sharing among healthcare providers (HCPs) (Ambinder, 2005). Telemedicine, leveraging video conferencing and remote monitoring tools, has emerged as a tool to extend the reach of healthcare professionals, particularly to geographically remote or underserved populations (R. J. Chan, Crichton, et al., 2021). Moreover, mobile health (mHealth), using smartphones and other mobile devices, can empower patients to actively participate in their care through personalized health information, medication reminders, and symptom tracking (Figueiredo et al., 2017a; Y. Jiang et al., 2017). Wearable sensors, such as fitness trackers and smartwatches, provide continuous monitoring of vital signs and activity levels, enabling early detection of potential health issues and facilitating proactive interventions (Fisch et al., 2016; Millstine et al., 2019; H. Onyeaka et al., 2021). Furthermore, artificial intelligence (AI) is rapidly being integrated into various aspects of healthcare, from assisting with diagnosis and treatment planning to automating administrative tasks and analysing large datasets to identify trends and improve outcomes (Derbal, 2022; Ho, 2020). Among the latest conceptualisations of digital health, is connected health (CH).

#### 1.3.1 Connected Health

Building upon the broader digital health landscape, CH represents a paradigm shift in healthcare delivery, leveraging technology to bridge the gap between patients and providers, empowering individuals, and extending the reach of care beyond traditional settings (Caulfield & Donnelly, 2013). CH encompasses the use of digital technologies within healthcare settings to facilitate a two-way flow of information between the user and the technology (Awad et al., 2021; Iglehart, 2014). It includes a range of tools and technologies, including remote patient monitoring devices, telehealth platforms, mobile health applications, wearable sensors, and online patient portals (Awad et al., 2021; Iglehart, 2014). These interconnected technologies work in synergy

to provide holistic and patient-centred care, empowering individuals to actively participate in their health journey (Iglehart, 2014).

Connected health differs from general digital health applications in its emphasis on two-way communication and data exchange for improved patient outcomes (Caulfield & Donnelly, 2013), and this distinction informs its relevance in this thesis. CH is not merely about providing information but about creating an interactive, bidirectional feedback loop between the user, in this case the PLWBC and the technology. For example, a simple web-based platform offering cancer information without data collection would not be considered CH. In contrast, a cancer support programme such as the online delivered Cancer Thriving and Surviving (CTS)'s (described in detail in Chapter 4) use of technology for both delivering programme content and facilitating communication and support, exemplifies CH in action.

In practical terms, CH has become an increasingly integrated and scalable model of care delivery, particularly in the management of chronic conditions and survivorship care (Awad et al., 2021; WHO, 2021a). While early conceptualisations of CH date back over a decade (e.g., Caulfield & Donnelly, (2013) who were earlier proponents of this model), its adoption has accelerated considerably in recent years, catalysed by digital health strategies, technological advances, and the shift to remote care during the COVID-19 pandemic (Golinelli et al., 2020a; Murthy et al., 2023, 2023). These technologies encompass a wide range of applications, including remote patient monitoring, virtual support groups and educational resources, and tools for symptom tracking and management (Signorelli et al., 2019). CH's potential to some of the unmet needs in PLWBC has been examined in numerous studies, with promising results. For instance, online platforms and mobile applications provide avenues for PLWBC to connect with peers, support groups, and HCPs (Signorelli et al., 2019), reducing social isolation and fostering overall well-being (Aapro et al., 2020; Shaffer et al., 2023). Moreover, CH has the potential to address many of the unmet needs in traditional cancer care, particularly for PLWBC facing geographical barriers, socioeconomic disparities, or limitations in mobility. However, like all digital health interventions, the concerns such as digital divide and disparities in access, which is discussed later in this chapter, need to be factored in the design and implementation of CH.

<u>Cohen & Wills', (1985)</u> stress-buffering hypothesis posits that social support can protect individuals from the harmful effects of stress on psychological and physical health (Bowen et al., 2014; S. Cohen & Wills, 1985). In the context of cancer

survivorship, CH interventions often aim to recreate or augment social support networks through online peer groups, health coaching, and digital facilitator engagement (Aapro et al., 2020; Klemm, 2012). These features may help mitigate the psychological toll of uncertainty, isolation, or treatment-related distress often prevent in PLWBC populations (Gao et al., 2010). Thus, though the lens of this framework, CH can enhance psychosocial wellbeing, not simply through content delivery, but by enabling connection, validation, and empowerment (Aapro et al., 2020; Beatty et al., 2015). This framework has been utilised in some of the empirical studies in this thesis.

## 1.3.2. Digital Health Initiatives in Ireland

Ireland's trajectory in the development of digital health, while promising, is uniquely shaped by infrastructural and systemic challenges (B. Walsh et al., 2021). While the COVID-19 pandemic accelerated the uptake of telehealth and remote care services, systemic challenges persist (HSE, 2024c; B. Walsh et al., 2021). For instance, according to recent Organisation for Economic Cooperation and Development (OECD) reports, Ireland ranks behind several EU counterparts in key digital readiness indicators, including national broadband coverage and EHR integration (OECD, 2023). Infrastructure wise, rural broadband access remains uneven, contributing to digital exclusion, particularly for older adults and those living outside major urban centres (Carroll et al., 2021; P. Walsh et al., 2016).

Despite these challenges, policy momentum has increased in recent years. The recently published "Digital for Care" Framework for Ireland 2024-2030 outlines Ireland's vision for a future where digital health technologies empower patients and modernize healthcare delivery (HSE, 2024a). This framework aims to leverage data, digital solutions and innovation to improve access to care, enhance patient safety, and promote health equity. Key goals of this framework include providing patients with access to their health information, enabling informed decision-making, and promoting self-care. Furthermore, the framework emphasizes the importance of digital inclusion, ensuring that all individuals, including vulnerable groups, can benefit from technological advancements in healthcare. The National Cancer Strategy (2017-2026) further emphasizes technology's role in improving cancer care delivery and outcomes (Department of Health, 2017). The 'eHealth Ireland' strategy reinforces this strategic focus, envisioning a 'digitally enabled' health service that improves access to care, empowers patients, and enhances efficiency (HSE, 2024a).

Several noteworthy initiatives highlight the growing presence and potential of digital health within cancer care in Ireland. For instance, the National Telehealth Service, established in 2007, has significantly advanced remote healthcare, particularly for chronic disease management (HSE, 2024c). While not solely focused on cancer, the service has facilitated remote consultations, monitoring, and support for diverse patient groups, including patients with cancer and those in post treatment.

Charitable organizations, such as the ICS, play a crucial role by offering various online resources for those affected by cancer. These include comprehensive information hubs, virtual support groups, and online counselling services, aiming to bridge information gaps, reduce social isolation, and provide essential emotional support to those affected by cancer and their families. One such programme is the Life and Cancer Enhancing Survivorship (LACES) programme (NCCP, ICS, 2024). LACES is patient education workshop that aims to bridge the gap between the end of active cancer treatment and longer-term support services. Designed for adult cancer patients transitioning to long-term follow-up care, LACES primarily functions as a signposting workshop, directing PLWBC to appropriate resources and support. Furthermore, the HSE, through the NCCP, supports local cancer centres to offer survivorship support programmes in person and more recently online using CH technologies. An example of this is the online delivered CTS programme (NCCP, 2024), whose setting has been utilised in three out of the six studies in this thesis.

These examples demonstrate the expanding role of digital health, and CH in particular, in cancer care within Ireland, reflecting the goals outlined in national strategies (Department of Health, 2017; National Cancer Registry Ireland, 2023). However, while the efforts are clear, Ireland has been noted as relatively slow in CH adoption, compared to other countries such as the United Kingdom, Denmark and Netherlands, as also noted in recent report from the Economic and Social Research Institute (ESRI) (B. Walsh et al., 2021). Continued research and evaluation are crucial to determine the effectiveness, accessibility, and acceptability of these initiatives, ultimately paving the way for wider adoption and seamless integration into routine cancer care pathways.

While CH holds promise for improving cancer care in Ireland, several opportunities and challenges warrant consideration. Ireland's well-developed technological infrastructure, coupled with a growing and strategic focus on digital health within the healthcare system, presents a favourable environment for implementing and

scaling up CH interventions (HSE, 2024b). The increasing adoption of EHRs, for instance, and the government's commitment to eHealth initiatives provide a strong foundation for data integration and interoperability, crucial for the success of CH programmes (HSE, 2024a). However, certain challenges may hinder the widespread adoption of CH in Ireland. For instance, the 2021 report from the National Economic & Social Development Office (NESDO) highlighted persistent digital disparities, with older individuals, those with lower socioeconomic status, and rural residents demonstrating lower engagement with technology (NESDO, 2021). This disparity, if not addressed, risks exacerbating health inequities as healthcare digitalization gathers momentum.

### 1.3.3. Digital Health Disparities and Digital Divide

As already noted, while cancer survival rates continue to improve, access to care, support and rehabilitation remains either limited or unevenly distributed, both internationally (Dos-Santos-Silva et al., 2022) and in Ireland (O'Connor et al., 2019). Significant disparities persist, with various barriers limiting access to timely and equitable care for many PLWBC (Dos-Santos-Silva et al., 2022; Prager et al., 2018). This underscores the need for innovative approaches that can bridge these gaps and ensure that the benefits of medical progress, and supports, reach all corners of society.

Traditional models of in-person cancer care, often located in urban tertiary care centres, can present significant hurdles for PLWBC, particularly those in underserved communities. For instance, geographical location and distance to treatment and cancer support centres pose a substantial barrier, often necessitating long and potentially expensive travel for patients seeking care (Patel et al., 2020; Saeed & Masters, 2021). This challenge is further compounded by the limited availability of HCPs in many regions, particularly oncologists (Erikson et al., 2007) and specialised nurses; resulting in protracted waiting times for appointments and consultations (Trapani et al., 2021). This shortage, against the demands of the rising PLWBC population, has been described by WHO as a 'health workforce crisis' (WHO, 2024b). In addition, financial constraints, including the high cost of treatment, loss of employment and return to work challenges create additional barriers for patients (Algeo et al., 2021; Carrera et al., 2018; Zhu et al., 2020), potentially leading to treatment delays or forgoing necessary care altogether, a situation put bare during the global COVID-19 pandemic (Gallicchio et al., 2021). These barriers contribute to significant health disparities, resulting in unequal cancer care,

support and outcomes across different populations (Patel et al., 2020). These disparities further highlight the need for innovative solutions that prioritize equity and accessibility in cancer care delivery (Levit et al., 2013; Mao et al., 2022), especially now in the face of growing numbers of PLWBC.

While advancements in the technology and its increasing adoption have the potential to create a more equitable and accessible cancer care landscape (Bhatia, 2021; Iglehart, 2014), it is important to note that if not designed and implemented with careful consideration of patient needs and their abilities to access and engage with it, digital health technologies could further exacerbate existing health disparities (Fareed et al., 2021; Saeed & Masters, 2021). This duality has been aptly described as *technology having the power to empower and disempower patients* (Lupton, 2013). Therefore, the double-edged sword nature of technology (Fiske et al., 2020), particularly in the context of self-care and self-management, requires careful consideration. For instance, improved access to care, particularly for underserved populations, is a key benefit, as digital tools can transcend geographical barriers and connect patients with HCPs regardless of location (Awad et al., 2021; Derbal, 2022; Fisch et al., 2016a). However, this assumes equitable access to technology itself, which is not always the case.

Health disparities, defined as avoidable and unjust differences in health outcomes between population groups remain a persistent feature of cancer survivorship (Saeed & Masters, 2021a). These disparities are shaped by a complex interplay of social, economic, geographic, and systemic factors, including income, education, ethnicity, rurality, and access to healthcare services (Dos-Santos-Silva et al., 2022; Saeed & Masters, 2021a). In recent years, the increasing reliance on digital health technologies has introduced a new axis of inequity; the digital divide.

Digital divide refers to the gap between those who have adequate access to digital technologies, literacy, and connectivity, and those who do not (Chikomba et al., 2023; Western et al., 2025). This divide manifests across three overlapping dimensions. These include the (i) *access divide*; disparities in physical access to devices and reliable internet connections, (ii) *use divide*; differences in digital literacy, confidence, and skills to use technology effectively, and (ii) *outcome divide*; disparities in the benefits gained from technology use, which may reflect broader social and health system inequities (Coca et al., 2022; Saeed & Masters, 2021a). Most recently, the traditional notion of the 'digital divide' has evolved to encompass a more nuanced understanding of digital exclusion (Coetzer et al., 2024). This expanded conceptualisation recognises that digital

participation is constrained by a complex interplay of individual characteristics as well as broader political, social, and economic structural factors (Chikomba et al., 2023; Helsper, 2017).

In survivorship context, the digital divide has critical implications. As technology becomes increasingly embedded in survivorship care, from symptom tracking and telehealth appointments to psychoeducational interventions, those lacking digital access or capability risk being left behind. These may include older adults, people with lower socioeconomic status, those living in rural or underserved areas, and individuals with lower educational attainment are disproportionately affected (Parker et al., 2020; Lee et al., 2021). This exclusion not only limits access to care but may reinforce existing disparities in survivorship care (Fareed et al., 2021a; Patel et al., 2020). In Ireland, digital infrastructure and health system digitalisation remain variable. A recent report from the Health Information and Quality Authority (HIQA) report noted substantial differences in digital readiness across Irish healthcare settings, and highlighted barriers including inconsistent broadband coverage, low clinician and patient uptake, and limited interoperability between systems (HIQA, 2024). This thesis recognises the digital divide as both a determinant of CH adoption and a mediator of psychosocial outcomes. Further, concerns regarding data privacy, security, and the potential misuse of personal health information have been found to reduce trust in technology driven solutions (Delemere et al., 2022; Signorelli et al., 2019).

While digital health technologies are often marketed as tools for patient empowerment, it is important to acknowledge that they may also introduce new burdens to responsibilities and potential the patients (Lupton, 2013). 'Responsibilisation' of the patient, in which the work of maintaining health migrates from clinical settings to individuals' everyday lives, commonly referred to as the 'digitally engaged patient' is an emerging discourse in digital health (Lupton, 2013; Rich et al., 2019). Smartphone apps, patient portals and remote-monitoring wearables which are promoted as 'empowerment tools' that 'give patients control' (Affinito et al., 2022; Mesko et al., 2025), yet they simultaneously enrol patients in continuous self-surveillance regimes that track behaviours, biometrics and symptoms (Davies, 2021). Systematic reviews of eHealth interventions show that such tools can deepen engagement and improve outcomes when patients have resources and digital literacy (Barello et al., 2016; T. Lu et al., 2025), but qualitative work reveals the hidden labour and emotional load this self-management imposes on patients and informal caregivers (Scott Duncan et al., 2022). Marketing analyses of online healthcare services further reframe users as savvy consumers responsible for optimising their own care pathways (S.-Y. Park et al., 2022), aligning with broader policy narratives that cast health as a matter of individual choice and accountability (Asada et al., 2022; Rich et al., 2019). Ultimately, this suggest that while digital transformation can indeed broaden access and agency, it also redistributes clinical responsibilities, and associated risks, from HCPs to patients, demanding careful attention to equity, support infrastructures and ethical design.

Techno-utopianism is the belief that technological innovation will inherently produce positive social, economic, or health-related outcomes, often underestimating the complexities and systemic barriers to equitable implementation (Lupton, 2014; Tuner, 2006). Within the field of cancer survivorship, this perspective often overlooks the complex social, ethical, and political implications of these technologies, neglecting the nuanced realities of patient experiences (Lupton, 2014). For instance, patients may feel overwhelmed by the demands of self-monitoring and self-care, leading to anxiety or resistance towards constant tracking. The emotional impact of self-monitoring, in particular, requires further investigation, as it significantly shapes patient engagement and trust in HCPs. Ultimately, a deeper understanding of how these technologies affect power dynamics within healthcare, and the lived experiences of patients is essential for responsible and patient-centered implementation. From a healthcare system perspective, while digital health interventions offer healthcare systems potential gains in efficiency and cost-effectiveness through streamlined workflows, reduced administrative burdens, and proactive monitoring (Bhatia, 2021), careful consideration must be given to the initial implementation costs, ongoing maintenance, and adequate training for HCPs. These concerns require proactive action if the potential of digital health is to be harnessed while also mitigating unintended consequences and ensuring equitable access for all.

The Socioecological Model (SEM) widely used in public health, conceptualises the multiple levels of influence on health behaviours and outcomes, typically categorised as individual, interpersonal, organisational, community, and policy levels (McLeroy et al., 1988). The model derives directly from Bronfenbrenner's Ecological Systems Theory, a foundational framework positing that human development is shaped by the interplay of individuals within diverse environmental systems (Bronfenbrenner, 1977, 2000). While SEM retains the ecological emphasis on interconnected systems, it

emphasises the interconnectedness of these systems and is frequently applied to the design, implementation, and evaluation of multi-level public health interventions (Kilanowski, 2017; Lee et al., 2017), including those in digital health (Kolff et al., 2018; McCall et al., 2022), making it especially relevant in this thesis. Notably, Bronfenbrenner's later work extended this framework through the bioecological model, highlighting the importance of the process—person—context—time (PPCT) elements in shaping development (Navarro & Tudge, 2022; P. Tong & An, 2024). In this thesis, the SEM is utilised as a practical extension of Bronfenbrenner's theory to explore factors influencing the adoption and utilisation of CH technologies, allowing for both individual and contextual determinants to be considered. The model becomes especially useful in framing inequities in CH access and outcomes by highlighting how structural factors, including socioeconomic status, rurality, and health system readiness, interact with individual capacities such as self-efficacy and digital literacy.

#### 1.4. Aim and Objectives of the Thesis

#### 1.4.1 Overall Aim

With an increasing number of PLWBC, the demand for holistic support, addressing physical and psychosocial challenges, has never been greater. The treatment, care, support and rehabilitation gap for survivorship is projected to continue to widen (Bray et al., 2024; R. J. Chan, Hollingdrake, et al., 2021). While the promise of CH in healthcare is widely acknowledged (Kvedar et al., 2014; Signorelli et al., 2019), research specifically examining their utility in supporting the psychosocial well-being and QoL of PLWBC remains limited and mixed. This thesis aims to examine the role of CH technologies in supporting the psychosocial well-being and QoL of PLWBC, and to identify key factors influencing CH use and implementation in the Irish survivorship care context.

#### 1.4.2. Sub Objectives

To achieve the overall aim, this thesis addresses three specific objectives. First, it examines the potential of CH on the psychosocial well-being and QoL of PLWBC. This is achieved by a systematic review of literature from the past decade examining the impact of CH interventions on psychological wellbeing and QoL (study 1), a contextualised examination of the usability and utility of the online delivered CTS

programme in Ireland (studies 3a, 3b), and a post programme comparison of its online and in-person delivery modalities (study 4). Second, to identify the factors influencing CH adoption and utilisation among PLWBC, a secondary data analysis of the US-based population-level Health Information National Trends Survey (HINTS) dataset, investigating who uses CH after a cancer diagnosis is conducted (study 2). Third, to explore the barriers, facilitators, and experiences of CH in Ireland, a qualitative study with PLWBC is conducted (study 5).

These objectives are summarised in the table 1.1 below.

**Table 1.1** *Specific objectives and their implementation.* 

O	bjective	Implementation	
i.	Examine the role of CH technologies on the psychological well-	Conduct a systematic review and meta-analysis of existing literature to assess the impact of CH interventions on psychological wellbeing and QoL	1
	being and QoL of PLWBC	Examine the usability and utility of CH technologies and potential of a specific CH-delivered cancer survivorship programme in Ireland on participants' psychosocial wellbeing and QoL.	3
		Compare online and in-person delivery modalities within the CH-delivered cancer survivorship programme in Ireland	4
influ and t tech	Identify the factors influencing the adoption and utilization of CH technologies among	Analyse HINTS dataset to determine the sociodemographic and health-related characteristics associated with CH use among PLWBC	2
	PLWBC.	Explore the motivations, preferences, and experiences of PLWBC participating in an online cancer survivorship programme	4
iii	Explore the barriers and facilitators to CH implementation in survivorship care within the Irish context	Qualitative interviews with PLWBC in Ireland to understand their perspectives on the challenges and benefits of using CH technologies	5

# 1.5. Operational Definitions of Key Terms

To establish conceptual clarity and consistency across the thesis, this section defines key terms central to the research. These concepts include CH, psychological

wellbeing, depression and anxiety, QoL, and psychosocial wellbeing. These constructs, while sometimes overlapping, have distinct definitions and implications for intervention design, measurement, and interpretation of findings in the context of survivorship. Other terms commonly used in the thesis including PLWBC, digital health, and survivorship are defined.

Connected Health. The definition of CH by Caulfield & Donnelly, (2013) has been adopted in this thesis, where CH is defined as a conceptual model for health management where devices, services or interventions are designed around the patient's needs, and health-related data is shared in such a way that the patient can receive care in the most proactive and efficient manner possible. CH is conceptualised not as a single intervention or modality, but rather as a framework that integrates multiple digital technologies to support prevention, diagnosis, treatment, and survivorship. This thesis adopts a person-centred perspective of CH, focusing particularly on digitally delivered survivorship support programmes. Specifically, the case study intervention in this thesis, the CTS programme, was delivered via online platforms and complemented with digital resources. Within the broader CH typology, the CTS programme qualifies as a CHdelivered psychosocial intervention. It differs from other CH types such as EHRs (Ambinder, 2005), which primarily serve clinical documentation and inter-provider communication functions, or telemonitoring technologies, which are more common in chronic disease management and often require biometric feedback. To ensure clarity, CH in this thesis does not refer to broader systemic digitisation efforts (such as EHRs or hospital-wide (Information Technology (IT) systems), but rather to interactive, supportive interventions accessed and experienced directly by PLWBC via digital platforms.

Digital Health. Digital health is a broader term than CH and refers to the use of digital technologies for health-related purposes (WHO, 2019, 2021a). It includes mobile health (mHealth), health information technology, wearable devices, telemedicine, AI, and personalised medicine. While CH is a subset of digital health that emphasises connectivity and integration between patient and provider, digital health also includes standalone tools like symptom trackers, chatbots, or national electronic registries. This thesis focuses on CH as a subdomain of digital health, especially where digital platforms are used to deliver psychosocial interventions like CTS.

Psychological Wellbeing vs. Depression, Anxiety, QoL, and Psychosocial Wellbeing. As noted earlier, there is considerable conceptual overlap between psychological wellbeing, depression, anxiety, QoL, and psychosocial wellbeing. In this thesis, these terms are operationalised as follows:

- *Psychological wellbeing* draws on positive psychology traditions and refers to an individual's subjective sense of purpose, autonomy, personal growth, and life satisfaction (Ryff, 2013). However, because the studies included in this thesis did not directly measure psychological wellbeing using dedicated multi-dimensional scales (such as the *Ryff's psychological wellbeing Scale*) (Tricia A. Seifert, 2017), psychological wellbeing is treated as a conceptual lens, not a direct outcome. As evidenced by a previous review, depression and anxiety are often the predominant components used to quantify psychological well-being in patients with chronic diseases (Speight et al., 2009).
- Depression and Anxiety are understood as specific psychological symptoms or states (Eysenck & Fajkowska, 2018; Pitman et al., 2018). They are assessed using validated tools such as the HADS Scale (Zigmond & Snaith, 1983) and are used in this thesis as quantifiable indicators of distress. These constructs represent a component of psychosocial wellbeing, rather than proxies for psychological wellbeing.
- Quality of Life is used in line with the WHO's definition, as an individual's perception of their position in life in the context of the culture and value systems in which they live (WHOQOL Group, 2025). In this thesis, QoL thus refers to an individual's overall perception of their physical, emotional, social, and functional wellbeing in the context of living with and beyond cancer. It is measured using validated scales such as the EORTC QLQ-C30 (Fayers et al., 2002) and FACT-G (Cella et al., 1993). These scales assess domains such as physical functioning, emotional wellbeing, and social role participation.
- *Psychosocial wellbeing* is used as an umbrella term encompassing mental, emotional, social, and spiritual aspects of wellbeing (C. Kumar, 2020). It includes, but is not limited to, anxiety, depression, QoL, social connectedness, and coping. It is relevant to survivorship as it captures broader life satisfaction and adjustment after cancer treatment (Y. Wang & Feng, 2022). In this thesis, it

provides the broader contextual framing within which CH technologies are evaluated.

Across all empirical chapters, precise terminology is used to reflect what was actually measured in each study. For instance, in Study 1 (systematic literature review), depression and anxiety were assessed in most studies and reported as such. Further, in Studies 3a and 3b, self-reported utility and unmet needs are discussed with reference to QoL but not psychological wellbeing and finally in Study 4, validated measures of QoL and psychological distress (HADS and FACT-G) are used.

**People Living With and Beyond Cancer.** PLWBC is used in this thesis to describe adults who have received a cancer diagnosis and are living with the physical, psychological, and social consequences of cancer and its treatment. This terminology aligns with person-centred language used in survivorship care and advocacy, moving away from clinical labels like "patients" or time-bound categories such as "survivors." In the empirical chapters, PLWBC refers to individuals who:

- Have completed active cancer treatment (such as surgery, chemotherapy, radiotherapy), and/or
- Are managing long-term effects or chronic health challenges post-treatment.

Survivorship. I am Howard. I have cancer. Please don't call me a cancer survivor, a hero, a warrior, a conqueror, a victim. — No chemo, no radiation, no symptoms, a few biopsies -- hardly the stuff of heroism

-Howard Wolinsky, Contributing Writer, MedPage Today April 15, 2019

The above extract from Howard is a snapshot reflection of how the language used to describe individuals diagnosed with cancer has undergone significant evolution over the last few decades, reflecting changing societal perceptions and a growing emphasis on patient empowerment. This shift in language reflects a more empowered and proactive understanding of the cancer experience, further signifying a move away from paternalistic models of care (Gray et al., 1990) towards approaches that prioritize patient autonomy, agency, and active participation in their health journey (Jørgensen et al., 2018; C. Taylor, 2024).

Historically, terms like "cancer patient" and "cancer victim" have been used, but they have been continuously, especially in the recent times, criticised as implying passivity and suffering, fostering a narrative that may not resonate with everyone affected by cancer (Berry et al., 2019; C. L. Park et al., 2009). In 1986, the founders of the NCCS emphasized the need to transform the discourse surrounding cancer (NCCS, 2024). The organisation advocated for the replacement of the term "cancer victim" with "cancer survivor." However, while widely used today, the term "survivor" has been criticised as a narrow and singular narrative of overcoming adversity that oversimplifies the experience, particularly for individuals on active surveillance or living with low-risk cancers (Berry et al., 2019; Cheung & Delfabbro, 2016; Khan et al., 2012).

This thesis prioritizes person-first language, recognising the individual rather than the disease. Informed by participant feedback through Patient and Public Involvement (PPI) in research, where participants in the empirical studies expressed discomfort with word 'survivor' or 'patient', this thesis adopts terms such as 'Person living with cancer,' 'People living with and beyond cancer," or "People impacted by cancer.' This deliberate choice aligns with the prevailing principles of person-centered care and the ongoing shift towards patient-centric models in cancer care and survivorship (Khan et al., 2012; C. Taylor, 2024). This approach acknowledges the continuing nature of the cancer experience and moves away from rather outdated labels that fail to reflect the complexities of individual journeys (Cheung & Delfabbro, 2016; Khan et al., 2012). Key organisations both in Ireland and elsewhere, advocate for personcentered care, emphasising the importance of recognising and respecting the individual needs and experiences of those affected by cancer. Such organisations include the US National Cancer Institute (Robinson et al., 2021), the UK's Macmillan Cancer Support (2024), the PPI Ignite Network (2024), and Patient Voice In Cancer Research (2024) among others. Ultimately, this evolving terminology reflects a more inclusive and nuanced understanding of the diverse experiences of individuals navigating the complexities of a cancer diagnosis and treatment.

#### 1.6. Methodological Framework and Philosophy

This thesis employs a constructivist, and mixed methods approach to gain a deeper understanding of the multifaceted experiences of PLWBC. Recognising that knowledge is not passively received but actively constructed within social contexts (Gergen, 2001), this research acknowledges the subjective nature of individual experiences (Atkinson et al., 2019; Hernandez et al., 2006) and the influence of social factors on health and wellbeing (Das et al., 2020; WHO, 2024c). Therefore, the studies

draw upon both quantitative and qualitative data to provide a comprehensive and nuanced perspective. In this case, quantitative data is utilised to explore patterns, trends, and relationships, while qualitative data gives insights into the lived experiences, perspectives, and meanings individuals ascribe to their interactions with CH technologies. The integration of these diverse methodologies, a defining characteristic of mixed methods research (Clark & Clark, 2022; Tashakkori et al., 2021), allows for a robust exploration of the research topic, and is particularly integral in social science research. This approach further enables the triangulation of findings, enhancing the credibility and trustworthiness of the research, and ultimately fostering a more holistic understanding of the role of CH technologies in psychological wellbeing and QoL outcomes in PLWBC. *Study 1* employs a systematic review methodology, *study 2* a secondary analysis of a quantitative dataset, *study 3-4* adopt a cross-sectional mixed methods approach and *study 5* adopts a qualitative methodology.

#### 1.7. PPI and Stakeholder Involvement

Integrating PPI and stakeholder perspectives is crucial for conducting effective research. INVOLVE, the UK's National Institute for Health and Care Research (NIHR) advisory group on public involvement, defines PPI as research conducted 'with' or 'by' the public, rather than 'to,' 'about,' or 'for' them (NIHR, 2024). This approach ensures that research addresses the needs of its intended beneficiaries. PPI necessitates a collaborative and reciprocal partnership between researchers and participants (Arumugam et al., 2023), recognizing that non-academic stakeholders possess valuable expertise that can significantly enrich the research process (Greenhalgh et al., 2019), and that lived experience is evidence.

Although still evolving as a standard practice in health research, PPI is increasingly gaining recognition for its ability to enhance the quality, relevance, and impact of research endeavours (Gilfoyle et al., 2022; Pearce, 2020). Sometimes described as participatory research, PPI recognizes the diverse forms of expertise and strives to involve community members throughout the entire research journey, from inception to dissemination. Patients, as experts in their own experiences, are uniquely positioned to guide research priorities, ensuring that research efforts are directed toward areas of greatest need and impact (Chevalier, 2019). In cancer research, PPI can enhance the relevance of research questions, increase the impact and social validity of findings, and empower patients and caregivers (Chiu et al., 2013; Pii et al., 2019).

Reflecting this commitment to PPI, empirical studies were designed with input from people with lived experience of cancer and key stakeholders. These stakeholders included staff working at cancer centres, particularly those providing cancer survivorship support services in Ireland through the HSE's NCCP, as well as charitable organizations such as the ICS. The specific roles and contributions of the PPI members and the relevant stakeholders have been described more comprehensively in each of the chapters, as appropriate.

#### 1.8. Overview of Thesis Structure

This thesis examines the role of CH technologies in supporting the psychosocial wellbeing and QoL in PLWBC. The thesis is structured into eight chapters.

The next chapter (*Chapter 2*) presents the findings from the first study. Specifically, the chapter presents findings from a systematic literature review investigating the impact of CH interventions on the psychological well-being and QoL of PLWBC. *Chapter 3* presents findings from Study 2, a secondary analysis of the US based HINTS dataset investigating the sociodemographic and disease characteristics of PLWBC who use CH technologies in their survivorship care.

The following three chapters (*Chapters 4-6*) utilise the setting of the CTS programme to conduct empirical studies that further explore the adoption, utilisation, and utility of CH technologies among PLWBC in Ireland. Specifically, *Chapter 4* presents findings from Study 3a, a mixed methods cross section survey of the participants in the online CTS programme, evaluating the usability of CH technologies and their utility in supporting the psychosocial well-being and QoL. Following on, *Chapter 5* presents findings from Study 3b, focused on a subset of unmet needs and QoL following participation in online CTS programme. *Chapter 6* presents findings from Study 4 which compares the in-person and online delivery CTS modalities to understand modality preferences, experiences and psychosocial outcomes.

The last empirical chapter, *Chapter 7*, presents findings from Study 5, which builds upon the learnings from Studies 1-4. This study uses a descriptive qualitative approach to conduct in-depth qualitative interviews to explore how PLWBC experience, perceive and navigate CH technologies in their survivorship journeys. The final chapter (*Chapter 8*) synthesises findings across all studies, connecting individual results and discussing their implications for research, practice, and policy in light of study objectives.

# **Chapter 2**

# Study 1

Impact of connected health interventions on psychological wellbeing and quality of life in patients with cancer: A systematic review and meta-analysis

Adapted from: Gitonga, I., Desmond, D., Duda, N., & Maguire, R. (2022). Impact of connected health interventions on psychological wellbeing and quality of life in patients with cancer: a systematic review and meta-analysis. *Psycho-Oncology*, 31(10), 1621-1636. doi: 10.1002/pon.6019

#### Abstract

**Objective:** Connected health technologies offer opportunities to enhance access to care, reduce healthcare costs and support the psychological wellbeing and QoL of PLWBC. Study 1, a systematic literature review, aimed to assess the impacts of interventions delivered using CH technologies on psychological and QoL outcomes in this population.

Methods: PUBMED, PsycINFO, Web of Science, and EMBASE databases were systematically searched using terms relating to (i) cancer, (ii) CH, and (iii) QoL/psychological wellbeing. Studies were included if they evaluated interventions using CH technologies and assessed psychological and/or QoL outcomes for adults at any stage of their cancer survivorship journey. Data on study characteristics, intervention components, and outcomes were extracted and summarised. Thematic synthesis was employed to identify recurrent patterns and synthesise evidence relating to the impact of CH on psychological wellbeing and QoL. Where appropriate, a random-effects meta-analysis was conducted, and standardised mean differences (SMDs) were calculated to estimate pooled effects.

**Results**: 37 studies met the inclusion criteria with a total of 8,956 participants. Connected health technologies included web-based applications (n=24), smart applications (n=12), and wearable devices (n=1). Studies were heterogeneous in terms of intervention components. Thematic synthesis identified five intervention clusters: (i) Psychosocial support and rehabilitation, (ii) psychoeducation and information support, (iii) symptom monitoring, reporting and self-management, (iv) peer and social support, and (v) health coaching and physical activity training. Meta-analysis of seven RCTs indicated that CH interventions were moderately effective in reducing symptoms of depression (SMD: -0.226, 95% CI -0.303/-0.149) and anxiety (SMD: -0.188, 95% CI: 0.279/-0.0963) compared with usual care.

**Conclusion**: While the considerable heterogeneity observed highlights the need for more rigorous studies to improve reproducibility and efficiency, results suggest that CH interventions have the potential to improve psychological wellbeing and QoL outcomes in PLWBC.

#### 2.1. Introduction

As outlined in Chapter 1, advances in cancer screening, diagnosis and treatment have resulted in an increasing number of PLWBC (Shapiro, 2018; Torre et al., 2019). Given the range of symptoms experienced (Ferrer et al., 2013), there is a clear need to identify ways to enhance QoL in this group. Beyond the effects that cancer can have on physical health, it may have an even greater and, arguably, more significant impact, on psychosocial wellbeing (Naughton & Weaver, 2014; Singer et al., 2010). Feelings of uncertainty, fear, or sadness resulting from diagnosis are associated with increased psychological distress (Schuurhuizen et al., 2015), which may interfere with coping strategies (Gao et al., 2010). While effective management of symptoms can reduce distress, enhance coping, and improve QoL (Benedict et al., 2022), psychological wellbeing still remains a top unmet need for PLWBC.

Psychosocial interventions such as cognitive behavioural therapy (CBT) and behaviour change techniques can enhance coping skills and improve QoL in PLWBC (Duijts et al., 2011; Osborn et al., 2006). However, as noted in Chapter 1, in person interventions can be costly and sometimes hard to access, especially for individuals in hard-to-reach areas, those working or with caring responsibilities (Ambroggi et al., 2015). Rising cancer incidence, the growing population of PLWBC (Bray et al., 2024) and shortages in healthcare providers, such as the psycho oncologists (WHO, 2024b), may exacerbate challenges (Ambroggi et al., 2015; Farmer et al., 2010) with COVID-19 most recently presenting obstacles for in-person care (Al-Quteimat & Amer, 2020). Technology-based approaches to care, such as CH, may help overcome challenges by facilitating increased access to individualised support (Fu et al., 2020; Signorelli et al., 2019). As noted in *Section 1.3.1*, CH is a fast-growing paradigm in healthcare innovation where devices, interventions and services are designed around patients' needs through efficient data collection, analysis, and transfer (Caulfield & Donnelly, 2013).

Recent interest in the psychological impact of CH interventions in cancer survivorship can be understood through several theoretical lenses. Notably, the stress-buffering hypothesis (S. Cohen & Wills, 1985) posits that social support can mitigate the negative effects of stress on mental health. CH technologies, through features such as remote support groups, symptom tracking, and telehealth consultations, may function as alternative or supplementary forms of support (Klemm, 2012), thereby alleviating distress among PLWBC (Fu et al., 2020; Signorelli et al., 2019). Additionally, using the self-determination theory lens (Ryan & Deci, 2023), CH delivered interventions may

enhance psychological wellbeing by promoting autonomy, competence, and relatedness. For instance, digital tools that enable individuals to self-monitor their symptoms, access tailored information, or set recovery goals may foster a sense of control and capability in managing one's health (Figueiredo et al., 2017a; McCorkle et al., 2011). While criticisms have been raised against the risk of shifting responsibility to the patient (Lupton, 2013; Scott Duncan et al., 2022), these frameworks suggest plausible mechanisms through which CH can influence outcomes such as anxiety, depression, and self-efficacy.

The impact of CH interventions in cancer survivorship has been evaluated in previous reviews with mixed, albeit promising, evidence. For example, CH was found effective in enhancing patient engagement (Eland-de Kok et al., 2011), self-management (Kuijpers et al., 2013) and reducing barriers to care (Butow et al., 2012). Other reviews evaluated design features of CH in cancer care (Ventura et al., 2013), its utility in cancer follow-ups (Dickinson et al., 2014), effects on wellbeing and QoL outcomes (Agboola et al., 2015) and the benefits in supportive care (Aapro et al., 2020). However, these reviews reported mixed findings, acknowledging a lack of quality evidence regarding the efficacy of CH technologies. A recent review noted the need for more high-quality trials, especially those using standardized outcome measures (Marthick et al., 2021).

CH technologies are acceptable among cancer patients, particularly those including elements of social support, self-management, and remote access to professionals (Escriva Boulley et al., 2018). However, while CH can enhance outcomes such as self-efficacy, coping, and perceived social support (Escriva Boulley et al., 2018; Marthick et al., 2021; McAlpine et al., 2015a), there is limited evidence for its impact on severe symptoms of psychological distress, such as anxiety or depression (Agboola et al., 2015). Additionally, the impact of CH on other psychological and QoL outcomes in PLWBC remains unclear.

Previous reviews have restricted their evaluations to specific subsets of CH (Escriva Boulley et al., 2018; Marthick et al., 2021; McAlpine et al., 2015a), noting a shortage of interventions and study heterogeneity. Thus, a quantitative analysis of CH efficacy is needed. Given the sharp increase in CH interventions over the last decade, rapid shifts in digital technologies, and the increased demand for virtual services in the context and aftermath of the COVID19 pandemic, it is critical that their efficacy is continuously evaluated (WHO, 2019). This study addresses the first objective by

systematically reviewing literature on impact of interventions delivered using CH technologies on psychological and QoL outcomes in PLWBC.

#### 2.2. Methods

This review was conducted in compliance with the Preferred Reporting Items for systematic review and meta-analysis (PRISMA) guidelines. The protocol is registered with the Prospective Register for Systemic Reviews Database (ID: CRD42021246828).

## 2.2.1. Search Strategy

Searches were completed in May 2021 to identify articles pertaining to CH interventions for PLWBC. Any study evaluating a CH-facilitated intervention and reporting psychological wellbeing and/or QoL directly or indirectly, either as a primary or secondary outcome, published in a peer-reviewed journal and in the English language was deemed eligible for inclusion. Only technologies that were 'connected' and offered a two-way communication in the flow and use of data were included (Iglehart, 2014; Pattichis & Panayides, 2019). Considering the technological advancements in the last decade, only studies published in the past 10 years (2010-2020) were considered (*see Table 2.1*). Bibliographic mining and citation searching of studies obtained were also conducted.

**Table 2.1**Study eligibility Criteria

	Inclusion Criteria	Exclusion Criteria
Population	Adult diagnosed with cancer (No	Cancer patients below 18 years.
	restriction on type, severity, time	Caregivers and families of adult
	since diagnosis, or cancer prognosis.	patients with cancer
	An adult is defined as an individual	Healthcare providers
	aged 18 years or above.	
Intervention	Connected health interventions with	Interventions that are not
	a measure of psychological	connected to the internet.
	wellbeing and/or quality of life.	CH interventions without a
	Includes smartphones, web-based	measure of psychological
	interventions, online group-based	outcomes or quality of life.
	interventions, telehealth, and	CH interventions without a
	wearables.	comparator
	No restrictions on the timing of the	
	intervention as long as the	

	Inclusion Criteria	Exclusion Criteria
	intervention is on patients with a confirmed cancer diagnosis.	
Measures	Primary data from the patient using validated measures	Secondary data Measures that have not been validated
Outcomes	Psychological outcomes or QoL, with either being the primary outcome.	Outcomes unrelated to psychological wellbeing or QoL.
	Psychological wellbeing: Presence or absence of self-reported distress {e.g., anxiety, depression, fear of recurrence, sadness, panic} as well as the presence or absence of self-reported positive constructs such as happiness and satisfaction	
	QoL: Subjective appraisal or evaluation of one's life, with emphasis on perceived health status and activity limitation.	
Study Design	All study designs as long as there is some evaluation of CH intervention and the effect of the intervention on psychological outcomes or QoL was reported.	Literature reviews, systematic reviews, meta-analysis, background articles, commentaries, descriptive designs
Reporting	Reports must be in the English language and have appeared in peer-reviewed journals published within the past 10 years.	Reports in non-English languages. Grey literature Studies published prior to 2010.

Studies were identified by searching electronic databases (PubMed, PsychINFO, Web of Science, EMBASE) using terms relating to (1) Cancer, (2) QoL/Psychosocial Wellbeing and (3) CH. Search terms were developed by IG, RM and DD based on previous literature (Fayers et al., 2002; Ryff & Singer, 1996). Boolean operators were employed to search the selected databases. MeSH, EMTREE, PsycINFO thesaurus or equivalent terms were used and exploded. A search syntax used in PsycINFO is outlined below;

TX ((Cancer OR Neoplasms) AND TX (Psychology\* OR mental health OR Distress OR Depression OR Anxiety OR Sadness OR Posttraumatic stress disorder OR Life satisfaction OR Health related quality of life) AND TX (Electronic health

#### 2.2.2. Screening

Results of database searches were exported to Endnote and duplicates removed. A standardized online platform Rayyan (Johnson & Phillips, 2018) was used to screen studies. Title and abstract screening was completed by two reviewers (IG and ND) independently. The remaining articles underwent full-text reviews by independent reviewers to confirm eligibility. Disagreements were discussed amongst until consensus was obtained. Available data for aggregation were required for inclusion in the meta-analysis.

#### 2.2.3. Data extraction

The following data were systematically extracted by IG (checked by ND) and inputted into an Excel spreadsheet: author, year, title, design, number/characteristics of participants, including cancer type, intervention type, outcome measures, results obtained, and study limitations. If required data were not reported, the corresponding author was contacted to obtain this or to seek additional details.

#### 2.2.4. Methodological quality assessment

IG and ND independently conducted a quality assessment for included studies using the updated Mixed Methods Appraisal Tool (MMAT) (Hong, Fàbregues, et al., 2018; Hong et al., 2019). The MMAT was selected for its versatility in assessing methodological quality across multiple study designs, including qualitative, quantitative, and mixed methods designs within a single framework (Hong, Gonzalez-Reyes, et al., 2018). Since we did not exclude any studies based on the design, as long there was some evaluation of CH intervention and the effect of the intervention on psychological outcomes or QoL, MMAT was deemed as most suitable. The MMAT is intended to critically assess the quality of quantitative, qualitative, RCTs, non-randomized and mixed methods studies. It has been widely used in health research (Delemere & Maguire, 2021b; Hong, Gonzalez-Reyes, et al., 2018) and offers a structured yet accessible approach to appraising diverse methodologies (Hong, Fàbregues, et al., 2018). The tool consists of two screening questions followed by five

design-specific questions. Conflicts in quality assessments were resolved through discussion until consensus was reached. The latest MMAT guidelines discourages presenting a single number to denote quality as it does not tell what specific study areas are problematic (Hong, Fàbregues, et al., 2018). For this reason, interpretation took the following form: 4–5 criteria met=high quality, 2–3 criteria met=moderate quality, 0–1 criterion met=low quality, as per previous analysis (Hong, Fàbregues, et al., 2018).

### 2.2.5. Synthesis of findings

Study characteristics, interventions, and outcomes were described in table form. A preliminary analysis was employed to assess the nature of data available for metaanalysis. Considering the heterogeneity in outcomes variables and measures, thematic synthesis was deemed suitable to summarise the evidence (Dixon-Woods et al., 2005). This enabled us to aggregate evidence regarding the impact of CH on the outcomes of interest, and to identify patterns within data relating to these outcomes. We synthesized findings in three stages. First, data pertaining to psychological wellbeing/QoL outcomes from CH interventions were coded. Here, the primary reviewer developed a coding frame, with codes being the different intervention targets/components (see appendix 1) derived from the data, which was reviewed by the other reviewers, with discrepancies resolved through discussion. Next, similarities between codes were identified. Codes were grouped into themes that captured outcomes/patterns, in this case the target of the CH intervention as applied across included studies. Each theme was entered as a separate column in a table, while coded data from each study were entered in rows to illustrate themes. This technique facilitated comparison within and between studies as part of the constant comparison process (Anderson & Jack, 2015; Rennie, 2006). The focus of interventions was summarized into five thematic areas that emerged from the codes: (i) psychosocial support and rehabilitation, (ii) psychoeducation and information support, (iii) symptom monitoring and self-management, (iv) peer and social support, and (v) health coaching and PA training. Studies within each of these clusters were evaluated based on reported psychological and QoL outcomes. Where a study reported on more than one intervention component, this was also noted and reported.

#### 2.2.6. Measures of intervention effect.

Only seven studies had complete data for inclusion in the meta-analysis. Outcome measures of included studies were all continuous and reported on the Hospital Anxiety and Depression (HADS) scale (Zigmond & Snaith, 1983), therefore standardized mean difference (SMD) and standard error (SE) were used to summarize estimates of effects from individual studies (Borenstein et al., 2011). The magnitude of SMD was interpreted using Cohen's conventions for small (SMD = 0.2), medium (SMD = 0.5), and large (SMD = 0.8) effects (J. Cohen, 1992). Given the anticipated variability across the included studies in terms of intervention design, delivery format, population characteristics, and outcome measures, a random-effects meta-analytic model was employed (Borenstein et al., 2011). This approach assumes that the true effect size may vary between studies, in contrast to a fixed-effects model which assumes a single true effect. The random-effects model therefore accounts for both within-study sampling error and between-study heterogeneity, providing a more conservative and generalisable estimate of the overall effect (Zhai & Guyatt, 2024). Its choice was particularly appropriate considering the complex psychosocial interventions, where contextual and implementation differences are expected (Morgan & Florez, 2022; Zhai & Guyatt, 2024).

# 2.2.7. Assessment of heterogeneity.

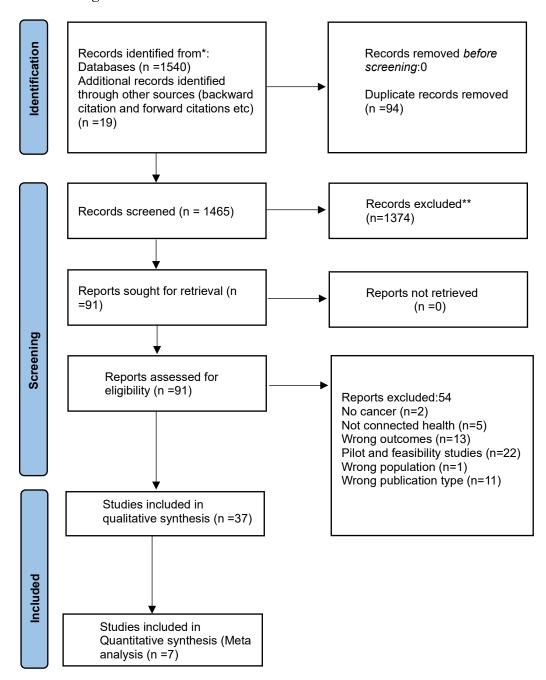
Inconsistency between study estimates was both visually and statistically examined through inspection of forest plots and consideration of the I<sup>2</sup>, respectively. The I<sup>2</sup> was calculated to assess heterogeneity. In general, heterogeneity was categorized as low (0–40%), moderate (30–60%), substantial (50–90%), or considerable (75–100%) (Higgins & Thompson, 2002). To examine small study effects, funnel plots and the Egger's test was used. Data available for meta-analysis was analysed using R software.

#### 2.3. Results

Database searches yielded 1,446 articles for title and abstract screening following duplicate removal. After initial screening, 90 full texts were assessed for eligibility, with 54 excluded. Full rationale for article exclusion is presented in the PRISMA diagram (*Figure 2.1*).

Figure 2. 1

PRISMA Diagram



An additional 19 studies were identified through other sources such as manual forward and backward citation chasing and trial registry search leading to 37 studies included. Of these, 36 were controlled trials, with 35 being randomized and one nonrandomized. One study utilized a qualitative methodology. Of the 36 trials, nine (Bruggeman-Everts et al., 2017; Compen et al., 2018; Greer et al., 2019; Stevenson et al., 2019; Sui et al., 2020; Willems, Mesters, et al., 2017; Yun et al., 2012, 2020) used the HADS as a measure anxiety and depression symptoms and were considered for meta-

analysis. However, two studies (Bruggeman-Everts et al., 2017; Compen et al., 2018) were not included because complete data were not available. The European Organisation for the Research and Treatment of Cancer (EORTC) Core QoL questionnaire (EORTC QLQ-C30) (Fayers et al., 2002) was most frequently used to assess different aspects of QoL depending on the cancer type, with other studies measuring different outcomes related to psychological wellbeing/QoL. The possibility of conducting a meta-analysis on QoL using EORTC QLQ-C30 data was explored. However, due to variability in scoring, reporting formats, and incomplete data in some of the included studies, a robust meta-analysis was therefore not deemed appropriate. All studies were included in the qualitative synthesis.

Studies included 8,956 participants in total (mean age = 44-69 years). Sixteen studies evaluated impact of interventions in the post treatment survivorship phase, while the rest were evaluated either in active treatment or across active treatment and post treatment phases. Participants in included studies had various types of cancer namely breast (n=15), haematological (n=2), colon (n=1), nasopharyngeal (n=1), prostate (n=1), lung (1), and mixed/multiple cancers (n=16) (See Table 2.2).

Table 2.2

Study Characteristics

Author	Country	Cancer type	Age (mean)	Sample Size	Survivors hip Phase	Measures	Primary outcomes	Secondary outcomes	Platform	HCP/ Facilitat or
Owen et al. (2017)	USA	Mixed	52.9	347(176, 171)	Post Treatment	Distress Thermometer (DT) Outcomes Questionnaire, Profile of mood states, Epidemiologic studies Depression scale, Impact of Events Scale (IES-R)	Distress, psychological functioning, depression, and trauma-related anxiety	Fatigue and Vigor	Website	Psycholo gists
Yun et al. (2020)	South Korea	Stomac h, Colon, Lung, and Breast	54.4	394(135, 125,134)	Post Treatment	Post Traumatic Growth Inventory (PTGI), Hospital Anxiety and Depression Survey (HADS), Brief Fatigue Inventory (BFI) & McGill QoL	Physical Activity (PA), Weight, and positive growth	Anxiety and Depression, Fatigue, social support, and QoL	Website	Nurses
Beatty et al. (2015)	Australia	Mixed	51.6	60 (30,30)	Treatment phase	Post-Traumatic Stress Scale- Self Report (PSS-SR), EORTC QOL-C30, and Mini-Mental Adjustment to Cancer Scale (mini-MAC)	Cancer Related Distress	Coping	Website	None
Abraham s et al. (2017)	Netherla nds	Breast	52.5	132 (66,66)	Post Treatment	CIS Fatigue Severity, Sickness Impact Profile, Brief Symptom Inventory, EORTC QOL-C30	Fatigue severity	Functional Impairment, Psychologic al Distress, QoL	Online CBT	Therapist s
Lally et al. (2019)	USA	Breast	55.1	100 (57,53)	Treatment phase	DT, Centre for Epidemiologic Studies Depression Scale (CES-D), IES	Cancer Related Distress	NR	Website	None
Greer et al. (2019)	USA	Mixed	56.5	145 (72,73)	Treatment phase	Hamilton Anxiety Rating Scale (HAM-A), Clinical Global Impression Scale, HADS, PHQ-9, and Functional Assessment of Cancer Therapy-General	Anxiety	Depression and QoL	mobile	None

Author	Country	Cancer type	Age (mean)	Sample Size	Survivors hip Phase	Measures	Primary outcomes	Secondary outcomes	Platform	HCP/ Facilitat or
Stevenso n et al. (2019)	Australia	Hemato logical cancers	50	60 (30,30)	Treatment phase	Health System and Information Needs Domain of the Supportive Care Needs Survey Short Form (SCNS-SF34), HADS	Unmet information needs	Depression and Anxiety	Website	Nurse
Sherman et al. (2018)	Australia	Breast	57.4	304 (149,155 )	Post Treatment	Body Image Scale. Body Appreciation Scale. Self-Compassion Scale—Short Form. Depression, Anxiety, and Stress Scales & Appearance Schemas Inventory-Revised	Body image–related distress (BID) and Body appreciation	Psychologic al distress (depression and anxiety) and self- compassion	website	None
Spahrkäs et al. (2020)	Australia , Canada, the United Kingdom , and the US	Mixed	55.5	799 (519, 280)	Mixed	Fatigue Symptom Inventory [FSI]. EORTC-QLQ-30	Fatigue severity and Interference	Quality of Life	mobile	None
Sui et al. (2019)	China	Lung	61.4	50(100,1 00)	Treatment phase	HADS, EORTC-QLQ-30	Depression, anxiety, and QoL	Loss to follow up and survival data analysis	smartpho ne	Nurses
Beatty et al. (2018)	Australia	Mixed	54.9	191 (86,78)	Treatment phase	PSS-SR, EORTC QOL-C30, and Mini- Mental Adjustment to Cancer Scale(mini-MAC), Australian Bureau of statistics Health Service Utilisation Questionnaire	Cancer-specific distress	General distress, QoL, Coping and Health service utilization	website	None
Ruland et (2013)	Norway	Breast and Prostat e	56.7	325 (162,163 )	Treatment phase	Memorial Symptom Assessment Scale Short Form (MSAS-SF), Global Distress Index (GDI) CES-D 15D HRQoL Instrument. Medical Outcomes Study Social Support Survey	Symptom distress	Depression, self-efficacy, HRQoL, and social	website	Cancer nurses
Zhou et al. (2019)	China	Breast	49.9	111(56,5 5)	Treatment phase	Functional Assessment of Cancer Therapy-Breast version 4.0 (FACT-Bv4.0) and the Numerical Rating Scale	Health-related quality of life	support Pain, fatigue, and sleep	smartpho ne	Nurses and doctors

Author	Country	Cancer type	Age (mean)	Sample Size	Survivors hip Phase	Measures	Primary outcomes	Secondary outcomes	Platform	HCP/ Facilitat
Korkmaz et al. 2019	Turkey	Breast	47.8	72 (24,24,24 )	Treatment phase	Risk Factors for Breast Cancer and Data Collection Form for the Disease, SF 36 QoL Scale, State-Trait Anxiety Inventory, and Website Usability Scale	Anxiety and Quality of Life	NR	Website	None
Brugger man- Everts et al. (2017)	Netherla nds	Breast	56.3	167(62,5 5, 50)	Post treatment	Checklist Individual Strength - Fatigue Severity, HADS. Positive and Negative Affect Schedule	Self-perceived fatigue severity	Mental Health	Website	Psycholo gist
Willems et al. (2017)	Netherla nds	Mixed	55.86	462 (231,231 )	Post treatment	EORTC QoL, HADS, Checklist Individual Strength (CIS)	Emotional and Social functioning, Depression and Fatigue	NR	website	None
Rosen et al. (2018)	USA	Breast	52.31	112 (57, 55)	Treatment phase	Functional Assessment of Cancer Therapy—Breast version 4 (FACT-B). Mindful Attention Awareness Scale (MAAS)	Quality of Life	Dispositiona l Mindfulness	smartpho ne	None
Kuhar et al. (2020)	Slovenia	Breast	51.7	91(46,45)	Treatment phase	EORTC C-30, BR- 23 Breast Cancer Questionnaires	Global quality of life	Use of health resources (doctor visits and hospitalizati ons)	smartpho ne	Oncologi st
Vallance et al. (2020)	Canda and Australia	Breast	NR	83 (43,40)	Post treatment	Actigraph and activPAL accelerometers. Functional Assessment of Cancer Therapy-Breast (FACT-B) and the Functional Assessment of Chronic Illness Therapy Fatigue (FACIT-Fatigue)	Physical activity	HRQoL and fatigue	Wearable	Health promotio n experts/ Kinesiol
Anja van der Hout et al. (2020)	Netherla nds	Mixed	65	625 (320,305 )	Post treatment	Patient Activation Measure. EORTC QLQ-C30. The mental adjustment to cancer scale. The Supportive Care Needs Survey Short Form 34. The General Self-Efficacy. The Pearlin & Schooler Mastery Scale. The Multidimensional	Patient activation (knowledge, skills, and confidence for self-management)	HRQoL, Mental Adjustment to Cancer, Supportive	website	ogy Specialis ts

Author	Country	Cancer type	Age (mean)	Sample Size	Survivors hip Phase	Measures	Primary outcomes	Secondary outcomes	Platform	HCP/ Facilitat or
Fjell et al. (2019)	Sweden	Breast	46	149 (74,75)	Treatment phase	Health Locus of Control. The eHealth Impact Questionnaire Memorial Symptom Assessment Scale (MSAS). EORTC QLQ-C30	Symptom burden	Care Needs Survey HRQoL	smartpho ne	Nurses
Sundberg et al. (2017)	Sweden	Prostat e	69	110(66, 64)	Treatment phase	EORTC QLQ-C30.Sense of Coherence questionnaire	Symptom burden	HRQoL	smartpho ne	Nurses
Compen et al. (2018)	Netherla nds	Mixed	51.65	245(90,7 7, 78)	Treatment phase	HADS. Structured Clinical Interview for DSM-IV-TR Axis I Disorders. Fear of Cancer Recurrence Inventory. Rumination and Reflection Questionnaire. Mental and physical scales of the Short-Form 12. Five Facet Mindfulness Questionnaire-Short Form. Mental Health Continuum-Short Form. Neuroticism Extraversion Openness-Five Factor Inventory	Psychological distress	Psychiatric diagnosis, fear of cancer recurrence, rumination, HRQoL, mindfulness skills, and positive mental health.	website	Therapist s
Syrjala et al. (2018)	USA	Haemat ologica l cancers	52	755 (344, 411)51	Post Treatment	Cancer and Treatment Distress (CTXD), Symptom Checklist-90-R depression scale (SCL-90-R), Short Form 36 Health Survey (SF-36), and Fatigue Symptom Inventory (FSI)	Cancer Related Distress	Fatigue, depression, and general health	website	Psycholo gists
Ridner et al. (2019)	USA	Breast	56.8	160 (80,80)	Post Treatment	Lymphedema Symptom Intensity and Distress Scale—Arm (LSIDS-A). Profile of Mood States-Short Form (POMS-SF). Perceived Medical Condition Self-Management Scale. Medical Outcomes Study Social Support Survey. Resource Utilization and Economic Burden Questionnaire (RUEBQ)	Symptom burden, psychological well- being, function, and costs, and arm volume	NR	website	None
Helmond t et al. (2019)	Netherla nds	Breast	55.8	262 (130,132 )	Post Treatment	Fear of Cancer Recurrence Inventory (FCRI-SF-NL). Psychosocial Distress Questionnaire-Breast Cancer (PDQ-BC)	Fear of cancer recurrence	Coping strategies, functioning	web	None

Author	Country	Cancer type	Age (mean)	Sample Size	Survivors hip Phase	Measures	Primary outcomes	Secondary outcomes	Platform	HCP/ Facilitat or
								impairments, and psychologica l distress		
Chamber s et al. (2018)	Australia	Mixed	NR	163 (79,84)	Treatment	Brief Symptom Inventory. The Impact of Event Scale. Supportive Care Needs Survey Short Form. Posttraumatic Growth Inventory. Assessment of QoL 8D. The Internet Evaluation and Utility Questionnaire and internet Intervention Adherence Questionnaire (Process Measures)	Psychological and cancer-specific distress and unmet psychological supportive care needs	Positive adjustment and QoL.	Web- based CBT	Psycholo gists
Hou et al. (2020)	Taiwan	Breast	52 - 64 (Range	112 (53, 59)	Active Treatment	EORTCQLQ-C30). EORTC Breast Cancer-Specific QOL (QLQ-BR23)	Quality of Life	NR	mobile app	Psycholo gists
Hauffma n et al. (2020)	Sweden	Breast, colorec tal, prostate cancer	59	15	Mixed	Interview Guide	Anxiety and Depression	NA	Web- based program	Psycholo gists
Li and Di (2018)	China	Nasoph aryngea l Carcino ma	44.3	132 (65,67)	Treatment	EORTC QOL	complications and quality of life	NR	smartpho ne	Oncologi st
Admiraal et al. (2017)	Netherla nds	Breast	53.2	139 (70, 69)	Post Treatment	EORTC QOL. Breast cancer-specific QOL(QLQ-BR23) Constructs empowering outcomes (CEO). DT, and 47-item Problem List (PL)	Optimism and control over the future, feeling informed, and acceptance of the illness	Distress and QoL	Web- based program	Psycholo gists
Willems et al. (2017)	Netherla nds	Mixed	56.3	462 (231,231	Post Treatment	EORTCQL-C30. HADS. Checklist Individual Strength	QoL, anxiety, depression, and fatigue	NR	website	None
Mayer et al. (2018)	USA	Colon	58.6	284 (140,144 )	Post Treatment	Godin Leisure-Time PA Questionnaire (GLTPAQ). Functional Assessment of Cancer Therapy-Colon (FACT-C,	Physical Activity	Distress and QoL	SMART PHONE	Coaches

Author	Country	Cancer type	Age (mean)	Sample Size	Survivors hip Phase	Measures	Primary outcomes	Secondary outcomes	Platform	HCP/ Facilitat or
Greer et	USA	Mixed	53.3	181	Active	version 4). NCCN Distress Tool. Treatment Self-Regulation Questionnaire [TSRQ]. McTavish Bonding Scale Electronic Pill Caps, MD Anderson	Medication	Anxiety and	mobile	None
al. (2020)				(91,90)	Treatment	Symptom Inventory (MDASI). Functional Assessment of Cancer Therapy—General (FACT-G). Morisky Medication Adherence Scale (MMAS-4). Functional Assessment of Chronic Illness Therapy—Treatment Satisfaction— Patient Satisfaction (FACIT-TSPS)	adherence, Symptom burden, and QoL	depression, social support, quality of care, and healthcare utilization	app	
Freeman et al. (2015)	USA	Breast	55.4	118(23,4 8, 47)	Post Treatment	Medical Outcomes Study 36-item short- form survey (SF-36). FACT-B. FACIT- Fatigue Scale (FACIT-F, version 4). FACT-Cog (version 2). Functional Assessment of Chronic Illness Therapy Spiritual Well-Being Expanded Scale (FACIT-Sp-Ex; version 4). Brief Symptom Inventory (BSI-18) Global Severity Index (BSIGSI). Pittsburgh Sleep Quality Index (PSQI)	Health-related and breast cancer-specific QoL	Fatigue, cognitive function, spirituality, distress, and sleep	tele delivery/l ive streamin g	Therapist
Yun et al. (2012)	South Korea	Mixed	NR	273 (136,137 )	Post Treatment	Brief Fatigue Inventory (BFI). Fatigue Severity Scale (FSS). HADS. EORTC QLQ-C30	Cancer-related Fatigue	Anxiety, depression, QoL	website	Health professio nal -Not specified
Basch et al. (2016)	USA	Mixed	61.5	766 (539, 227)	Treatment	EuroQol EQ-5D Index	HRQoL	Emergency Room visits, Hospitalizati on, and survival.	Web- based interface	Nurses and oncologi sts

### 2.3.1. Quality Appraisal

Variability in methodology and study quality were noted (*Table 2.3*). Fourteen studies met 4-5 criteria (high quality) while the remaining twenty-three met 2-3 criteria (moderate quality). Frequent limitations related to the randomization processes, non-blinded outcome assessors, non-representative samples, and non-adherence to interventions.

### 2.3.2. Intervention characteristics

The duration of interventions and measurement points varied. Twelve studies had one follow-up, while the rest had multiple follow-ups (range:2-5). Ten studies had a waitlist control, 11 had active controls, and 15 used care as usual. Of 36 controlled studies, 24 evaluated interventions that included contact with health care providers or PA coaches. These included nurses (n=8), trained coaches (n=2), oncologists (n=4), trained therapists and psychologists (n=10). Others were unguided or self-guided.

### 2.3.3. Connected Health technologies

In terms of CH technologies, 21 interventions utilised web programmes, including web-based self-guided psychosocial interventions (n=8), web-delivered CBT and mindfulness sessions (n=8), and web-based psychoeducational programmes (n=5). Thirteen interventions used smart applications with symptom monitoring, self-assessment, and self-management programmes (n=9), and those that facilitated social networking (n=4) such as WeChat. Two studies evaluated live therapist streamed sessions via videoconferencing software, while one evaluated a wearable device. Only one-sixth (n=6) of included CH technologies were publicly available platforms/websites.

#### 2.3.4. Intervention outcomes

Impacts of interventions were categorized based on outcomes in psychosocial wellbeing and QoL domains. For psychosocial wellbeing, patient-reported outcomes included depression, anxiety, and symptom distress, while QoL outcomes included HRQoL, physical activity, and fatigue. Several studies evaluated multiple outcomes. Impacts of interventions on various outcomes are discussed in terms of the thematic clusters of interventions identified, with a select number of studies described as illustrative examples (*Table 2.3*).

Table 2.3

Intervention Outcomes

Study	Design	Intervention Description	Control	Intervention duration	CH Intervention Components	Outcomes	MMAT
Owen et al. (2017)	RCT	Social networking Platform (The Health-Space Intervention(health-space.net)	Waitlist control (WC)	12 weeks	Self-management, peer support, psychosocial support, coping skills training	Lower clinically significant depression in both conditions. Intervention did not improve depression, trauma-related anxiety symptoms, or overall mood disturbance.	3
Yun et al. (2020)	RCT (multi- centered)	Web-based support with health coaching and Web-based support without health coaching	Health education booklet	6 Months	Self-management, information support, health coaching	Greater reduction in anxiety in intervention than control. No differences in depression across the three groups.	3
Beatty et al. (2015)	RCT	Self-guided web-based CBT (Cancer Coping Online)	Web-based information only	6 weeks	Psychoeducation, psychosocial support (CBT-based activities)	Lower cancer distress at 6-month follow-up and higher global QOL in intervention than control.	4
Abrahams et al. (2017)	RCT	Internet-based CBT (ICBT)	Care as usual (CAU)	6 Months	Psychosocial support (CBT activities)	Lower functional impairment and psychological distress, and higher QOL for intervention.	5
Lally et al. (2019)	RCT	Unguided, web-based, psychoeducational program (CaringGuidance™ After Breast Cancer Diagnosis)	CAU	12 Weeks	Self-management, psychoeducation, information support	No overall effects but lower depressive symptoms and distress differences between months 2 and 3 in intervention.	4
Greer et al. (2019)	RCT	Mobile-based (app) CBT	mhealth education programme	12 weeks	Psychosocial support (CBT activities), psychoeducation	Improvements in anxiety, depression, and QoL for both groups. No differences in outcome measures but secondary analysis showed mobile CBT group had less anxiety compared with control.	3
Stevenson et al. (2019)	RCT	Web-based information tool and nurse-delivered telephone support	CAU	12 weeks	Information support	No differences in unmet information needs, depression, or anxiety between groups.  Decrease in unmet information	4

Study	Design	Intervention Description	Control	Intervention duration	CH Intervention Components	Outcomes	MMAT
					•	needs in both groups.	
Sherman et al. (2018)	RCT	Web-based psychological intervention (structured online writing exercise) plus usual care	Expressive writing plus CAU	1 Week	Psychosocial support	Lower body image distress and psychological distress in intervention.	5
Spahrkäs et al. (2020)	RCT	Self-management mHealth app (Untire App).	WC	12 weeks	Psychosocial activities (CBT),Psychoeducation, PA training	Greater improvements in average overall QoL but not for overall QoL in the past week for intervention.	3
Sui et al (2019)	RCT	WeChat app-based education and rehabilitation program	Simple education and rehabilitation guidance	12 Months	Health education, Rehabilitation, PA supervision, psychosocial support	Lower anxiety scores, anxiety rate, depression scores, and depression rate in intervention. Higher QLQ-C30 global health status score and functional score, but no difference in QLQ-C30 symptom score in the intervention compared with control.	5
Beatty et al. (2018)	RCT	Online self-guided psychotherapeutic intervention (Finding My Way)	Information-only	6 weeks	Psychosocial support, psychoeducation	Both groups reported reduced cancer-specific and general distress over time, with no group differences.	4
Ruland et al. (2013)	RCT	WebChoice: Internet-based, interactive health communication application	Information sheet with suggestions for publicly available, cancer- relevant Internet sites	12months	Self-assessment, self- management, information support, peer/social support	No group differences in depression and HRQoL, with only global symptom distress index on MSAS-SF lower in intervention.	4
Zhou et al. (2019)	RCT	WeChat-based multimodal nursing program plus routine nursing care	CAU	6 Months	Peer/social support, psychosocial rehabilitation	Improvement in HRQOL in intervention group.	5
Korkmaz et al. (2019)	RCT	Web-based Patient education Or Brochure group	CAU	40 days	Health education	The differences in the state of anxiety scores were statistically lower in the web-based education group than in the brochure and CAU group	3

Study	Design	<b>Intervention Description</b>	Control	Intervention duration	CH Intervention Components	Outcomes	MMAT
Bruggerman- Everts et al. (2017)	RCT	Psychologist-guided web- based mindfulness-based CBT (Embct) or Psychotherapist guided Ambulant Activity Feedback	Psychoeducational Emails	9 Weeks	Psychosocial support, psychoeducation, PA support	Fatigue severity decreased more in intervention groups compared to control. Mental health improved in all groups	4
Willems et al. (2017)	RCT	Stand-alone web-based psychosocial intervention [Kanker Nazorg Wijzer (KNW; Cancer Aftercare Guide)].	WC	12 Months	Psychosocial, self- management, information support	Intervention effective in improving social functioning for men, reducing fatigue for participants ≤56 years, and depression for participants who received chemotherapy at six months. Effects not sustained at 12 months.	3
Rosen et al. (2018)	RCT	Mobile app-delivered mindfulness training (AMT) (Headspace)	WC	8 weeks	Psychosocial Support (mindfulness training)	Higher QOL in intervention than control from baseline through follow-up.	3
Kuhar et al. (2020)	RCT	Mobile App (mPRO Mamma)	CAU	Varied	Symptom monitoring/management	Summary global QoL higher for intervention than control after first week and at end of treatment.	5
Vallance et al. (2020)	RCT	ACTIVity And TEchnology (ACTIVATE)- wearable technology-based intervention	WC	12 Weeks	Physical rehabilitation, psychosocial/behaviour change facilitation	No HRQoL differences between groups but small improvement in fatigue at T2.	3
Anja van der Hout et al. (2020)	RCT	Web-based eHealth application (Oncokompas)	WC	6 months	Behaviour change, information support, self-efficacy, self- management confidence	Improvements in HRQoL and tumor-specific symptom burden. No differences in patient activation between groups over time.	3
Fjell et al. (2019)	RCT	Interactive smartphone application (Interaktor)	Standard care (SC)	Varied	Self-assessment, symptom monitoring, information support	Lower overall symptom distress and physical symptom distress, and higher emotional functioning in intervention group.	4
Sundberg et al. (2017)	CT (non- Randomized)	Interactive smartphone application (Interaktor)	CAU	5- 8 weeks	Self-assessment, symptom monitoring/management	Lower levels of fatigue, nausea, burden on emotional functioning, insomnia, and urinary-related symptoms in	2

Study	Design	Intervention Description	Control	Intervention duration	CH Intervention Components	Outcomes	MMAT
				uuration	Components	intervention group at end of radiotherapy and 3 months later.	
Compen et al. (2018)	RCT	Face-to-Face MBCT Or eMBCT	CAU	3 months	Psychosocial support (mindfulness-based CBT), information support	Less psychological distress in intervention groups, with reduced fear of cancer recurrence, increased mental HRQoL mindfulness skills, and positive mental health compared with TAU. No improvements in physical HRQoL.	3
Syrjala et al. (2018)	RCT	Internet-based Survivorship Program with Information and REsources, with Problem- Solving Treatment (PST) telehealth calls ( <i>INSPIRE</i> )	WC	6 Months	Psychosocial support (Problem-solving therapy), Information support	No reduction in aggregated outcomes for either intervention. INSPIRE+PST participants were more likely to improve in distress than controls, with INSPIRE alone marginally more likely to improve in distress.	3
Ridner et al. (2019)	RCT	Web-based Multimedia Intervention (WBMI)	Educational pamphlets	12 modules, each lasting 30 minutes	Psychosocial support, information support	Group differences in symptom reduction between baseline and 1/12 months, apart from mood symptoms.	3
Helmondt et al. (2019)	RCT	CAncer REcurrence Self-help Training (CAREST): CBT- based online tailored self-help training	CAU		Psychosocial support, psychoeducation	No differences between groups suggesting treatments did not differ in their change in fear of cancer recurrence over time.	2
Chambers et al. (2018)	RCT	CBT-based online self-help training (CancerCope program)	CAU	6 weeks	Psychosocial support, self-assessment, management	No significant intervention effects on fear of cancer recurrence, psychological distress, or other outcomes. Analysis showed a greater decrease in psychological distress, cancer-specific distress and unmet psychological care needs from baseline to 8 weeks in intervention group compared with the patient education group.	2

Study	Design	Intervention Description	Control	Intervention duration	CH Intervention Components	Outcomes	MMAT
Hou et al. (2020)	RCT	Breast cancer self- management support mHealth (BCSMS) app.	CAU	6 months	Self-management, information support	Mean total QoL summary scores from the QLQ-C30 significantly higher among experimental group versus the control group at 3 months.	3
Hauffman et al. (2020)	Qualitative	iCAN-DO': internet-based stepped-care program	NA	10 weeks	Psychosocial and information support	The intervention was experienced as a useful and reliable source of information and support and was used as a complement to standard care	5
Li and Di (2018)	RCT	Smartphone medical app after discharge.	CAU	Varied	Self-management, information support, link to experts	QoL was higher in intervention group than in the control group at 6 months.	2
Admiraal et al. (2017)	RCT	Web-based tailored psychoeducational program (ENCOURAGE)	SC	12 weeks	Self-assessment, self- management, psychoeducation	Study groups did not differ across outcome measures.	3
Willems et al. (2017)	RCT	Web-based psychosocial intervention [Kanker Nazorg Wijzer (KNW; Cancer Aftercare Guide)]	WC	6 Months	Self-management, information support	Intervention effective in reducing depression and fatigue levels.	4
Mayer et al. (2018)	RCT	SurvivorCHESS (Comprehensive Health Enhancement Support System): a smartphone application	Educational booklets	6 Months	Skills building, psychosocial support, PA	No differences between groups over time for QOL or distress items. At 6 months, physical activity in intervention group improved from moderate to vigorous but improvement not sustained 3 months after study ended.	3
Greer et al. (2020)	RCT	Smartphone app and Fitbit integration for tracking PA	SC	12 Weeks	Symptom monitoring/management, PA tracking	Study groups did not differ across outcome measures	3
Freeman et al. (2015)	RCT	Envision the Rhythms of Life (ERL): imagery-based group intervention either Livedelivery Vs therapist streamed via telemedicine	WC	3 Months	Psychosocial support, social support, self- assessment	Clinically significant improvements in fatigue, cognitive dysfunction, sleep disturbance, health-related and breast cancer-related QOL in intervention groups compared to	3

Study	Design	Intervention Description	Control	Intervention duration	CH Intervention Components	Outcomes	MMAT
						control after 3 months. No differences between live and telemedicine-delivered interventions.	
Yun et al. (2012)	RCT	Internet-based, individually tailored CRF education program	CAU	12 weeks	Psychosocial support, information support, physical rehabilitation	Decrease in anxiety scores, global QoL, and several functioning scores of EORTC QLQ-C30 in intervention group.	3
Basch et al. (2016)	RCT	Web-based Symptom Tracking and Reporting (STAR)	CAU	6 months	Symptom tracking and reporting	HRQoL improved among more participants in the intervention group than control group	3

# (i) Psychoeducation and information support.

Twenty-six studies evaluated the impact of CH-delivered psychoeducation and information support on distress and anxiety. Technologies included web-based psychoeducation and information support programmes (Admiraal et al., 2017; Bruggeman-Everts et al., 2017; Chambers et al., 2018; Compen et al., 2018; Hauffman et al., 2020; Korkmaz et al., 2019; Lally et al., 2019; Ridner et al., 2019; Stevenson et al., 2019; Syrjala et al., 2018; van der Hout et al., 2019; van Helmondt et al., 2019; Willems, Bolman, et al., 2017; Willems, Mesters, et al., 2017; Yun et al., 2012, 2020) or Interactive Heath Communication Applications (IHCA) (Fjell et al., 2019; Greer et al., 2019, 2020; Mayer et al., 2018; Rosen et al., 2018; Ruland et al., 2013; Spahrkäs et al., 2020; Sui et al., 2020; Sundberg et al., 2017; Zhou et al., 2019). These included dedicated information where users could access reliable and relevant web resources related to their illness, allowing them to stay connected with health care providers to address concerns that would cause undue anxiety and distress. There were mixed efficacies.

One web-based information tool and nurse-delivered telephone support was intended to reduce unmet information needs, depression, and anxiety among haematological cancer patients; however, this did not yield any differences in comparison to usual care (Stevenson et al., 2019a). Similarly, when compared to usual care, a web-based, psychoeducational distress self-management programme, *CaringGuidance* Mafter Breast Cancer Diagnosis, found no significant overall effects post-intervention (Lally et al., 2019). Another web-based patient education intervention for patients hospitalized following breast surgery showed state anxiety was lower at three time points compared to control groups (Korkmaz et al., 2019), while a qualitative study exploring user experiences of internet-based stepped care (iCAN-DO) in patients with concurrent symptoms of anxiety and depression reported that finding information was considered a "survival strategy" to reduce symptoms of anxiety and depression when receiving a cancer diagnosis, suggesting that this intervention was helpful in reducing symptoms (Hauffman et al., 2020).

### (ii) Psychosocial support and rehabilitation.

Half of interventions (n=18) targeted psychosocial support and rehabilitation, measuring the impact on various domains of psychosocial wellbeing and QoL.

Interventions encompassed web-based CBT (Abrahams et al., 2017; Beatty et al., 2016; Bruggeman-Everts et al., 2017; Chambers et al., 2018; Compen et al., 2018; van Helmondt et al., 2019; Willems, Bolman, et al., 2017; Willems, Mesters, et al., 2017), mobile-based CBT (Greer et al., 2019; Spahrkäs et al., 2020; Stevenson et al., 2019), WeChat app-based education and rehabilitation programme (WERP) (Admiraal et al., 2017; Sui et al., 2020; Zhou et al., 2019), Web-based psychologist-guided interventions (Freeman et al., 2015), mobile app-delivered mindfulness training (AMT) (Rosen et al., 2018) and Web-based Multimedia Interventions (WBMI) (Ridner et al., 2019; Sherman et al., 2018; Yun et al., 2012). Topics covered included self-care, goal setting, self-reward, dealing with negative feelings and building social support. Mixed efficacies were reported.

One study examined the efficacy of a tailored CBT mobile application compared with mobile health education to treat anxiety in patients with incurable cancer (Greer et al., 2019). While groups did not differ in improvements in anxiety, depression, and QoL, the CBT intervention was more beneficial for patients with severe baseline anxiety. In a related study, participants in the 'My Changed Body (MyCB)', a web-based psychological intervention, reported less body image distress and greater body appreciation and self-compassion than expressive writing participants (control) (Sherman et al., 2018). An internet-based mindfulness-CBT intervention led to less psychological distress, reduced fear of cancer recurrence and improved HRQoL, mindfulness skills, and positive mental health compared with treatment as usual, but no improvements in physical QoL(Compen et al., 2018). An Imagery-based Behavioral Intervention for Breast Cancer Survivors "Envision the Rhythms of Life" (ERL)' resulted in clinically significant improvements in multiple QoL domains compared to a waitlist control (Freeman et al., 2015).

### (iii) Symptom monitoring, reporting, and self-management.

Eighteen studies examined the role of CH interventions on symptom burden, symptom monitoring, and self-management and evaluated the resultant impact on psychological wellbeing and QoL outcomes. Most studies (n=12) examining symptom management were based on smart applications (Basch et al., 2016; Di & Li, 2018; Fjell et al., 2019; Grašič Kuhar et al., 2020; Greer et al., 2019, 2020; Mayer et al., 2018; Rosen et al., 2018; Spahrkäs et al., 2020; Sui et al., 2020; Sundberg et al., 2017; Zhou et al., 2019) while one employed a wearable device (Vallance et al., 2020). These interventions

involved a symptom assessment section for patients, and tailored symptom self-management support. Mixed findings on psychological wellbeing and QoL were reported.

One mobile app 'MPRO mamma' to support symptom management and associated QoL in early-stage breast cancer (Grašič Kuhar et al., 2020) involved daily tracking of symptoms, allowing users to grade symptom severity, and provided in-depth descriptions and recommendations based on reported symptom levels. This was associated with better QoL compared to the control group. Separately, an interactive smartphone application 'Interaktor' was associated with lower levels of fatigue and nausea at the end of radiotherapy, and less burden in emotional functioning, insomnia, and urinary-related symptoms among prostate cancer patients at the end of treatment and three months later (Sundberg et al., 2017). A web-based symptom tracking and reporting (STAR) resulted in improvements in HRQoL in patients receiving routine outpatient chemotherapy compared to care as usual (Basch et al., 2016). Another study found differences in global symptom distress index between the 'web choice' intervention and control groups, but no differences in depression, self-efficacy, and HRQoL(Ruland et al., 2013).

## (iv) Peer and social support.

One quarter (n=9) of included studies involved CH-mediated peer support and social networking interventions. Participants could share experiences with other patients and obtain professional support. In addition, users had access to a support forum for group discussion allowing them to ask questions and share experiences in the comfort of their homes and with confidentiality. The impact of these interventions on psychological and QoL outcomes was evaluated with overall promising efficacy.

One study evaluated the effects of a 12-week social networking intervention 'healthspace.net' on distress, depression, anxiety, vigour, and fatigue in participants reporting high levels of cancer-related distress. Post-intervention, the prevalence of clinically significant depression symptoms declined from 67 to 34% in both groups (Owen et al., 2017). A WeChat-based multimodal intervention led to significant improvements in HRQoL among postoperative breast cancer patients (Zhou et al., 2019). Additionally, a 12-month WeChat-based education programme was found effective in improving psychosocial wellbeing and QoL in non-small lung cancer patients after undergoing surgical resection (Sui et al., 2020).

### (v) Health coaching and PA training

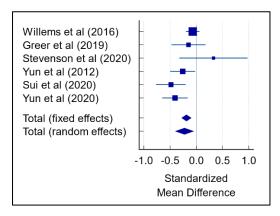
Three CH interventions targeted health coaching, skills training and physical rehabilitation with a working hypothesis that improved PA after diagnosis may decrease recurrences and improve QoL and physical functioning (Bruggeman-Everts et al., 2017; Mayer et al., 2018). PLWBC of colon cancer using 'SurvivorCHESS', increased their moderate to vigorous PA, but this was not sustained three months post-intervention, with no QoL or distress differences over time (Mayer et al., 2018). The ACTIVATE Trial examined the efficacy of a wearable-based intervention to increase PA in PLWBC of breast (Vallance et al., 2020) A 4.6-point difference in fatigue was observed between groups at the end of intervention indicating improvement in fatigue profiles in the intervention group, with no effects on HRQoL. In a related study, a self-management mHealth app "Untire mobile app" improved fatigue and QoL, with larger improvements in fatigue severity fatigue interference and overall QoL (Spahrkäs et al., 2020).

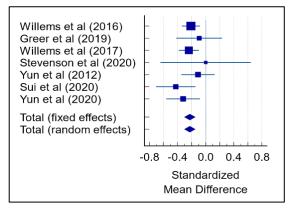
### 2.3.5. Meta-analysis findings

Seven trials (Greer et al., 2019; Stevenson et al., 2019a; Sui et al., 2020; Willems, Bolman, et al., 2017; Willems, Mesters, et al., 2017; Yun et al., 2012, 2020) evaluating the impact of CH interventions on anxiety and depression using HADS were included in the meta-analysis. One trial (Willems, Mesters, et al., 2017) reported HADS - Depression subscale only and so was not included. Pooled estimates of both depression and anxiety scores from HADS showed that CH interventions were moderately effective for depression (SMD: -0.226, 95% CI -0.303/-0.149) and anxiety (SMD: -0.188, 95% CI: 0.279/-0.0963) compared to controls. The overall I<sup>2</sup> (inconsistency) was 63.7% for anxiety, indicating moderate heterogeneity. No heterogeneity was observed for depression. We did not find significant publication bias based on the insignificant Egger's test and through funnel plot examination. Figure 2.2 shows the effect on interventions on the HADS subscales of anxiety and depression.

Figure 2.2

Effects of interventions on Anxiety and Depression





Anxiety Subscale

**Depression Subscale** 

#### 2.4. Discussion

Study 1 examined CH-mediated interventions on psychosocial wellbeing and QoL outcomes in cancer. Depression and anxiety were the most-commonly evaluated outcomes, with findings suggesting potential for CH to improve anxiety and depression symptoms in PLWBC. This is consistent with previous reviews that found depression and anxiety as top psychological concerns and targets for CH interventions in cancer (McAlpine et al., 2015a; Watts et al., 2014). Overall, this review found a generally positive effect of interventions on QoL, with several studies reporting improvements in overall QoL, specific domains and/or symptom specific scales such as fatigue. However, while evidence suggests benefits for CH in all five clusters reviewed, the diversity of interventions and outcome measures call for more evidence-based evaluations.

The studies reviewed used a wide range of CH technologies, with content similar to that of traditional face-to-face/person-to-person/inperson interventions. Results indicate that psychosocial and behaviour change interventions perform well when delivered via CH, with equal or higher efficacy compared to usual care. This could help in reducing travel burden, commonly reported as barrier to cancer care (Ambroggi et al., 2015).

This review evaluated a diverse spectrum of CH interventions, with many trials evaluating multiple outcomes in different cancer phases. While this is encouraging, it may not be possible to associate specific outcomes with specific intervention components, thus possibly diluting effects. This concern has been consistently noted in previous reviews (Seiler et al., 2017; Ventura et al., 2013) suggesting future studies

should aim to assess specific CH components and outcomes separately to maximize efficiency.

A considerable number of trials investigating CH interventions show the promising role of CH in supporting psychological wellbeing. To our knowledge, this is the first study to attempt a meta-analysis, albeit with a limited selection of outcomes. However, like previous reviews (such as Goliță & Băban, 2019; Seiler et al., 2017; Ventura et al., 2013), thematic synthesis revealed varying efficacies on different measures of psychological wellbeing. Mixed findings reflect the diversity of outcome measures and heterogeneity of studies in terms of sample compositions and mechanisms through which improvements were proposed to occur (Kvedar et al., 2014). Mixed findings may also be because the 'usual care' in studies differed considerably (ranging from active controls, waitlist control or in-person care). Thus, additional research is needed to understand the optimal timing and delivery of interventions through standardised control conditions. It is important to note that most records identified from the initial database searches were pilot and feasibility studies, which were excluded from this review given the focus on full-scale interventions. The increased demand for remote services and accelerating pace of CH technologies in response to the COVID-19 pandemic (Golinelli et al., 2020) is a likely driver of the increase in such feasibility trials, further indicating the need for continued evaluation of efficacy.

Our review found promising efficacy of emerging technologies such as wearable devices and social networking platforms in supporting psychosocial and QoL related outcomes. The 12-week social networking application by Owen et al., (2017) reported improvements in distress that were not associated with severe anxiety symptoms, while the 12-month WeChat app-based programme by Sui et al., (2020) reported higher reductions in anxiety and depression compared to controls, with overall improvements in QoL in both groups. Vallance et al., (2020)'s wearable technology reported small improvements in fatigue, but no effects on overall HRQoL. Taken together, the findings suggest that emerging technologies may be useful in improving certain outcomes for psychological wellbeing and QoL but may not be effective among patients with severe mental disorders.

Studies included in our review evaluated the impact of CH based interventions across different phases of cancer, with majority in post treatment survivorship phases. While CH intervention targets were largely similar across the survivorship phases, CH was found useful in symptom monitoring to reduce symptom related distress in the

active treatment phase, while cancer related distress, body image distress, QoL and fear of recurrence were largely targeted in the post treatment phase. These concerns have been reported previously as among the unmet needs in different phases (Chen et al., 2022; O'Connor et al., 2019; Puts et al., 2012). As outline in Chapter 1, this finding is not surprising, with more people now living well with and beyond cancer. Notably, the meaning of 'cancer survivor' varied across contexts. In some contexts, survivorship was defined as the post-treatment period of care with a focus on 'cured' or having completed active treatment with curative intent but excluding end-of-life care, while other studies defined a 'cancer survivor' as a person with cancer from the time of diagnosis through the end of life. This inconsistency reflects the evolving landscape of cancer survivorship, including the terminologies used, as described in *Chapter 1, Section 1.5* 

The large variability in intervention durations was another notable finding, with some interventions lasting as short as a few days to others taking several months. This highlights the need to identify the most effective durations for CH interventions. Only one study explored user experiences of internet-based stepped care in patients with cancer and concurrent symptoms of anxiety and depression (Hauffman et al., 2020). Very few explored participants' reasons for using or not using CH interventions. This suggests a for further studies targeting non-users to understand their reasons behind non usage. Further, even though the majority of studies reported considerable adherence to interventions with an intention to treat analysis, a finding consistent with other studies on CH technologies (Murray et al., 2004), further research is needed to understand the main components and delivery approaches to maximise patient engagement.

On a positive note, the quality of the included studies was generally high. This is an additional strength indicating an increasing standard of evidence for CH interventions and an improvement from a previous systematic review (Marthick et al., 2021), which noted a general lack of high-quality primary studies and RCTs. However, the lack of standardised outcome measures remains a major concern.

# 2.4.1. Study Limitations

There are several limitations to the present review. Firstly, considering CH is a developing concept in digital health with a somewhat broad definition, the lack of consistent terminology may have hampered record identification for analysis. Secondly, while QoL was one of the outcomes of interest, and despite multiple studies employing the EORTC QLQ-C30, a meta-analysis of these studies was not feasible due to

variability in scoring, reporting formats, and inconsistent data across included studies, and the fact that different types of cancers were evaluated in different studies. Thirdly, pilot and feasibility studies were excluded, and considering many of them might have deployed to offer remote services during COVID-19 pandemic, it is possible that additional technologies with improved efficacy have been more recently developed. On the flip side, this reflects the urgent need for further examination of CH in line with the recent call from WHO for enhanced evaluation to inform integration and use of digital technologies (WHO, 2019). Fourthly, the included studies may not comprehensively represent CH technologies and cancer subtypes as they were incidental to psychological wellbeing and QoL outcomes. As such, any conclusions should be tentative in light of the likely partial data. Finally, only reports in English were included, thus excluding studies published in other languages.

#### 2.5. Conclusion

CH-mediated psychosocial interventions have the potential to reduce anxiety and depression symptoms, thereby supporting psychosocial wellbeing and improve QoL in cancer survivorship. However, future rigorous research employing both qualitative and experimental designs is needed to comprehensively inform the relevant components, timing, design, intensity and delivery of these interventions, particularly for the emerging technologies. Additionally, research examining the generalisability of CH should be conducted to establish the scalability of interventions, particularly during and after the COVID -19 pandemic when face-to-face interventions have been restricted.

While the current review demonstrates the positive impact of CH interventions on various outcomes related to psychosocial well-being, such as anxiety and depression, it also reveals uneven uptake across different sociodemographic groups affected by cancer. Therefore, further research is needed to understand the factors influencing CH intervention uptake. Study 2 addresses this gap by analysing a nationally representative sample to factors influencing CH uptake and usage.

# **Chapter 3**

# Study 2

Who uses connected health technologies after a cancer diagnosis? Evidence from the U.S Health Information National Trends Survey

Adapted from: Gitonga, I., Desmond, D., & Maguire, R. (2024). Who uses connected health technologies after a cancer diagnosis? evidence from the US Health Information National Trends Survey. *Journal of cancer survivorship:*\*\*research and practice\*\*

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#### **Abstract**

**Purpose.** As the number of people living with and beyond cancer increases, CH technologies offer promise to enhance access to care and support, while reducing costs. However, uptake of CH technologies may vary depending on sociodemographic and health-related variables. This study aimed to investigate demographic and health predictors of CH technologies use among PLWBC.

**Methods.** Cross-sectional data from the U.S Health Information National Trends Survey Version 5 Cycle 4 (H5c4) collected between February and June 2020 was used. Regression analysis was used to examine associations between sociodemographic factors and the use of CH technologies. The sample was restricted to individuals who self-reported a cancer diagnosis or history of cancer.

Results. In this cycle, 626 respondents self-reported a cancer diagnosis, with 41.1% using CH technologies (health and wellness apps and/or wearable devices). Most were female (58.9%) and white (82.5%); 43.4% had graduated college or higher education. One third (33.6%) had a household income of \$75,000 or more. Respondents who were younger, higher educated, living as married, had higher incomes, higher self-rated health and higher health-related self-efficacy were significantly more likely to use CH technologies. There were no significant associations between sex at birth, race, stratum, time since diagnosis, history of anxiety or depression and use of CH technologies among PLWBC.

**Conclusion.** Connected health technologies usage among PLWBC is associated with sociodemographic factors. Future research should examine these demographic disparities as the use of CH technologies in healthcare continues to gather momentum.

#### 3.1. Introduction

The growing population of PLWBC requires expansion of healthcare services to meet their needs and to reduce access gaps (Prager et al., 2018). As technology continues to be integrated into both healthcare and society at large, digital technologies offer promising possibilities for organisation and delivery of care and support (Fisch et al., 2016). As described in *Chapter 1 and 2*, CH is one such area gaining prominence in supporting patient education, self-management and personalised support. Additionally, CH could reduce logistical barriers associated with in-person care and participation such as time and travel burden (Fisch et al., 2016), making them especially useful in the cancer survivorship context (Mikles et al., 2021; Penedo et al., 2020).

Adoption and usage of CH technologies has been widely examined across various patient populations (Kemp et al., 2021; Sim, 2019), with a growing body of research in the aftermath of the global COVID-19 pandemic (Golinelli et al., 2020; Murthy et al., 2023; Paterson et al., 2020), but also noting gaps related to digital health disparities. The systematic literature review (*Chapter 2*) found mixed but promising findings on uptake and efficiency across the studies, indicating the need for further research to examine predictors, preferences and attitudes towards use and adoption. Moreover, recent studies examining technology usage over the course of the decade found that while the prevalence and adoption of digital health technologies among PLWBC has continued to rise, the digital divide remains prevalent in this population (Delemere & Maguire, 2023; Fareed et al., 2021b).

The digital divide, described in *Chapter 1 (section 1.3.3)* as the gap between individuals who have access to, confidence with and benefit from digital technologies, and those who do not, (Chikomba et al., 2023; Western et al., 2025), has been associated with health inequities, and may result in uneven health outcomes (Fareed et al., 2021). This divide is shaped by multiple intersecting factors including socioeconomic status, age, education, health literacy, digital literacy, and broader structural inequalities such as availability of broadband infrastructure and access to digital devices (Coca et al., 2022; Western et al., 2025). A recent review by Yao et al., (2022) found that digital health can foster health disparities based on individuals' ability to adopt technology and their health outcomes, influenced by factors like age, race, location, economic status, education, health status, and eHealth literacy. In their analysis of health disparities, Saeed & Masters (2021)

posited that while technological advancements in healthcare aim to enhance outcomes, it's imperative to ensure equitable distribution of these outcomes across various demographics. Moreover, the WHO's digital health strategy 2020-2025 underlines the importance of acknowledging and addressing demographic disparities when implementing digital health technologies to ensure equitable health outcomes (WHO, 2021b). Despite significant evidence linking socioeconomic factors, access to technology, and digital literacy to technology usage and adoption (Delemere & Maguire, 2021a; Kemp et al., 2021a), there is limited research on these associations amidst the rapidly evolving technology landscape.

Understanding who is most and least likely to engage with CH technologies is critical to ensuring digital equity and avoiding the exacerbation of existing health disparities. In study 2, we analysed the nationally representative, population-level US Health Information National Trends Survey (HINTS) Five, Cycle 4 data (Finney Rutten et al., 2020; Institute, 2020) to investigate demographic and health-related variables associated with CH technology use among PLWBC. The National Cancer Institute (NCI) has conducted HINTS every few years since 2003 to assess health-related information use among civilian, non-institutionalized adults aged 18 or older in the US. HINTS provides the NCI with a comprehensive assessment of the American public's access to and use of information about cancer across the cancer care continuum from cancer prevention, early detection, diagnosis, treatment, and survivorship.

While collected in the U.S., the HINTS data are relevant to the Irish context for several reasons. First, Ireland, and Europe by extension, share many characteristics with the U.S. in terms of increasing cancer survivorship trends, digitalisation of health services, and challenges in reaching underserved groups, as noted by Rowland et al. in their comparative analysis of cancer survivorship research in Europe and the United States (Rowland et al., 2013). Relevant organisations such as the European Cancer Association (European Cancer Organisation, 2024), the European Society for Medical Oncology (ESMO) expert consensus statements on cancer survivorship (Vaz-Luis et al., 2022), and their American counterparts, the American Society for Clinical Oncology (ASCO) (ASCO, 2025), have called for enhanced and collaborative efforts to support high quality care and research in cancer survivorship. Second, in the absence of equivalent national survey data in Ireland, HINTS offers valuable insights into emerging patterns of digital health engagement in PLWBC.

Thus, justified by the limited availability of large-scale, population-level data examining CH use specifically among PLWBC in Ireland, this analysis adopts an exploratory approach.

In line with the second objective of this thesis, and drawing on the socioecological model (Bronfenbrenner, 1977; McLeroy et al., 1988), discussed in *Chapter I*, this study conceptualises CH use as influenced by individual-level factors (e.g., age, education), interpersonal factors (e.g., marital status, social support), and broader structural contexts (e.g., healthcare access, digital infrastructure). In addition, concepts from digital health behaviour models, including constructs from the Technology Acceptance Model (TAM) (Davis et al., 1989) and the newer Unified Theory of Acceptance and Use of Technology (UTAUT2) (Venkatesh et al., 2016), help frame how perceptions of usefulness, self-efficacy, digital health literacy, social influence, and facilitating conditions shape a person's engagement with CH tools. These models have been used in previous research to help understand digital health acceptance and usage (Kamal et al., 2020; Marangunić & Granić, 2015), and informed the variables of interest in the present analysis.

#### 3.2. Methods

#### 3.2.1. Data source

This study used the 5<sup>th</sup> version of HINTS dataset (HINTS 5 Cycle 4; H5c4) which was collected solely by mail between February 2020 and June 2020. This data is publicly available and downloadable from the HINTS website (Institute, 2020). As with prior HINTS iterations, the sampling frame for Cycle 4 consisted of a database of addresses used by Marketing Systems Group to provide random samples of all non-vacant residential addresses in the United States. A two-stage stratified random sampling methodology was used. In the first stage, residential addresses across the US were selected. In the second stage, one adult was selected within each sampled household. The full sampling and weighting process of H5c4 is described in the HINTS methodology report (Institute, 2020). Ethical approval for this secondary analysis was obtained from Maynooth University Research Ethics Committee (reference: SRESC-2022-2475301).

## 3.2.2. Participants

Participants included adults aged 18 years or older who responded "Yes" to the question: 'Have you ever been diagnosed with cancer?' The total number of addresses selected for Cycle 4 was 15,350 out of which 3,865 completed surveys were collected, with a response rate of 37%. Respondents who responded 'no' to this question, and those who did not respond to the question (or whose data were missing) were excluded from these analyses. Of 3,865 participants who responded to the survey and whose data was complete for analysis, 626 (16.2%) self-identified as PLWBC and formed the basis for the current analysis.

#### 3.2.3. Measures

## Demographic information and disease history.

Demographic variables such as participants' age, sex at birth, marital status, highest level of education, household annual income, race/ethnicity, region/stratum and years since diagnosis were drawn from the data set. These were based on structured survey questions with fixed response options, some of which were recoded where necessary for analysis. The full wording and response options are detailed in the HINTS methodology report, (NCI, 2025b), which is freely accessible via the HINTS website: <a href="https://hints.cancer.gov/data/methodology-reports.aspx">https://hints.cancer.gov/data/methodology-reports.aspx</a>. These demographics have been reported in previous HINTS analysis (Y. Jiang et al., 2017; H. K. Onyeaka et al., 2021). Psychometric information was not available for single-item measures, which were used consistently across HINTS cycles for population-level tracking. The specific questions for other variables used in this analysis are included below.

# Ownership and use of connected health technologies

Use of CH technologies (health or wellness apps and wearable devices) was determined based on an affirmative response to either of the following two questions In the past 12 months, have you used any of these health or wellness apps? and In the last 12 months, have you used an electronic wearable device to monitor or track your health or activity? For example, a Fitbit, AppleWatch or Garmin Vivofit... with response of 'yes' or 'no'. The first question was preceded by a question that required respondents to indicate if they had any "apps" related to health and wellness. On your tablet or smartphone, do you have any 'apps' related to health and wellness,

with response of 'yes' or 'no.' However, we did not analyse this question as our focus was on active use of the "apps".

### Health related factors

Self-rated health was measured using a single item on a five-point Likert scale (from 1= excellent to 5= poor). For analysis, responses were dichotomised by combining 'excellent, very good and good' into one category and 'fair and poor' into another category; combined categories were renamed 'good' and 'poor', respectively to ensure adequate group sizes for logistic regression and improve interpretability. This approach has been previously applied in social sciences research for Likert item response formats to improve interpretability (Wilson et al., 2023), with accompanying limitations acknowledged (MacCallum et al., 2002).

## Health related self-efficacy.

Health related self-efficacy was measured using a single item 'Overall, how confident are you in your ability to take care of your health?' (1= completely confident to 5= not confident at all). As with the self-rated health measure, for analysis, we reduced the five categories into a binary variable (confident/not confident) by combining 'completely confident, very confident, somewhat confident' into one category and 'a little confident and not confident at all' into another category.

# History of depression or anxiety.

Lifetime history of depression or anxiety was measured by the item 'Has a doctor or other health professional ever told you that you had depression or anxiety disorder?' (yes/no). Onyeaka et al., (2021) have previously utilised this question as the central question in their examination of CH usage among people with anxiety and depression.

## 3.2.4. Data Analysis

The Statistical Package for Social Sciences (SPSS) was used for analysis. Where available, item wording and response options were drawn directly from the HINTS Codebook. Descriptive statistics were used to examine the usage of CH technologies (health apps and wearable devices). Associations between CH use and

independent variables were first explored bivariate analyses (chi-squared tests and unadjusted odd ratios. Finally, multivariate logistic regression was conducted to examine adjusted associations with CH technology usage. Assumptions for logistic regression were assessed. Multicollinearity was checked using variance inflation factor (VIF), with a mean VIF of 1.64, indicating no serious concerns for multicollinearity (Kim, 2019). Self-rated health and health-related self-efficacy were recoded into binary categories to ensure adequate cell sizes and model stability upon initial exploration and also based on past research guidance (Wilson et al., 2023). Although this may have reduced some precision, it enhanced interpretability given the modest sample size. No corrections were applied for multiple comparisons; therefore, results are interpreted with appropriate caution. Variables were reviewed for completeness, and missing data were handled using listwise deletion in multivariate models. Statistical significance was set at p<0.05.

#### 3.3. Results

## 3.3.1. Sample characteristics

The sample characteristics are provided in Table 3.1. A total of 626 respondents reported to have ever been diagnosed with cancer and formed the analytic sample for this study. The majority were female (58.9%) and over the age of 65 (63.6%). Nearly half of the respondents were married (49%). Over two thirds had completed at least some college education (71%), and approximately half had an annual household income above \$50,000 (50.8%). Most identified as white (82.5%) and lived in high minority areas (57.2%). 48.4% were diagnosed with cancer eleven or more years ago. Almost three quarters of the participants (74%) rated their general health as 'good' and 69% 'felt confident' in their ability to take care of their health. About a quarter of the respondents (24.4%) had been diagnosed with depression or anxiety.

**Table 3.1**Sociodemographic characteristics and disease history of PLWBC

Variable	Category	Frequency (N=626)	Percentage (%)
Age in Years	18-64 Years	225	36.4
	65 and above	393	63.6

Variable	Category	Frequency (N=626)	Percentage (%)
	Missing/ non-response	8	
Sex at birth	Male	256	41.1
	Female	367	58.9
	Missing/non-response	3	
Marital Status	Married/living as married	314	51.6
	Divorced/separated	115	18.9
	Widowed	106	17.4
	Single, never been married	73	12.0
	Missing/non-response	18	
Level of Education	Less than High School	43	7.1
	High School Graduate	132	21.9
	Some College	167	27.6
	College Graduate or More	262	43.4
	Missing/non-response	22	
Household Income	Less than \$20,000	104	19.0
	\$20,000 to < \$35,000	79	14.4
	\$35,000 to < \$50,000	87	15.9
	\$50,000 to < \$75,000	94	17.2
	\$75,000 or More	184	33.6
	Missing/non-response	78	
Race	White	495	82.5
	Other	105	17.5
	Missing/non-response	26	
Stratum	High Minority Areas	358	57.2
	Low Minority Areas	268	42.8
Time since diagnosis	Less than 1 year	78	13.3
	2-5 years	110	18.7
	6-10 years	115	19.6
	11+ years	284	48.4
	Missing/non-response	39	
Self-rated general health	Poor	162	26.0
_	Good	460	74.0
	Missing/non-response	4	
Self-rated ability to take	Not Confident	193	31.0
good care of their health	Confident	429	69.0
	Missing/non-response	4	
Ever been diagnosed of	Yes	151	24.4
Depression/Anxiety	No	468	75.6
	Missing/non-response	7	

## 3.3.2. Ownership and usage of connected health technologies

Of the 626, 265 (42%) reported having apps related to health and wellbeing. Overall, 41.1% (n=257) of the sample reported using health or wellness apps and/or wearable devices to manage the health and wellbeing in the past year (Table 3.2).

Table 3.2

Use of CH technologies among PLWBC

Use of CH Technology	Frequency	Percentage	95% Confidence Interval	
	(N=626)	(%)	Lower	Upper
Use of Health Wellness Apps in the last 12 months	224	35.8	32.1	39.9
Use of Wearable Devices to Track Health in the last 12 Months	127	20.3	17.4	23.8
Use of Connected Health Technology	257	41.1	37.2	45.2

#### 3.3.3. Bivariate association between demographic variables and CH use.

Associations between sociodemographic variables and CH usage in the past year were examined. Age, marital status, level of education, and household income were significantly associated with technology use at the bivariate level. PLWBC aged 18-64 years were more likely to use technology compared to those aged 65 and above (OR=2.65, 95% CI=1.89-3.72, p<0.001). Those with a college degree or higher had higher odds of CH use compared to those with less than a high school education (OR=10.69, 95% CI=3.71-30.76, p<0.001). Similarly, PLWBC with a household income of \$75,000 or more had higher odds of CH use compared to those with an income of less than \$20,000 (OR=4.98, 95% CI=2.93-8.47, p<0.001). Additionally, PLWBC who rated their health as 'good' were more likely to use CH (OR=2.39 95% CI 1.61; 3.54 p<0.001) compared to those who rated their health as 'poor'. Similarly, respondents who reported being confident about their ability to take good care of their health were more likely to use CH (OR =1.50 95% CI 1.05; 2.13, p<0.001) compared to those who were less confident. Sex at birth, race, time since diagnosis, and lifetime diagnosis of depression/anxiety were not significantly associated with CH use (See table 3.3).

Table 3.3

Associations between CH use and demographic and health variables among PLWBC.

Variable	Category	Use of Techr	nology [n (%)]	O.R[95%C. I]	(p-	
		No	Yes	_	value)	
Age in	18-64 Years	98(27.1%)	127(49.6%)	2.65[1.89; 3.72]	< 0.001	
Years	65 and above	264(72.9%)	129(50.4%)	Ref.		
Sex at	Male	148(40.4%)	108(42.0%)	1.07[0.77; 1.48]	0.692	
birth	Female	218(59.6%)	149(58.0%)	Ref.		
Marital Status	Married/living as married	154(43.4%)	160(63.19%)	1.67[0.99; 2.81]	0.054	
	Divorced/separated	75 (21.1%)	40 (15.81%)	0.86[0.47; 1.57]	0.619	
	Widowed	81(22.8%)	25(9.9%)	0.50[0.26; 0.95]	0.035	
	Single, never been married	45(12.7%)	28(11.1%)	Ref.		
Level of Education	Less than High School	39(11.1%)	4(1.6%)	Ref.		
	High School Graduate	92(26.2%)	40(15.8%)	4.24[1.42;12.66]	0.010	
	Some College	95(27.1%)	72(28.5%)	7.39[2.53;21.62]	< 0.001	
	College Graduate or More	125(35.6%)	137(54.2%)	10.69[3.71;30.6]	< 0.001	
Household	Less than \$20,000	77(24.6%)	27(11.5%)	Ref.		
Income	\$20,000 to < \$35,000	61(19.5%)	18(7.7%)	0.84[0.42; 1.67]	0.621	
	\$35,000 to < \$50,000	59(18.8%)	28(11.9%)	1.35[0.72; 2.54]	0.345	
	\$50,000 to < \$75,000	49(15.7%)	45(19.1%)	2.62[1.44; 4.76]	0.002	
	\$75,000 or More	67(21.4%)	117(49.8%)	4.98[2.93; 8.47]	< 0.001	
Race	White	282(81.3%)	213(84.2%)	1.23[0.80; 1.89]	0.353	
	Other	65(18.7%)	40(15.8%)	Ref.		
Stratum	High Minority Areas	216(58.5%)	142(55.3%)	0.87[0.63; 1.21]	0.414	
	Low Minority Areas	153(41.5%)	115(44.7%)	Ref.		
Time Since	Less than 1 year	43(12.6%)	35(14.2%)	1.15[0.69; 1.90]	0.599	
Diagnosis	2-5 years	61(17.9%)	49(19.8%)	1.13[0.72; 1.76]	0.589	
	6-10 years	70(20.6%)	45(18.2%)	0.90[0.58; 1.41]	0.656	
	11+ years	166(48.8%)	118(47.8%)	Ref.		
Self-rated	Poor	119(32.5%)	43(16.8%)	Ref.		
general health	Good	247(67.5%)	213(83.2%)	2.39[161; 3.54]	< 0.001	
Self-rated	Not Confident	126(34.5%)	67(26.1%)	Ref.		
ability to take good care of their health	Confident	239(65.5%)	190(73.9%)	1.50[105; 2.13]	0.025	
Lifetime	Yes	84(23.2%)	67(26.1%)	1.17[0.81; 1.69]	0.414	
diagnosis of Depression /Anxiety	No	278(76.8%)	190(73.9%)	Ref.		

## 3.3.4. Predictors of CH use among PLWBC.

A multivariate logistic regression was conducted to identify predictors of CH technology use. The model included age category, marital status, education level, household income, self-rated general health, and health-related self-efficacy as predictors. Model diagnostics indicated acceptable performance. The pseudo  $R^2$  was 0.1681, suggesting that the model explained approximately 17% of the variance in CH use. The overall model was statistically significant (F (13, 523) = 8.13, p < 0.001), indicating a good fit to the data. No multicollinearity issues were detected; the mean VIF across all predictors was 1.64, well below the commonly accepted threshold of 5 (Kim, 2019) .

Age, marital status, household income and self-rated general health were significant predictors of CH usage. Specifically, those aged 18-64 years were significant more likely to use CH (aOR 2.06 95% CI: 1.35-3.13, p=0.001) than older adults. PLWBC with an income of \$75,000 were more likely to use CH (aOR 3.10 95% CI: 1.48-6.49, p=0.003) compared to those with less than \$20,000. Those who rated their general health as good were more likely to use CH (aOR 1.92 95% CI: 1.09-3.38, p=0.023) compared to those who rated their health as poor (see Table 3.4)

**Table 3.4**Sociodemographic and health related predictors of CH technologies of PLWBC.

Variable	Category	a.O.R[95% C.I]	Sig.
Age in Years	18-64 Years	2.09[1.38; 3.15]	0.001
	65 and above	Ref.	
Marital Status	Married/living as married	1.22[0.63; 2.36]	0.566
	Divorced/Separated	0.8[0.62; 1.79]	0.727
	Widowed	1.15[0.52; 2.56]	0.732
	Single, never been married	Ref.	
Level of Education	Less than High School	Ref	
	High School Graduate	2.49[0.65; 9.60]	0.185
	Some College education	3.35[0.88; 12.68]	0.075
	College Graduate or More	2.65[0.69; 10.17]	0.155
Household Income	Less than \$20,000	Ref.	
	\$20,000 to < \$35,000	1.06[0.47; 2.35]	0.895
	\$35,000 to < \$50,000	1.09[0.52; 2.30]	0.819
	\$50,000 to < \$75,000	1.86[0.89; 3.90]	0.101

Variable	Category	a.O.R[95% C.I] Sig.		
	\$75,000 or More	3.10[1.48; 6.49]	0.003	
Self-rated general health	Poor Good	Ref 1.92[1.09; 3.38]	0.023	
Self-rated ability to take good care of their health	Not confident Confident	Ref 0.89[0.54; 1.47]	0.661	

#### 3.4. Discussion

Study 2 investigated sociodemographic, health related and structural predictors of a subset of CH technologies (health and wellness apps and wearable devices) among PLWBC using a nationally representative sample of US adults. We found that nearly half of PLWBC had wellbeing and health apps in their smartphones, however usage varied across sociodemographic and health-related variables. Our study found higher CH usage in PLWBC compared to analysis of previous HINTS datasets (Y. Jiang et al., 2017; H. K. Onyeaka et al., 2021), suggesting that usage is increasing among this population. The findings contribute to a growing body of evidence on CH use among PLWBC and offer important insights for informing equitable CH implementation strategies, particularly in the Irish context. In this sample, 16.2% of the respondents self-identified as PLWBC. While this figure may appear higher than expected, it aligns with population trends in the US (Siegel et al., 2025), particularly when considering the HINTS sample's older age profile. National data from the American Cancer Society estimate that over 18 million Americans, roughly 5–6% of the total population, are PLWBC, with prevalence increasing substantially among adults aged 65 and above (American Cancer Society, 2025; NCI, 2025a). The overrepresentation of older adults in HINTS may therefore explain the higher rate observed in this sample. In the Irish context, over 200,000 people, approximately 4% of the population, are estimated to be PLWBC (National Cancer Registry Ireland, 2023). While broadly similar in trajectory, the Irish population is smaller and somewhat younger on average, which may explain the modest difference in rates.

Findings from the current analysis suggest that CH usage varies across various sociodemographic and health related variables. Younger individuals, those with higher levels of education, higher income and living as married were more

likely to use CH. These findings are consistent with prior studies which reported disparities in the use of CH technologies in PLWBC (Fareed et al., 2021b). This suggests that, although CH usage and adoption is on the rise, digital divide still persists and this could potentially worsen health disparities (Saeed & Masters, 2021), implying that certain individuals may be 'digitally disconnected' and therefore unable to use the technologies for their heath needs (Meskó et al., 2017; Torous et al., 2021). Furthermore, it is important to address these disparities in CH usage to prevent exacerbation of existing health inequalities as was the case during the COVID-19 pandemic (Beaunoyer et al., 2020). This may include working to improve access to and knowledge of these technologies as well as ensuring that these technologies are designed in a way that is accessible and usable for all people impacted by cancer, regardless of their socioeconomic status.

The finding that there was no association between a history of anxiety and depression and usage of CHT suggests that mental health history may not play a significant role in an individual's likelihood of using CHT. Although there is evidence suggesting that severe mental illness could be a barrier to technology usage (Abu Rahal et al., 2018), and as also reported in the previous chapter, these findings are consistent with a previous study that found people with a history of depression and anxiety used CH technologies at similar rates to the general population (H. Onyeaka et al., 2021). This suggests that mental health history may not be a barrier to CH use for managing conditions such as cancer. Furthermore, it suggests that CH may be a useful tool for individuals with a history of mental health conditions who are managing other health issues. However, it's also possible the questions used in this survey were not sensitive enough to establish this association, and further research is needed to examine the association.

The present analysis found that PLWBC with higher self-rated health were more likely to use CH technologies, a finding consistent with previous research (Figueiredo et al., 2017b; van Bussel et al., 2022). This suggests that technologies designed to enhance self-rated health, and self-efficacy may be particularly effective in engaging PLWBC and promoting their use. For instance, by providing features that enable individuals to track and manage their health, set goals, and receive feedback, these technologies may help foster a sense of control and confidence in managing their health. However, further research is needed to better understand the

mechanisms through which these factors influence technology usage among PLWBC, and to identify strategies for promoting the adoption and effective use.

These findings can be understood through the lens of established models of digital health engagement. The TAM (Davis et al., 1989) posits that two key perceptions, namely the perceived usefulness and perceived ease of use, influence an individual's intention to use a new technology. In the context of CH technologies, PLWBC who believe that CH tools will meaningfully support their cancer care and are easy to use are more likely to adopt them. This may help explain why older adults, those with lower education, and those with limited digital literacy were less likely to report CH use in the current study; these groups may be more likely to perceive CH tools as difficult to navigate or of limited benefit, a gap explored further in Chapter 7.

Additionally, the closely related UTAUT2 model (Venkatesh et al., 2016) offers a more comprehensive framework by incorporating social influence, facilitating conditions, and habitual behaviour into the understanding of technology use. Our findings, such as the association between marital status or higher income and CH use, can be interpreted in light of these constructs. For instance, social encouragement or better infrastructural access (e.g., home broadband, tech support) may act as enabling conditions that increase CH engagement. UTAUT2 also highlights the role of environmental and systemic supports, aligning well with the SEM adopted in this thesis. These frameworks offer practical insights for the design and implementation of CH interventions, particularly the need to improve digital literacy, tailor interventions to varying levels of digital readiness, and address infrastructural and support barriers.

Although HINTS data reflect the U.S. population, findings have relevance for Ireland, which faces similar demographic and infrastructural challenges (Rowland et al., 2013). In the absence of nationally representative data on digital health use among Irish PLWBC, these results provide a provisional evidence base. The findings highlight a need to address digital inclusion and to ensure that CH interventions do not inadvertently widen health inequalities. This has implications for ongoing reforms in Ireland (Burke et al., 2018) and the rollout of digital health strategies in survivorship care (HSE, 2024c). However, while overarching similarities between the two contexts are clear, subtle cross-national differences must be acknowledged. For instance, the US operates a largely private and

insurance-driven healthcare system (Kwok & Léger, 2023; Sorum et al., 2023), whereas Ireland has a mixed public-private system, with ongoing reforms under Sláintecare aimed at increasing universal access. These differences, particularly around access, affordability, and digital readiness, may affect CH adoption. Ireland also lags somewhat behind the US in digital infrastructure, although recent policy shifts, such as the 2023 Digital Health Framework (HSE, 2024a), are accelerating digital transformation.

## 3.4.1. Study Limitations and strengths

There are several limitations to this study. Firstly, the cross-sectional nature of the data means that it can only provide information on associations of CH technology usage rather than causal relationships. Secondly, there is the possibility of recall bias since the survey relied on self-reported information and required participants to recall past behaviours, such as their use of apps or wearables in the past year. Third, the HINTS survey only examined a subset of CH technologies (health and wellness apps and wearable devices), and this is not inclusive of all CH technologies, whose usage might be different. Additionally, due to the nature of questions used in the survey, this study was unable to obtain specific information on the types, content, design, and characteristics of health apps, number of apps, their frequency of use, and costs. Fourthly, some variables had small subgroup sizes, reducing the reliability of certain estimates. Additionally, decisions to dichotomise ordinal variables (e.g., self-rated health) may have reduced analytic power and since no corrections were applied for multiple comparisons, complete case analysis may have introduced bias, and reliance on single-item measures limits psychometric robustness. Fifth, although general survivorship dynamics are comparable, HINTS items may reflect U.S. health system structures and terminologies, which may limit direct transferability to the Irish context.

Finally, data collection in this HINTS cycle was impacted by COVID-19 mitigations which reduced the workforce available for distributing survey packets, leading to a modified mailing schedule with longer intervals between mailings and possible delays (Institute, 2020). The main strength of this study is that the responses in this iteration (H5c4) were collected through mail, thereby avoiding any bias that may arise from 'using technology to study technology.' Secondly, the sample used

for the study was nationally representative, enhancing the generalizability of the findings to the broader population.

#### 3.5. Conclusion

This analysis reveals meaningful patterns in CH use among PLWBC, identifying individual and structural factors that shape engagement. While uptake of CH technologies among PLWBC is evidently on the rise, usage varies across sociodemographic and health-related variables, with those who are older, and with lower SES less likely to use CH technologies, The findings underscore the need for inclusive digital health strategies that actively address disparities in access, confidence, and usability. As Ireland continues to invest in CH innovation for survivorship care, equity must be a central consideration in policy and practice.

Overall, the findings from this study reinforce and extend the conceptual foundations outlined in *Chapter 1*, particularly around structural and behavioural determinants of CH engagement. By empirically demonstrating the influence of sociodemographic, infrastructural, and psychological factors on CH use among PLWBC, this study provides real-world evidence of the digital divide previously theorised. In doing so, it substantiates the call for more equitable and person-centred CH implementation strategies, as discussed in the Irish context. However, while *Chapter 2* highlighted potential impact on outcomes such as anxiety, depression and QoL, the current analysis points to gaps in reach and access. These insights underscore the importance of tailoring future interventions to ensure equitable adoption and sustained engagement. Together, *Chapters 2 and 3* illustrate a critical tension earlier introduced in *Chapter 1*, that while CH interventions hold promise for supporting psychosocial wellbeing, their reach and utility may be uneven due to persistent access and engagement disparities.

#### 3.5.1 Preface to Chapters 4 and 5

The next chapters build on these findings to narrow the focus by shifting from population-level patterns to real-world programme evaluations of a specific CH intervention, the online delivery of the CTS programme in Ireland. *Chapters 4, 5, and 6* explore how CH interventions function in practice, including their benefits on psychosocial wellbeing and QoL. *Chapters 4 and 5* present findings from a single dataset generated during the evaluation of online-delivered CTS in Ireland. While both chapters are based on the same participant cohort and share recruitment procedures and data collection methods, each study addresses a distinct research objective and makes a unique contribution to the thesis.

The next chapter, *Chapter 4 (Study 3a)* focuses on the usability and perceived utility of the CTS programme, examining participants' experiences with the online format, the delivery process, and satisfaction with the intervention. In contrast, *Chapter 5 (Study 3b)* explores participant-reported QoL and identifies ongoing residual needs following programme participation, offering insights into areas where further support may be required.

Separating these studies into two chapters was deemed necessary for clearer alignment of methods, measures, and discussion with each study aim, and to improve the overall structure, clarity, and coherence of the thesis. This division of focus allows for a more comprehensive and nuanced understanding of both the implementation and perceived benefits of the CTS programme within the context of survivorship care in Ireland.

# **Chapter 4**

# Study 3a

Connected Health in Cancer Survivorship care: Evaluating the Usability and perceived utility of the Cancer Thriving and Surviving Programme in Ireland

Adapted from: Gitonga, I., Desmond, D., Mullen, L., Thomas, D., Osborne, C., O'Loughlin, B., & Maguire, R. (2025). Connected health in cancer survivorship:

Evaluating the usability and utility of the cancer thriving and surviving programme in

Ireland. *Irish Journal of Medical Science (1971-)*, 1-12

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#### **Abstract**

**Background:** The preceding chapters have shown that cancer survivorship care has become increasingly complex, with a growing population of PLWBC, requiring holistic support and follow-up care. CH technologies have emerged as a promising solution to enhance accessibility and sustainability of care. However, despite the increasing global interest, as noted in previous chapters, there is limited empirical evidence on the usability and utility of CH delivered interventions for PLWBC in the Irish context.

**Aim:** This study aimed to evaluate the usability and perceived utility of online survivorship programmes in Ireland, with a focus on the Cancer Thriving and Surviving (CTS) programme delivered via CH technologies.

**Methods:** A cross-sectional study was conducted with PLWBC who completed online cancer survivorship programmes in Ireland between December 2022 and April 2023. Closed and open-ended questions captured participants motivations for engaging in the programmes, and the perceived impact of these programmes on psychological wellbeing, QoL and self-management. The Telehealth Usability Questionnaire (TUQ) assessed CH usability. Qualitative content analysis examined recurring themes in participant responses.

Results: 50 respondents completed the survey on Qualtrics, with 44 having participated in the online CTS programme. The remaining participants had completed other programmes including the one day workshop Life After Cancer Enhancing Survivorship (LACES) among others. For analysis and interpretation purposes, analysis focused on the CTS participants only, due to its structured format and delivery. Out of the 44 participants, the majority were female (88%), with third-level education or higher (86%). Most had breast cancer (76%), and one third (36%) were in full time employment. The TUQ indicated high usability of the CH systems. Motivations for engaging in CTS included seeking peer support, psychosocial assistance, and practical self-management tools. Most respondents agreed that the programme improved their psychological wellbeing (90%), QoL (77%) and helped them take more control of their health (86%).

Conclusion: The online delivered CTS programme was perceived as usable and beneficial by PLWBC. This analysis contributes to Irish specific evidence supporting the potential of CH to enhance survivorship care. The high CH system usability and positive user experiences highlight its potential to complement in-person delivery of survivorship programmes, supporting the continued development and evaluation of digital health systems to enhance cancer survivorship care, particularly within Irish digital health initiatives.

#### 4.1. Introduction

While *Chapter 2* identified moderate evidence on the impact of CH delivered interventions in improving outcomes such as anxiety and depression, *Chapter 3* highlighted individual and structural barriers influencing its use in a nationally representative sample, with reflections in the Irish context. This chapter builds directly on these findings by focusing on the experiences of CH delivered survivorship programmes in Ireland, with a specific focus on the cancer surviving and thriving (CTS) programme.

Evidence shows that in order to reap the potential benefits of CH technologies, the CH delivery system has to be usable for both patients and clinicians (Mair, 2000). Usability is the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use (Gonçalves et al., 2023; Jordan, 2020). The key components of usability in CH systems are usefulness, ease of use, learnability, interface quality, interaction quality, reliability, and user satisfaction (Parmanto et al., 2016). Usefulness evaluates the system's effectiveness in emulating in-person healthcare and improving patient outcomes or reducing costs. Ease of use and learnability measure how easily users can operate the system efficiently. Interface quality focuses on the user interface, navigation, and overall experience. Interaction quality assesses audio and video clarity in patientclinician interactions and their resemblance to in-person consultations. Reliability pertains to error recovery and consistent safe patient care delivery. Lastly, satisfaction and future use gauge overall user satisfaction and willingness to continue using the system (Parmanto et al., 2016). While early work in CH usability evaluation was primarily focused on patient satisfaction (Aoki et al., 2003; Heinzelmann et al., 2005), later work incorporated satisfaction, usefulness, ease of use, and interaction quality (Bakken et al., 2006; Yip et al., 2003), all of which are measures of a system's effectiveness. This reflects the rapidly changing technological landscape, and points to a need for continuous evaluation.

Individuals' motivations to engage in CH interventions are crucial for the adoption and success of technologically mediated interventions (Coetzer et al., 2024). A significant body of literature underscores the importance of convenience and accessibility as primary motivators for engagement in CH (Cox et al., 2017; Shaffer et al., 2023). For PLWBC residing in rural areas, facing transportation challenges, or experiencing mobility limitations, CH eliminates the significant barrier of travel,

enabling access to care and support that might otherwise be out of reach (Zawahreh et al., 2019).

Beyond these practical considerations, the human need for social support and connection emerges as a powerful driver of engagement in CH programmes (Orlando et al., 2019). Cancer survivorship can be an isolating experience, and CH provides an opportunity to connect with others who understand the challenges faced (Aldana et al., 2023). Virtual support groups, peer mentorship programmes, and online communities facilitated through CH technologies can foster a sense of belonging, reduce feelings of isolation, and provide emotional support (Hubley et al., 2016), as seen through the stress buffering hypothesis (Cohen & Wills, 1985). Access to tailored information and resources has also been identified as a motivator for engagement in CH-delivered survivorship programmes (Rossetto et al., 2023). PLWBC are increasingly seeking information about managing treatment side effects, navigating the healthcare system, and making informed decisions about their health (Mountford et al., 2018). These dimensions are particularly salient in the context of CH, where poor usability may compound digital exclusion and limit intervention uptake and engagement.

Guided by the TAM (Davis et al., 1989), earlier described, and underpinned by principles from self-determination theory (SDT) (Ryan & Deci, 2023), the study described in this chapter examines how participants experienced the CH-delivered survivorship programmes. The TAM framework suggests that perceived ease of use and perceived usefulness are key determinants of acceptance and continued use of CH tools, while SDT posits that interventions which support autonomy, competence, and relatedness are more likely to promote sustained engagement (Ntoumanis & Moller, 2025; Ryan & Deci, 2023). Despite the increasing integration of digital health interventions into survivorship care, few studies have examined their usability and utility among PLWBC, especially in Ireland. This study seeks to address that gap and responds to calls for more implementation-focused research by evaluating not only participant satisfaction, but also the operational functionality of the CTS programme as delivered through CH modalities.

As earlier outlined in *Chapter 1, section 1.3.1*, Ireland has made strides in developing its eHealth infrastructure in the recent past. For instance, the eHealth Ireland strategy and the digital framework 2024-2030 outlines a vision for a CH enabled health service, with a focus on improving access to care, empowering patients, and enhancing efficiency (HSE, 2024a). In this regard, several survivorship support programmes have

since been established. These programmes are delivered by either the government (NCCP, 2024) or by charitable organisations such as the ICS (NCCP, ICS, 2024). In the recent past, particularly after the global COVID-19 pandemic, most of these programmes are now delivered both in-person and online using CH technologies. However, despite the growing body of research on CH in healthcare, there remains a need for studies specifically examining the usability of these technologies for PLWBC in the Irish context. While international evidence provides valuable insights, the unique characteristics of the Irish healthcare system, coupled with the specific needs and preferences of PLWBC within Ireland (O'Connor et al., 2019), necessitate further investigation. This study utilised the setting of the online delivered CTS programme to address this gap.

## 4.1.1. The Cancer Thriving and Surviving Programme

CTS is an evidence-based, supported self-management programme designed to empower cancer patients transitioning from active treatment to survivorship. Adapted from the Stanford Chronic Disease Self-Management Programme (CDC, 2018; Lorig et al., 2001), the CTS focuses on rebuilding self-confidence, adjusting to changed self-image, developing self-management skills, and promoting overall wellbeing. The programme was originally developed by Macmillan Cancer Support in the UK (Macmillan Cancer Support, 2024a), and the Stanford Patient Education Research Centre (National Library of Medicine, 2013) and has since been positively evaluated for feasibility and acceptability in the UK (Macmillan Cancer Support, 2024a), the USA (Risendal et al., 2014) and Ireland (Anneka et al., 2021).

The CTS was first introduced in Ireland on a limited basis in 2016 and 2017 by hospital and community organizations. Recognizing its popularity and effectiveness, the ICS and independent cancer support centers began training programme leaders and expanding programme availability. In September 2016, the first CTS Leader Training took place, supported by the ICS and Beaumont Hospital, training 22 new leaders (PLWBC and HCPs). CTS workshops were subsequently rolled out in several centers with positive participant feedback. Driven by increasing demand, the CTS programme, initially coordinated by a volunteer Master Trainer, conducted additional leader training in October 2017. However, continued growth necessitated further support and governance for capacity building and development. The programme's suitability for national implementation was recognized and supported by the National Cancer Strategy

2017-2026 (Department of Health, 2017)' recommendations (rec 43) that mandated the NCCP to work with organisations to develop and implement survivorship support programmes. Ireland's pilot study by Anneka and colleagues published in the University of Limerick's *National Institute of Health Sciences Research Bulletin*, evaluated the CTS in person programme using a quasi-experimental design (N = 47) (Anneka et al., 2021). This pilot examined the programme's effects on self-efficacy, health-related behaviours, and beliefs in post treatment survivorship. Results indicated statistically significant improvements in self-efficacy, QoL, and energy levels, and a significant decrease in depression levels across three time points. Post-programme improvements were also observed in pain, fatigue, distress, total activity level, and self-rated health status. While the pilot evaluated the impact of the in person delivery of this programme, the current study examines the both the intervention itself and the CH delivery modality.

Initially delivered in-person, the CTS programme transitioned to an online format in response to the COVID-19 pandemic and the closure of in-person centers. A pilot and subsequent successful rollout demonstrated the effectiveness of online delivery in meeting participant needs. This adaptation was supported by additional information systems support and online delivery training for leaders and participants. Since then, the programme is now offered both online and in person in over 20 acute hospital and community centers nationwide. As of 2023, more than 600 PLWBC had participated in the programme (NCCP, 2024).

The programme involves six sessions each conducted over 2.5 hours per week for six weeks. In addition, there is always an introductory pace setting session, *Session Zero*, which takes place before the formal six sessions begin. Sessions are facilitated by two trained leaders, at least one of whom is a PLWBC. The programme accommodates 12-16 participants and covers topics such as self-management, well-being, cancer prevention, long-term treatment effects, and psychosocial support. For the online delivery, participants require stable internet access and compatible devices like smartphones, tablets, or computers to access the programme via zoom, a videoconferencing platform (Singh & Awasthi, 2020).

The perceived utility of the online delivered CTS programme and the usability of technology have not been evaluated. The aim of the study is to explore the usability and perceived utility of online delivered survivorship programmes, with a focus on the CTS programme among the Irish PLWBC. Specifically, the study seeks to evaluate the usability of CH technologies using the telehealth usability questionnaire (TUQ), and to

understand participant's perceived utility of the programme in relation to their psychosocial wellbeing and QoL. While additional outcomes such as unmet needs and QoL were also examined in this cohort, these are reported separately in *Chapter 5 (Study 3b)*.

#### 4.2. Methods

## 4.2.1. Study Design and setting

A cross-sectional survey was designed targeting PLWBC who had engaged with survivorship programmes delivered online via CH technologies in Ireland. The study was embedded within a larger evaluation of the CH survivorship interventions in Ireland which is reported in the next two chapters. Ethical approval for this study was granted by Maynooth University Social Research Ethics subcommittee (Number SRESC-2022-2475301). Full consent was obtained from participants using a consent form and information sheet (see Appendix 2)

## 4.2.2. Participants and recruitment procedures

Participants were recruited between December 2022 and April 2023. Recruitment targeted PLWBC, aged 18 years or older, who had completed primary cancer treatment (all cancer types were eligible since the programmes are designed for all cancer types and stages) and participated in at least one of the online survivorship programmes in the Republic of Ireland. These included CTS and LACES, among others. Since online delivery of the programmes had just started during the pandemic, all online completers would be eligible. Nevertheless, the primary focus of this study was on CTS due to its nationwide implementation, structured content, and established evidence base in international contexts (CDC, 2018; National Library of Medicine, 2013). Individuals were excluded if they had only participated in in-person programmes, or if they were not PLWBC themselves (e.g., family members attending in a supportive capacity).

Recruitment was conducted by circulating an invitation to participate through the NCCP's and ICS's monthly newsletters and cancer support centre networks, and by sharing the call for participants on social media platforms namely X (formally twitter) and LinkedIn. Recruitment materials indicated the purpose of the study and invited eligible participants based on the above inclusion criteria. Interested individuals were invited to complete an anonymous post-programme survey questionnaire hosted on the Qualtrics platform (Qualtrics, L. L. C, 2020) upon providing consent.

#### 4.2.3. Role of PPI and Stakeholders

The study was designed in collaboration with PPI contributors and key stakeholders, including representatives from the ICS and the NCCP, and several cancer support centres (*See appendix 3 for the Support Letter from NCCP*). As part of the PPI, two former programme participants, themselves PLWBC were invited to share thoughts about the anticipated study, review early drafts of the questionnaire and provide input on relevance, clarity, and format. This was done through a series of virtual meetings. The programme facilitators, mostly drawn from the NCCP, advised on recruitment strategies, programme framing, and the integration of evaluation findings into service delivery planning. While the NCCP and ICS clearly identified the need for this evaluation, the PPI contributors provided input in the design of questionnaire, including recommendations for the use of a modified SF-SUNS scale (discussed in the next chapter), along with recommendations regarding the use of person first language such as the PLWBC (used in the entire thesis) instead of initial wording such as 'cancer patients' or 'survivors.'

# 4.2.4. Questionnaire development and measures

A bespoke post-programme questionnaire was developed, with input from PPI contributors and programme facilitators and coordinators. The development process was informed by a review of survivorship literature on CH, and digital health usability, previous CTS evaluations conducted locally, mainly the pilot evaluation by <u>Anneka et al.</u>, (2021) and other international CTS studies (Macmillan Cancer Support, 2024a; Risendal et al., 2014), and consultations with PPI members and stakeholders, as described above. The final survey included both closed and open-ended questions and comprised the following components, with the full survey included in *Appendix 4*.

**Demographic, Health details and programme information**; Participants indicated their age, gender, ethnicity, education level, employment status, place of residence (urban or rural), cancer type, time since diagnosis and completion of primary treatment, treatments received, the programme they participated in, when they completed it, and the number of sessions completed.

**Perceived Utility:** Participants were asked to rate their overall agreement with statement regarding the programme's perceived impact on their psychological wellbeing and QoL. Specifically, there were asked to rate their agreement with the following statements:

- Participation helped in improving my psychological wellbeing
- Participation helped in improving my Quality of Life
- Participation helped me to take more control of my health and wellbeing

Responses were recorded using a 5-point Likert scale (*l*=strongly disagree to 5-strongly agree). Next, participants were provided with all the components of the CTS programme and asked to select the components they found most useful as pertaining to their psychological wellbeing and QoL, with an option to elaborate each. To assess this, the following question was asked; 'Which components of the program did you find most useful for helping your psychological well-being? Select all that apply.' Options to choose from were derived from the CTS components/modules and included the following: Self-management, Mental health and wellbeing, Nutrition/Diet, Family, Finance and work-life, Confidence, Body image and intimacy, Available supports near me and Others (Please specify). The same question was repeated for QoL.

**Programme experiences:** To gather in-depth responses on participants' experiences with the programme, open-ended questions were posed. Specifically, the following questions were included:

- What was your main motivation for participating in the online programme?
- Overall, what aspects of the programme did you like the most? Please elaborate
- Did you encounter any barriers to participating in the programme? Please elaborate
- What support did you receive to enable you to complete the programme? Please elaborate

Programme Usability: The Telehealth Usability Questionnaire (TUQ): Usability of telehealth systems was assessed using the TUQ. TUQ is a comprehensive and validated survey instrument designed to assess user perceptions across several domains: usefulness, ease of use, interaction quality (effectiveness), reliability, and satisfaction (Parmanto et al., 2016). It was selected for use in this study due to its ability to evaluate changes in telehealth service delivery, such as varying platforms or devices, but also to measure the quality of telemedicine interactions and patient satisfaction with the encounter. The TUQ is most widely used in examining telehealth usability among various patient groups (Hajesmaeel-Gohari & Bahaadinbeigy, 2021), including among patients with cancer in Ireland (Brennan et al., 2022). It was developed from existing

telehealth questionnaires (Langbecker et al., 2017), and exhibits robust independent content validity and internal consistency (Parmanto et al., 2016; Santos et al., 2023). For example, the scale demonstrated robust internal consistency, with a value of 0.857 in the Danish sample (Bender et al., 2022). Furthermore, the Brazilian sample showed excellent internal consistency ( $\alpha$ =0.94 and  $\omega$ =0.94) and strong intra-rater reliability (intraclass correlation coefficient=0.85, 95% CI 0.75–0.91) (Santos et al., 2023). For scoring, each item within the TUQ is rated on a 7-point Likert scale, ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). The overall score is calculated by summing responses to all items and subsequently dividing by the number of items answered (Santos et al., 2023). For instance, if a participant strongly agrees with all 21 the total score would be 147 (*21 items* \* 7 *points*), and the average score would be 7. If a participant provides a mixture of responses, the average score will be a value between 1 and 7. A higher average score signifies a more positive perception of the telehealth system's usability, with scores ranging from 1 to 7.

#### 4.2.5. Analysis

Descriptive statistics were used to summarise participant demographics scores and perceived utility ratings. Means and standard deviations were calculated for TUQ subscales. To examine differences in TUQ scores across sociodemographic and disease categories, independent t-tests and ANOVAs were used for normally distributed data. For non-normally distributed data, non-parametric tests, including the Mann-Whitney U and Kruskal-Wallis tests, were employed (Whitley & Ball, 2002). Statistical significance was set at p<0.05. Missing data were reviewed and reported for each domain. No imputation procedures were applied. Only complete cases were analysed, considering the cross sectional design.

Open text responses were analysed through qualitative content analysis (Hsieh & Shannon, 2005). This method involves identifying, analysing, and reporting patterns (themes) within the data. As responses were often brief, the focus was on identifying and categorizing recurring themes and subthemes in the data (Braun & Clarke, 2021a). Qualitative content analysis allowed for a structured approach to interpret the data, capturing the key aspects of respondents' experiences, motivations, supports to complete the programmes and aspects they found most useful. This method provided a rich descriptive overview of the qualitative data, despite the brevity of some responses.

#### 4.3. Results

## 4.3.1. Response rates

A total of 56 responses were collected by the study's close. Of these, 50 were considered usable, as 6 responses were entirely blank, and some complete responses contained missing data for certain variables. The primary focus of this analysis was the online CTS programme, which 44 participants (88%) reported having attended. The remaining participants had engaged with various other programmes, including LACES (n=2), an unspecified survivorship clinic (n=1), an online exercise programme (n=1), 'reeeki' (n=1), and an unspecified American programme (n=1). Analysis was limited to CTS programme participants for several reasons: its clear structure facilitated easier interpretation of results, and other programmes, such as LACES (NCCP, ICS, 2024), were deemed unsuitable for comparative analysis given their nature as a one-day signposting workshop Furthermore, the structure of the remaining programmes could not be reliably ascertained, leading to their exclusion from further analysis.

## 4.3.2. Sociodemographic characteristics and cancer history

Participant characteristics are summarised in Table 4.1 Respondents were predominantly female (88%); a large majority (86%) had attained third level education. All participants identified as white, except for one individual who identified as Asian. One third were working full time (36%). Other reported employment statuses included part-time work (20%), on sick leave since diagnosis (18%), retired (16%) and homemakers or stay-at-home parents (7%), with one participant engaged in seasonal work. Concerning disease history, 76% were diagnosed with cancer 2-5 years prior; 54% had completed primary treatment within the last two years. Approximately three quarters (77%, n=34) had breast cancer. Other cases included Hodgkin's Lymphoma (n=2), ovarian (n=2), cervical (n=2), prostate (n=1), skin (n=1), Ewing's sarcoma (n=1), and thyroid (n=1) cancer. In terms of treatment, the majority (87%) received either surgery, radiotherapy, chemotherapy, or a combination of two of these, with others getting targeted therapies and immunotherapies. All participants completed the online programme between 2020 and 2022, a period coinciding with its launch during the pandemic.

Table 4.1

CTS participant's sociodemographic characteristics and cancer history

Variable	Category	Frequency (N=44)	Valid Percentage (%)	
Age in Years	29-44 Years	11	44	
	45+ Years	14	56	
	Non-Response	19		
Gender	Male	5	12	
	Female	38	88	
	Non-Response	1		
Education Level	Secondary and below	6	14	
	Third Level and above	38	86	
Employment Status	Working full time	16	36	
	*Others	28	64	
Residence	Urban	23	54	
	Rural	20	46	
	Non-Response	1		
Time Since Diagnosis	<2Yrs	4	10.	
	2-5 Yrs	31	78	
	6 Yrs and above	5	12	
	Non-Response	4		
Time since completing	<2Yrs	20	57	
primary treatment	2-5 Yrs	11	31	
	6 Yrs and above	4	12	
	Non-Response	9		

<sup>\*</sup> Part-time work, retired, seasonal worker, homemaker/stay at home parent.

# 4.3.3. Telehealth Usability

CH technology usability was assessed using the TUQ. Of the 44 survey participants, 35 completed at least one section of the TUQ, while full subscale completion rates ranged from 29 to 35 participants. Only complete responses for each subscale were analysed, and no data imputation procedures were applied. Participants found the technology they used to access the programme useful (M = 4.58, SD = 1.78) and easy to use (M = 5.69, SD = 1.19). It was perceived as effective (M = 5.43, SD = 1.31) and reliable (M = 4.40, SD = 1.33). Overall satisfaction with the technology used was high (M = 5.26, SD = 1.48). The total average score for CH usability was 5.18 out of 7, indicating a generally positive experience among the users. Table 4.2 shows the scores for each item, summary scales and the total average score.

Table 4.2

Telehealth Usability Item and summary scale Scores

TUQ Items				
10 Q 100ms	N	Mean±SD	Medi an	Range
1. Telehealth improved my access to healthcare	35	4.66±1.91	5	[1-7]
services.  2. Telehealth saved me time traveling to a hospital or specialist clinic.	35	4.66±2.17	5	[1-7]
3. Telehealth provided for my healthcare need.	31	$4.48 \pm 1.96$	5	[1-7]
Usefulness scale summary (Items 1-3)	35	4.58±1.78	5	
4. It was simple to use this system.	31	6.00±1.24	6	[1-7]
5. It was easy to learn to use the system.	29	6.03±1.12	6	[1-7]
6. I believe I could become productive quickly using this system	29	5.48±1.64	6	[1-7]
7. The way I interacted with this system is pleasant.	31	$5.58 \pm 1.36$	6	[1-7]
8. I liked using the system.	29	$5.34{\pm}1.65$	6	[1-7]
9. The system is simple and easy to understand.	30	$6.03 \pm 1.10$	6	[1-7]
Ease of use scale summary (Items 4-9)	34	5.69±1.19	6	
10. This system is able to do everything I would want it to be able to do.	29	5.07±1.77	6	[1-7]
11. I can easily talk to the facilitator using the telehealth	31	5.74±1.34	6	[1-7]
system.  12. I can hear the clinician clearly using the telehealth system.	29	6.00±1.16	6	[1-7]
13. I felt I was able to express myself effectively.	32	5.53±1.54	6	[1-7]
14. Using the telehealth system, I can see the facilitator as well as if we met in person.	30	4.73±1.95	6	[1-7]
Effectiveness scale summary (Items 10-14)	35	5.43±1.31	6	
15. I think the visits provided over the telehealth system are the same as in-person visits.	33	3.79±1.96	4	[1-7]
17. The system gave error messages that clearly told me how to fix problems.	34	4.09±1.58	4	[1-7]
Reliability scale summary (Items 15-17)	35	4.40±1.33	4.33	
18. I feel comfortable communicating with the facilitator using the telehealth system.		5.68±1.49	6	[1-7]
20. I would use telehealth services again.	32	5.72±1.44	6	[1-7]
21. Overall, I am satisfied with this telehealth system.	35	$5.46{\pm}1.63$	6	[1-7]
Satisfaction scale summary (Items 18-21)	35	5.26±1.48	5.75	[1-7]
Total Average Score	35	5.18±1.25	5.40	[1-6.9]

Note: Likert scale used: 1: strongly disagree; 2: disagree; 3: somewhat disagree; 4: neutral; 5: somewhat agree; 6: agree; 7: strongly agree.

# 4.3.4. Sociodemographic characteristics and usability

There were no statistically significant differences in CH usability across age, gender, education level, employment status, residence, time since diagnosis, and length of treatment, with all p-values > 0.05 as shown in Table 4.3.

 Table 4.3

 Differences between sociodemographic and cancer characteristics and usability

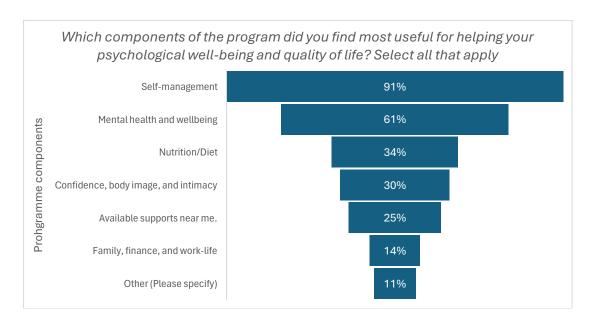
Variable	Category	Teleh	Telehealth Usability Score (TUQ)			
		N	Mean±SD	p-value		
Age in Years 29-44 Years		8	5.52±1.06	0.220		
	45+ Years	11	$4.94{\pm}0.94$			
Gender	Male	5	5.96±0.78	0.145		
	Female	29	$5.05 \pm 1.30$			
Education Level	Secondary and below	4	5.19±0.87	0.794		
	Third Level and Above	31	$5.18\pm1.30$			
Employment Status	Working full time	12	5.24±1.52	0.543		
	Others	23	5.15±1.12			
Residence	Urban	18	4.94±1.37	0.133		
	Rural	16	$5.53 \pm 1.06$			
Time Since Diagnosis	<2Yrs	4	5.75±0.76	0.671		
	2-5 Yrs	23	$5.05\pm1.39$			
	6 Yrs and above	4	$5.38 \pm 0.32$			
Time since completing	<2Yrs	17	5.21±1.04	0.934		
primary treatment	2-5 Yrs	6	$4.63\pm2.11$			
	6 Yrs and above	3	$5.23 \pm 0.17$			

# 4.3.5. Attendance and usefulness of various CTS components

Nearly all participants completed the required sessions, with 43 out of 44 (98%) completing the minimum 6 online 2.5-hour workshops between 2020 and 2022. A small percentage of participants reported having attended more than 6 sessions. While the programme has core 6 sessions, some may have counted the introductory "session zero" offered prior to the formal programme start as one session. Additionally, repeat attendance at one or more sessions may have contributed to variation in reported session numbers.

Self-management was the most frequently endorsed beneficial aspect of the programme for psychological well-being and QoL, while family, finance, and work-life were least endorsed (Figure 4.1). The percentages in figure 4.1 represent the proportion of participants who selected each component.

**Figure 4.1**Perceived usefulness of CTS components in supporting psychological wellbeing and QoL (N=44)



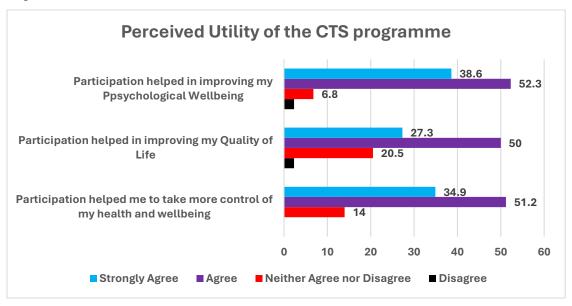
\*Others: Peer support, social aspect, meeting others

# 4.3.6. Perceived utility of the online CTS programme

Overall, the majority of participants agreed (including *strongly agreed*) that participation in the programme helped improve their psychological well-being (90.9%) and QoL (77.3%), and also that this allowed them to take more control of their health (86.1%) as shown in Figure 4.2.

Figure 4.2

Perceived utility of the CTS programme on psychological wellbeing, QoL and sense of empowerment.



Note: Perceived improvement in QoL refers to self-reported endorsement of a single item in this survey; validated quantitative assessments of QoL are presented in Chapter 5

# 4.3.7. Programme experiences

Analysis of participant open text responses revealed several key themes regarding motivations to participate in the CH delivered CTS programme, perceived programme benefits, supports received and barriers encountered. Primarily, participants were motivated by a desire for peer connection and psychosocial support, valuing the opportunity to interact with others who shared similar experiences, share their own stories, and learn from one another. The programme's creation of safe spaces for open communication and sharing fostered a sense of community among participants, which they greatly appreciated. Access to practical support, including technical assistance, end-of-programme resources, and family/caregiver support, was also highly valued. Additionally, the programme's accessibility, particularly its low or no-cost nature, was noted as an important factor for some participants. Almost all participants reported that they did not encounter any barriers. Among the few who did, difficulties with internet connectivity were the most frequently cited issue. These themes and subthemes, including number of participants mentioning these themes and illustrative quotes are summarized in Table 4.4

 Table 4.4

 Participant motivations, support and usefulness of programme aspects

Area	Theme/subtheme	<b>Description of the theme</b>	N	Illustrative quote
Motivations	Peer connection and interaction	Opportunity to interact with others who have had similar experiences to them. Participants valued the chance to communicate, connect, and speak with other	19	"To connect with others who would understand my thought, worries and feelings surrounding cancer."
		persons impacted by cancer, as well as the sense of understanding and shared experience that comes from this interaction.		"To communicate with other people who have gone through a similar experience".
	Seeking psychosocial	Seeking support to address psychosocial aspects of cancer diagnosis such as fear of progression and	21	"Needed support struggling with anxiety".
	support	recurrence of cancer and general psychosocial support		"To get the tools to help myself heal and to meet other people in my situation."
	Moving on	Desire to move on from their experiences with cancer. This could involve a psychological process, gain	12	Expert Psychosocial support and discussion with other cancer survivors' "To try to move on psychologically."
		confidence, or transitioning from a patient to a PLWBC mentality		"To move on and gain confidence"
	Comparison and validation	The opportunity to compare their progress and experiences with those of others	2	"To process the diagnosis before returning to work' "To communicate with people who went through a similar experience to me and to gauge where I was in my recovery in comparison to others."
				"I wanted to gauge where I was in my recovery in comparison to others who have experienced a similar illness."
	Covid- 19 Pandemic	Covid-19 Restrictions reduced in person engagements, so this was only option available	3	"Due to Covid, this was the only online support service available."
	T directiffe	so this was only option available		"I didn't get a chance to interact much with other individual patients during my treatment period due to Covid restrictions"
Programme aspects	Peer sharing and learning	Interacting with others who had similar experiences. In addition, they valued the chance to share their experiences and learn from others. They found it	20	"Being able to interact with other individuals who have been through a similar experience"
		helpful to receive advice from people who had experienced a similar illness and to pass on the learnings they had gained along their treatment or		"To be able to share some learnings I had gained along my treatment/illness journey."
		illness journey.		"To receive advice from people who have experienced a similar illness".

Area	Theme/subtheme	Description of the theme	N	Illustrative quote
	Safe spaces and good facilitators	A safe space to express themselves freely. Additionally, they felt that excellent facilitation skills	11	"Being able to communicate freely in a safe space"
	_	aided in promoting the safe spaces		"Openness able to discuss diagnosis and treatment. Forum to share experiences"
	Smaller Group Interactions or	smaller group interactions or discussions, such as 'break out rooms'	6	"Breakout groups where we got to chat."
	Discussions (Break out			"Interacting with the other participants in break out rooms."
	rooms):			'Making a group agreement to commit to individual goals set every week'.
	Sense of community	Feeling part of a group of individuals who had similar experiences.	3	"Sense of community with fellow survivors
				"The course leader was fantastic; there was a sense of community we still talk in our group."
Supports Received	Technical support	Instructions on how to navigate the program and the sessions materials. These instructions were provided	7	"Talking me through signing into meetings step by step'.
		through various means, such as email supports, manuals, videos, or in-session demonstrations. This also included updates, notifications, reminders, or		'Regular emails to share link to online session. Emails with documentation suitable to recovery'
		resources related to the programme.		'Phone support from the centre'
	End-of-	A take home handout/ package received at the end of	6	"We were provided with a book about living with long term health conditions.
	Programme Package/Handouts	the program This package contained summaries, resources, certificates, or other materials that wrap up		This book complimented the course and has been something I have referred back to after the course'.
		the program or support post-program progress	2	
	Family and caregiver support	Support from spouses, family members included technical support to navigate the program and/or help	3	'Support from my husband so I could attend'. 'Childminding'
		in responsibilities such as childcare duties		'Childcare from my partner.'
	Peer support	The term 'group' was common, suggesting that group- related support (which could include group discussions via WhatsApp, group activities, etc.)	3	"Peer support. Making a group agreement to commit to the individual goals set each week."
		11/0 1 //		"A group what's app, time to speak within the group'."
	Low cost/No cost	offering the program free of charge	1	'The program was free, so no financial support was required.'

#### 4.4. Discussion

Study 3a evaluated the usability, and perceived utility of the online delivered CTS programme in Ireland. Overall, findings indicate that the programme was well received by participants, with high levels of satisfaction, ease of use and perceived benefits across all domains including psychological wellbeing, QoL and self-management. These findings contribute to growing evidence supporting the feasibility of CH delivered programmes in survivorship, as noted in Chapter 2 and 3. Findings are consistent with other studies that have reported high usability scores for CH technologies among PLWBC (Børøsund et al., 2013; Omaghomi et al., 2024). Notably, these studies have also consistently reported a correlation between high usability and demographic characteristics, such as higher education and socioeconomic status, suggesting that PLWBC with greater educational attainment and financial resources are more likely to use CH technologies. Higher education and income are linked to greater digital health literacy (Børøsund et al., 2013) and higher CH uptake. Thematically, this chapter aligns with Study 1's findings (Chapter 2), which identified improvements in psychosocial outcomes and self-management through CH interventions, and Study 2 (Chapter 3), which highlighted disparities in CH uptake linked to socio-demographic and healthrelated factors.

The positive participant evaluations of the online CTS programme also reflect elements of SDT (Ntoumanis & Moller, 2025; Ryan & Deci, 2023), which proposes that autonomy, competence, and relatedness are key to psychosocial wellbeing. The ease of use and effectiveness in communication was particularly notable, reinforcing the importance of user-friendly interfaces in enhancing CH experiences (Gonçalves et al., 2023; Omaghomi et al., 2024). The flexibility and ease of use of the CH technologies supported users' autonomy and competence, while peer interaction addressed relatedness. Additionally, Cohen's stress-buffering hypothesis (Cohen & Wills, 1985) may explain the value of perceived social support within this programme where participants reported benefits from connecting with others and sharing experiences, potentially mitigating cancer-related stress.

The convenience offered by CH was noted as a key motivator for programme engagement, as CH eliminates the need for travel and allows patients to engage with services and supports from their homes. This is particularly important for PLWBC who may have caring responsibilities or who live relatively far from healthcare facilities that may be poorly served by public transport services (Carroll et al., 2021). A similar trend

was reflected in this sample, where half of the participants reported residing in rural areas. It is notable that some respondents referenced the no cost nature of the programme as a motivator, highlighting the need to continue providing the programmes without direct financial cost to participants.

Importantly, the usability data from TUQ highlighted positive experiences across all domains, especially in terms of usefulness, ease of use, and future intentions to engage with similar platforms. These findings are broadly consistent with previous studies using the TUQ in cancer and chronic disease contexts (Brennan et al., 2022; Layfield et al., 2020; Santos et al., 2023). The high TUQ scores observed in this study (mean >5.5 across most subscales) suggest that the online delivered CTS programme was perceived as highly usable by participants, a finding consistent with those reported by Brennan et al., (2022), who examined telehealth delivery of rehabilitation programme for patients with upper gastrointestinal cancer, and Layfield et al., (2020) who explored otolaryngology patient satisfaction with telemedicine visits during the COVID-19. Both studies reported similarly high usability ratings using the TUQ, reinforcing the robustness of our findings and further validating the programme's feasibility from a user experience perspective. Such usability evidence is critical for implementation, especially as the healthcare systems adopt remote and hybrid delivery models, and more so in the Irish context. Its however notable that of all the domains, the TUQ reliability scale received the lowest average score, suggesting that there may be concerns or perhaps areas of improvement related to the technologies' reliability and error handling in this context. CTS is delivered via video conferencing technologies, particularly zoom, and participants can engage using various devices such as tablets, computers or smartphones, and this may explain the variability noted in error handling. While our study did not examine the specific devices used or the network suitability, overall, the audiovisual delivery received a positive reception, suggesting a favourable inclination towards CH by the majority of the participants.

Notably, the variable perception of CH equivalence to in-person visits noted in this study highlights an area for improvement. While CH offers numerous benefits, there are still challenges in emulating the nuanced interactions of face-to-face interactions. This finding echoes other research (R. J. Chan, Crichton, et al., 2021; Delemere et al., 2022; Larson et al., 2020) which highlights that, while CH is useful for many aspects of care, certain elements of in-person visits remain unmatched. This has been commonly described as the lack of 'personal touch.'

In the present study, participants' reasons for engaging with the CTS programme included seeking peer support, psychosocial assistance, and practical tools for managing their health. These motivations align the themes identified in study 1, but also reflect the top concerns in PLWBC overall (Puts et al., 2012; Schmidt et al., 2022a). Additionally, the fact that the CTS programme is based on the self-management model could explain its high endorsement. Further, CTS covers topics on return to work after completing primary treatment and this may explain the higher proportion of participants who were on sick leave or awaiting to return to work, as financial issues following cancer and its treatment has been reported as among important concerns for PLWBC post treatment (Algeo et al., 2021; Desai & Gyawali, 2020; Yousuf Zafar, 2016).

In addition to motivations for participation in the programme, the supports participants received, such as technical assistance from the centres, were crucial for participant engagement and success. In CH programmes, technical supports could be amplified, specifically with respect to error handling which respondents identified as a concern. Family and caregiver support, especially with childcare and other responsibilities also played a significant role, suggesting the need for comprehensive approaches that consider the broader social context of cancer survivorship care (Darley et al., 2021). Moreover, Darly et al.'s review found that CH has a beneficial impact on PLWBC and their family caregivers, extending beyond the intended health-related outcomes. One such benefit is the extended family bonding time. This is also useful in circumstances where the patient has limited technological skills, necessitating assistance from family members or caregivers. Thus, future CH delivered cancer survivorship programmes need to go beyond the patients, to families and caregivers.

Nearly all the participants in our study had completed all the required CTS sessions, with some completing more than the minimum six sessions, highlighting the programme's high acceptability and engagement. This is further evidenced by the high perceived usefulness score, an important predictor of engagement in CH (Parmanto et al., 2016; Taherdoost, 2018). A CTS feasibility study conducted in the US also reported high acceptability, with over 95% of participants expressing satisfaction with the programme content (Risendal et al., 2014). Similar feedback was received from initial programme feedback in the UK and Ireland (National Library of Medicine, 2013; NCCP, 2024). However, these studies were based on in-person formats, whereas the current study pertains to CH delivery of the programme.

The COVID-19 pandemic's role in accelerating CH adoption, a trend observed globally (Burbury et al., 2021) was noted in this study. The sustained engagement during the pandemic when this study was conducted and afterwards underscores CH's role in maintaining continuity of care when in-person services are disrupted. Considering that lack of sustained engagement in CH delivered programmes, particularly pre- pandemic as noted in study 1 and in other studies (Butt et al., 2022; Spelten et al., 2021), this is a positive finding and suggests the CH potential to compliment in person care, but also could be a reflection of the increasing adoption of technology in healthcare and society overall (Stoumpos et al., 2023).

While the positive participant ratings indicate higher perceived utility and usability of the CH-delivered CTS programme, it remains difficult to disentangle the effects attributable to the content of the programme from those arising specifically due to the CH mode of delivery. The programme itself is rooted in established principles of peer support and self-management, which may drive much of the reported benefits. However, the high usability scores and participant endorsement of the online format also suggest that the digital delivery facilitated access, flexibility, and convenience. Further studies comparing in-person and CH delivery with robust controls are needed to isolate the added value of the CH modality

This study represents the first primary data collection within this thesis and specifically focuses on the Irish context. While preceding chapters (*Chapters 2 and 3*) examined international literature and US population-level data on CH, the current study investigated how the online-delivered survivorship support is experienced within the Irish healthcare setting. Although no formal cross-national comparison is undertaken, the usability and acceptability patterns reported here show broad alignment with international trends previously identified, offering important insight into the local feasibility and perceived value of CH-based survivorship care.

Overall, this study addresses a notable gap in literature and practice where few studies have evaluated the usability of CH delivered survivorship programmes in the Irish context. While previous CTS evaluations, which were pilot in nature (Anneka et al., 2021) focused on in person delivery, or clinical effectiveness in other countries (US and UK), this is one of the first studies to examine participant reported usability and satisfaction with the online format in Ireland. The national scope of the CTS, despite the small sample, enhances depth of the findings.

### 4.3.1 Study limitations

First, the small sample size may limit the generalizability of the findings. Second, the absence of pre-post data limits our ability to draw causal conclusions about the impact of the CTS programme on psychosocial outcomes. Third, the survey was cross-sectional and self-reported, which may introduce recall or social desirability biases. Additionally, the sample was predominantly female, white, and well-educated, which may limit the generalisability of findings to more diverse populations. Finally, while participants reported benefits from the CTS programme, it remains unclear to what extent these benefits were due to the content of the intervention itself or the mode of delivery (CH). Furthermore, participation and engagement in the CH programmes were potentially influenced by the COVID-19 pandemic, underscoring the importance of ongoing programme evaluation. The brevity of the open-text responses suggests the need for more comprehensive qualitative approaches to gain a deeper understanding of the full scope of patient experiences.

### 4.5. Conclusion

The findings suggest that CH delivered survivorship programmes, can be both usable and beneficial to PLWBC, supporting its integration of CH into survivorship care delivery models. However research is needed to disentangle the effects of programme content from the mode of delivery and assess outcomes over time and across large and diverse samples.

While study 3a established high usability and perceived utility of online CTS programme for PLWBC, further analysis is needed to understand its benefits in addressing unmet needs of PLWBC and how this relates to their QoL and overall health. Thus, *Chapter 5* (Study 3b) presents findings from further analysis of this dataset to explore subsections of unmet supportive care needs and QoL following participation in online CTS programme. Both studies draw on the same dataset and participant cohort, using the same recruitment and data collection procedures. However, they address distinct but complementary research objectives. This dual focus allows for a more comprehensive understanding of both the implementation experience and the perceived impact of the CH-delivered CTS programme within the broader context of survivorship care in Ireland.

# **Chapter 5**

# Study 3b

Unmet needs and Quality of Life following participation in a Connected Health Cancer Survivorship Programme: A case study of the Cancer Thriving and Surviving Programme

#### Abstract

**Purpose:** As described in *Chapter 4* (study 3a), the CTS programme aims to support survivorship care for PLWBC in Ireland. While previous evaluations have focused on the utility and usability of the online delivered CTS, fewer studies have examined the extent to which the programme address ongoing supportive care needs and QoL of PLWBC. Study 3b aimed to assess (1) ongoing unmet supportive care needs following participation in the online CTS programme, and (2) associations between unmet needs and QoL and overall health.

**Methods:** An adapted version of the 30-item short-form version of the Survivor Unmet Needs Survey (SF-SUNS) and the EORTC-QLQ-30 were used to assess subsection of the unmet needs and QoL respectively. Differences in unmet needs and QoL were examined between sociodemographic and disease categories, while associations between unmet supportive care needs, QoL, and overall health were assessed using correlational and group comparisons analysis.

**Results:** Findings showed that generally low but varying levels of unmet needs remained following CTS programme participation. While needs in managing stress, adjusting to changes in personal identity, and coping with body image changes were highest, information needs were low, with QoL and overall health rated moderately high. Negative correlations between unmet needs and both QoL (r=-0.423, p<0.05) and overall health (r=-0.504, p<0.01) were found, with no differences in unmet needs between sociodemographic and cancer variables.

**Conclusion**: Although the CTS programme may help address some supportive care needs, residual unmet needs still persist following programme participation. This highlights the importance of continuous follow up support for PLWBC post-treatment. Ongoing programme evaluation is recommended to ensure online CTS remains responsive to the evolving needs in survivorship journey.

### 5.1. Introduction

As outlined in *Chapter 1, section 1.2*, cancer survivorship encompasses a broad range of needs and challenges that extend well beyond the initial phases of diagnosis and treatment (Jones et al., 2020; Schmidt et al., 2022). With the number of PLWBC rising globally (Sung et al., 2021), there is a compelling need to understand and address long-term needs comprehensively (R. J. Chan, Hollingdrake, et al., 2021; Shapiro, 2018). This understanding is essential for enhancing the continuum of care and supporting QoL of PLWBC. While previous chapters examined broader international trends in CH adoption (*Chapter 3*) and usability and its perceived utility locally (*Chapter 4*), the current chapter involves further analysis of the same cohort described in *Chapter 4* and offers a more focused examination of ongoing needs and QoL in PLWBC, following participation in the online CTS programme.

Quality of life, as outlined in Section 1.2, is one of the main outcomes of interest in this thesis. Overall, QoL is a critical goal in cancer survivorship care, and a key outcome measure in research and implementation of survivorship programmes (Schmidt et al., 2018). Previous research show that unmet care needs, which can range from psychological, informational and daily living domains have been consistently associated with poorer QoL outcomes (Chen et al., 2022; Puts et al., 2012; Schmidt et al., 2022). A recent systematic review indicates approximately 4 in every 5 PLWBC report at least one unmet supportive care need, with the most commonly reported domains being financial, informational, psychological, and physical needs (Hart et al., 2022). These unmet care needs can vary based on cancer diagnosis and stage in the care continuum (Driessen et al., 2024). For instance, in one study that focused on head and neck cancer, long-term PLWBC required more emotional support, while those immediately post-treatment reported a greater need for informational support (Henry et al., 2020). In addition, the needs experienced by PLWBC vary considerably depending on their sociodemographic characteristics, specific diagnosis, and stage in the disease trajectory. For instance, Chen and colleagues analysed evidence from 4195 PLWBC in China and found that unmet needs for life and finances were more pronounced among older PLWBC. Further, time since diagnosis was also associated with unmet care needs, with those in early post treatment phase reporting higher needs that those in later survivorship phases (Chen et al., 2022). Additionally, several studies have explored how demographic factors affect survivorship, noting that younger adults impacted by cancer may face particular challenges related to fertility issues, career interruptions, and changes in peer

relationships (Bhatia, 2021; Jin et al., 2021). Similarly, variations in health outcomes and QoL based on gender, educational attainment, and employment status underscore the need for personalized survivorship support programs (Levinsen et al., 2023; Lui et al., 2022).

As outlined in Section 1.2, there are currently over 200,000 PLWBC in Ireland, representing 4% of the country's population (NCCP, 2024). With the number projected to double by 2045, there is a growing focus on identifying the needs of this cohort (Department of Health, 2017). An understanding of needs can in turn facilitate informed decisions on the optimal design, implementation and delivery of survivorship care. While evidence of unmet needs among various cancer populations is well established (Chen et al., 2022; Hart et al., 2022; Puts et al., 2012), fewer studies have investigated ongoing or evolving needs following participation in survivorship support programmes. CH delivered interventions, such as the online CTS programme are designed to bridge care gaps by offering flexible and accessible support that address these evolving needs. Although international evaluations of CTS have demonstrated positive effects on selfefficacy and health behaviours (CDC, 2018; National Library of Medicine, 2013), limited evidence exists, regarding the degree to which such programmes address ongoing unmet needs and influence QoL in the Irish context, especially when delivered online. While the analysis presented in Chapter 4 provided initial evidence that the CH delivered programme was well received by participants, its notable that positive perceptions do not necessarily translate to the full resolution of ongoing challenges.

The current chapter seeks to examine the levels of a subsection of unmet needs following participation online CTS programme, and how these needs relate to QoL. The analysis also draws on Bronfenbrenner's socio-ecological model (Bronfenbrenner, 1977; Kilanowski, 2017) and Cohen's stress-buffering hypothesis (Cohen & Wills, 1985), the guiding frameworks employed in this thesis, to consider how individual, interpersonal, and programme-level factors may interact to influence PLWBC's residual needs and QoL, if at all. Importantly, this analysis addresses a gap in the literature identified in previous chapters: while usability and access are necessary for CH impact, the goal remains improved psychosocial outcomes for PLWBC.

### 5.2. Methods

### 5.2.1. Study design and context

This cross sectional study employs the same participant cohort described in Chapter 4.

### 5.2.2. Measures

Measures of sociodemographic and health characteristics, including age, gender, education, employment status, and cancer type, are described in Section 4.2. These variables were included to explore differences in unmet needs and QoL outcomes across population subgroups. In addition, measures included the modified 30-item short-form version of the Survivor Unmet Needs Survey (SF-SUNS) and the EORTC QLQ-C30 to assess subset of unmet supportive care needs and QoL respectively.

**Unmet needs:** Unmet needs were examined using a modified version of the SF-SUNS (Campbell et al., 2014), which is freely available for download from the PhenX Toolkit (PhenX Toolkit., 2025). Recognising the potential for increased response burden and reduced clinical applicability due to its substantial length (89 items), the original SUNS was refined into the more concise 30 item SF-SUNS (Campbell et al., 2010). The 30-item SF-SUNS retains the original survey's four-factor structure (Information; Work/Financial; Access/Continuity of Care; Coping/Emotional), with exploratory and confirmatory analyses in 1,589 mixed-tumour PLWBC showing factor loadings that replicated the parent measure and Cronbach's  $\alpha \ge 0.85$  for every domain (overall  $\approx 0.90$ ) plus item-to-scale intraclass correlations (ICCs) > 0.90, while also discriminating between patients recently on-treatment versus off-treatment and exhibiting negligible floor/ceiling effects (Campbell et al., 2014). A separate five-day retest in 40 lymphoma PLWBC demonstrated good stability: 77% of items achieved ICCs of 0.45-0.74, subscale ICC of 0.65-0.94 and overall internal consistency rose from  $\alpha = 0.92$  to 0.95, indicating the scale is sensitive yet adequately reproducible over short intervals (K. Taylor et al., 2018). Cross-cultural work with 428 Chinese PLWBC confirmed the four-factor model and reported excellent reliability ( $\alpha = 0.894$ ; ICC 0.869-0.884) and supported content relevance, extending validity beyond English-speaking samples (Yan et al., 2021). Finally, a 2019 systematic review of cancer-needs instruments rated the SUNS family (Boyes et al., 2009; Hodgkinson et al., 2007; Richardson et al., 2007), which

includes the commonly used 34-item short-form SCNS (SCNS-SF34), as having strong evidence for internal consistency and moderate evidence for test–retest reliability and structural validity, but highlighted limited data on responsiveness and measurement error, underscoring the SF-SUNS's solid psychometric foundation while pointing to priorities for future longitudinal work (Tian et al., 2019).

The 30-item short-form version of the SUNS assesses unmet needs across four domains relevant to cancer care: Domain A; information needs (3 items); Domain B; work and financial needs (8 items); Domain C; access and continuity of care needs (6 items); and Domain D; coping, sharing, and emotional needs (13 items). For this study, domains related to work/financial (domain B) and healthcare access/continuity (domain C) were excluded, following structured consultation with PPI contributors and programme stakeholders from the NCCP and ICS (as described in Chapter 4), including those involved in CTS delivery and content. These domains were considered outside the scope of the programmes and not aligned to the overall study aims. This participatory refinement also ensured cultural and contextual relevance for the remaining items. For example, item 1, 'Finding information about complementary or alternative therapies' was modified to replace 'complimentary or alternative therapies with 'community support services' while item 2 'dealing with fears about cancer spreading' was modified to 'dealing with fears about cancer recurring' as the target was people who have completed cancer treatment. No other language changes were made.

In summary for instance, domain B contained questions such as 'insurance, and pensions' which were not applicable to the programme content, and to maintain domain structure, a decision was made to delete the entire domain. The same applied for Domain C which contained questions such as 'getting appointment with specialists.' In the end, only Domain A on information needs (3 items), and Domain C on emotional needs (13 items were retained) bringing a total of 16 items. The full list of original and retained items is available in Appendix 4. The 16 items used in this study are marked YES in the last column, and the 14 that were excluded marked as NA. Reliability analysis for the retained 16 items indicated strong internal consistency (Cronbach's alpha = 0.9392).

SF-SUNS is scored on a 5-point Likert scale ranging from 0 = no unmet need, 1 = low, 2 = moderate, 3 = high and 4 = very high unmet need, across the four domains. Item ratings are summed within each domain and divided by the number of items to produce four domain means (possible range 0–4; with higher values reflecting more severe unmet needs). Due to structural modifications, no clinical cut-offs were used. The

unmet needs analysis was thus descriptive in nature, aiming to provide insight into persistent information and emotional needs after programme participation and extensive comparisons with other studies using the full SF-SUNS were avoided due to this structural modification.

Quality of Life and Overall Health: The EORTC QLQ-C30 (version 3) (Aaronson et al., 1993) was used to measure QoL and overall health. The QLQ-C30 includes functional subscales (physical, role, emotional, cognitive, social), and symptom scales/items (e.g., fatigue, nausea, pain) and and two global health items. The 30-item EORTC QLQ-C30 has consistently shown solid psychometrics in adult cancer populations with multi-item scales consistently meeting or exceeding the 0.70 benchmark for internal consistency (e.g.,  $\alpha = 0.71-0.86$  in the original international sample (Aaronson et al., 1993), and short-interval test-retest studies in clinically stable patients yield high stability (Pearson r or ICC  $\approx 0.82-0.91$  for functional scales, 0.63-0.86 for symptoms) (Hjermstad et al., 1995). This tool has been widely used in this population (Kennedy et al., 2021; Maguire et al., 2017). The scale was used in full, with no modifications. Scoring and linear transformation followed EORTC guidelines (Fayers et al, 2001). According to the manual, each QLQ-C30 scale is first expressed as a raw score, the mean of its constituent items (most scored 1-4; the two global-health items 1-7) provided at least half the items in that scale have been answered. Raw scores are then linearly transformed to a 0-to-100 metric so results from different scales are comparable: for functional scales the direction is reversed so that higher values indicate better functioning, and the same positive direction is used for the two-item Global Health Status/QoL scale, but with range = 6. Because all items within a scale share the same response range, "range" simplifies to 3 for the 1–4 items and 6 for the 1–7 global items. Responsiveness is adequate, thus a change of roughly 5–10 points on the 0–100 metric is widely regarded as the minimally important difference, although recent work shows scale- and context-specific variation (Musoro et al., 2019). Higher functioning and global health scores reflect better QoL, while higher symptom scores reflect greater symptom burden.

# 5.2.3 Data Analysis

Descriptive statistics were calculated for unmet needs and QoL indicators. Differences in unmet needs and QoL across sociodemographic and health subgroups were

analysed using independent t-tests or ANOVA depending on the variable type. Where data were not normally distributed and given the small sample size, non-parametric tests (Y. H. Chan, 2003; Sprent & Smeeton, 2016), specifically Mann-Whitney U and Kruskal-Wallis tests was used. Spearman's correlation coefficients were computed to assess associations between unmet needs and overall QoL. Only complete data were included in analyses. Missing data were reviewed and reported for each item, and no imputation procedures were done considering the small sample size and cross sectional design. All analyses were conducted using SPSS Version 28, with statistical significance set at p < .05.

#### 5.3. Results

### 5.3.1. Sociodemographic and disease characteristics.

Sociodemographic and disease characteristics of the participants have been described in section 4.3.2.

### 5.3.2. Levels of unmet information and emotional needs

For unmet needs, item-level summaries were presented. Scores from the 16-item version of the SF-SUNS were summarised to provide an overall view of the 16 items. Average unmet needs were generally low across all items included in this analysis {M=1.47 (SD=1.38) out of 4} with the lowest unmet needs being needs for information about community support services (M=0.74, SD=1.11), managing expectations of normalcy (M = 1.00, SD=±1.25) and finding empathetic peers (M=1.16, SD=1.34). Comparatively, the highest unmet needs were for managing stress (M=1.87, SD=.38), adjusting to changes in personal identity (Mean =1.73±1.46), and coping with body image changes (M =1.65, SD=1.52). Table 5.1 shows the items included in the study and their respective means and standard deviations.

Table 5.1

Unmet information and emotional needs following participation in online CTS programme

Unmet Needs	N	Mean±SD	Range [0-4]
1. Finding information about Community	34	$0.74 \pm 1.11$	[0-4]
Support Services			

Unmet Needs	N	Mean±SD	Range [0-4]
2. Dealing with fears about cancer	34	$1.62\pm1.28$	[0-4]
recurring.			
3. Dealing with worry about whether the	34	$1.62\pm1.28$	[0-4]
treatment has worked			
4. Telling others how I was feeling	33	$1.33\pm1.14$	[0-3]
emotionally			
5. Finding someone to talk to who	31	$1.16\pm1.34$	[0-4]
understands and has been through a similar			
experience			
6. Dealing with people who expect me to	33	$1.00\pm1.25$	[0-4]
be "back to normal"		. =	
7. Dealing with people accepting that	33	$1.73\pm1.46$	[0-4]
having cancer has changed me as a person		4 60 4 00	F0 47
8. Dealing with reduced support from	34	$1.62\pm1.30$	[0-4]
others when treatment has ended	22	1.50:1.24	FO 47
9. Dealing with feeling depressed	32	1.50±1.24	[0-4]
10. Dealing with feeling tired	33	$1.36\pm1.25$	[0-4]
11. Dealing with feeling stressed	31	$1.87 \pm 1.38$	[0-4]
12. Dealing with feeling lonely	31	$1.48\pm1.29$	[0-4]
13. Dealing with not being able to feel	31	$1.26\pm1.34$	[0-4]
'normal'			
14. Trying to stay positive	31	$1.45\pm1.29$	[0-4]
15. Coping with having a bad memory or	33	$1.30\pm1.19$	[0-4]
lack of focus			
16. Dealing with changes in how my body	31	$1.65\pm1.52$	[0-4]
appears			
Unmet needs Average	34	1.47±1.38	[0-4]
Unmet needs Sum	34	23.09±15.59	[0-63]

Note: Likert scale used: 0: No Unmet Need; 1: Low Unmet Need; 2: Moderate Unmet Need; 3 High Unmet Need; 4: Very High Unmet Need.

# 5.3.3. Quality of Life and Overall Health

Table 5.2 shows the summary global health scores and the functional and symptom scale scores. Participants reported moderately high overall QoL, with a mean global health status/QoL score of 67.9 (SD = 25.1), consistent with moderate wellbeing post-treatment. Across the functional domains, the highest functioning was observed in physical functioning (M = 84.3), followed by role (73.0), emotional (65.5), cognitive (64.7), and social functioning (62.7), suggesting varying levels of reintegration and adjustment across different life domains.

In the symptom scales, fatigue was the most prominent symptom reported (M = 39.5, SD = 26.4), indicating a moderate symptom burden. Other symptom scores such as

pain (29.9), insomnia (46.5), and dyspnoea (18.6) also reflected ongoing physical challenges. Symptom scores for nausea and vomiting (5.9), diarrhoea (3.9), and appetite loss (9.8) were notably low, suggesting these were less burdensome for most participants. Notably, financial difficulties scored relatively high (M = 40.2, SD = 38.3), highlighting economic strain as a significant concern for some individuals.

**Table 5.2** *EORTC QLQ-C30 scores* 

The EORTC QLQ-C30	# of items	N	Mean±SD	Range [0-100]
Global health status / QoL				
Global health Score/QoL	2	34	67.9±25.1	[0-100]
<b>Functional scales</b>				_
Physical functioning	5	34	84.3±18.3	[33-100]
Role functioning	2	34	$73.0\pm30.7$	[0-100]
Emotional functioning	4	34	$65.5\pm26.9$	[0-100]
Cognitive functioning	2	34	$64.7 \pm 33.0$	[0-100]
Social functioning	2	34	$62.7 \pm 32.3$	[0-100]
Symptom scales / items				
Fatigue	3	34	39.5±26.4	[0-100]
Nausea and vomiting	2	34	$5.9 \pm 10.8$	[0-33]
Pain	2	34	$29.9 \pm 33.3$	[0-100]
Dyspnoea	1	34	$18.6\pm24.9$	[0-100]
Insomnia	1	33	$46.5 \pm 33.3$	[0-100]
Appetite loss	1	34	$9.8 \pm 24.0$	[0-100]
Constipation	1	33	$15.2\pm20.6$	[0-67]
Diarrhoea	1	34	$3.9 \pm 10.9$	[0-33]
Financial difficulties	1	34	$40.2 \pm 38.3$	[0-100]

### 5.3.4. Correlation analysis

Significant negative correlations were found between unmet needs and overall QoL (r = -0.423, p < 0.05), and between unmet needs and overall health (r = -0.504, p < 0.01) as shown in Table 5.3 below.

**Table 5.3**Correlations between unmet needs, QoL and overall health.

Correlations	1	2	3	
Overall Quality of life	1			
Unmet Needs of PLWBC	-0.423*	1		
Overall health	0.814**	-0.504**	1	

Note: \*\*Correlation is significant at the 0.01 level (2-tailed): \*Correlation is significant at the 0.05 level (2-tailed).

# 5.3.5. Differences in unmet needs and QoL according to sociodemographic characteristics and cancer history

Differences in unmet needs and overall QoL were explored across key sociodemographic and clinical characteristics. As described in the data analysis section, independent t-tests and one-way ANOVA were used to compare mean scores where assumptions were met; non-parametric tests were applied for small or non-normally distributed groups. As shown in *Table 5.4*, no statistically significant differences in unmet needs were found across any of the variables examined. With regard to overall QoL, statistically significant differences were observed based on employment status with participants working full-time reported significantly higher overall QoL scores (M = 5.91, SD = 0.83) than those not in full-time employment (M = 4.70, SD = 1.79, p = 0.04). Given the small cell sizes in some categories, results should be interpreted with caution, and findings are considered exploratory.

**Table 5.4**Differences in unmet needs and overall QoL according to sociodemographic and disease characteristics

Variable	Category	Unmet Needs		Ove	rall QoL		
		N	Mean ±SD	p- value	N	Mean± SD	p-value
Age in Years	29-35 Years	8	1.25±1.06	0.57	8	5.50±1.20	0.25
	45+ Years	11	$1.50\pm0.84$		11	$4.55 \pm 2.02$	
Gender	Male	4	1.34±1.11	0.84	4	6.25±0.96	0.12
	Female	29	$1.44 \pm 0.94$		29	$4.90 \pm 1.68$	
Education Level	Secondary and below	4	0.98±0.88	0.32	4	6.25±0.96	0.13
	Third Level and Above	30	$1.48\pm0.94$		30	4.93±1.66	
Employment	Working full time	11	1.05±0.96	0.11	11	5.91±0.83	0.04
Status	Others	23	$1.59\pm0.88$		23	$4.70\pm1.79$	
Residence	Urban	18	1.50±1.00	0.45	18	5.11±1.84	0.94
	Rural	15	$1.26 \pm 0.86$		15	$5.07 \pm 1.49$	
Time Since	< 2 Yrs	4	1.43±1.23	0.60	4	4.75±2.50	0.23
Diagnosis	2-5 Yrs	22	$1.45 \pm 0.90$		22	$4.95 \pm 1.62$	
	6 Yrs and above	4	$0.96 \pm 0.47$		4	$6.50 \pm 1.00$	
Time since	< 2 Yrs	17	1.77±0.83	0.13	17	4.94±1.43	0.09
Treatment ended	2-5 Yrs	6	$1.15\pm0.97$		6	$4.67 \pm 2.07$	
	6 Yrs and above	3	$0.88 \pm 0.55$		3	$7.00\pm0.00$	

### **5.4 Discussion**

This study examined the nature and prevalence of unmet information and emotional needs and QoL among PLWBC who participated in the online CTS programme. Results show that overall, the unmet needs were relatively low following the completion of the programme. However, some unmet needs remained, and it was evident that some PLWBC experienced a higher level of needs than others. Higher unmet needs included needs relating to stress management, social acceptance, and body image, suggesting that psychological and social challenges persisted for some after the programme completion. There was no evidence however to suggest that differences in unmet needs existed among the different groups analysed. Nonetheless, caution is warranted when interpreting these findings for several reasons. First, it is important to interpret these findings within the context of the adapted version of the SF-SUNS used in this study. Secondly, the sample was largely homogenous, primarily composed of highly educated women with breast cancer within 2-5 years post-diagnosis and absence of baseline data on participants' unmet needs and individual factors such as self-efficacy and social support. Previous research suggests that these factors can influence post-treatment recovery regardless of the specific treatment or disease characteristics (Foster et al., 2016; Wheelwright et al., 2020).

A notable finding is that needs relating to stress management, social acceptance, and fear of recurrence persist, while needs for information and peer support were comparatively low. This may be attributable to the nature and content of the CTS programme which harnesses group and peer-to-peer interactions, with distinct modules on social support (NCCP, 2024). This supports the notion that informational content may be more easily delivered and absorbed via CH formats, while emotional and identity based needs require more intensive or tailored approaches. Furthermore, the roll out and delivery of the CTS programme in both modalities across the country could explain the relatively low information needs uncovered here. This positive outcome needs to be sustained as the number of PLWBC continue to rise (Department of Health, 2017). As unmet needs evolve across the survivorship journey (Schmidt et al., 2022a; Sodergren et al., 2019) and between individuals, there is a need for ongoing evaluation and adaptation of the survivorship programmes such as the CTS to ensure they remain responsive to the evolving needs of people impacted by cancer (Sodergren et al., 2019).

Overall, while QoL was moderately high in our sample, the wide range (0-100) and standard deviation indicates significant variability between participants, with some

reporting low QoL. The negative correlation between unmet needs and QoL reported in the current study is in keeping with previous research (Cochrane et al., 2022), underscoring the importance of addressing residual needs even after structured interventions, such as the online CTS programme. This finding aligns with the broader survivorship literature which shows unmet needs such as emotional and social support, are predictive of poorer outcomes across multiple domains of psychosocial wellbeing post treatment (Cochrane et al., 2022; Hart et al., 2022). Identifying and addressing unmet needs through more targeted and tailored supports could enhance the overall QoL post treatment, as evidenced by moderate to strong correlations observed in this study.

Unsurprisingly, PLWBC in full employment reported better QoL and overall health than those not in full employment. This finding is in line with Andreu et al., (2023)'s findings that showed being employed (versus unemployed) had the greatest positive association with QoL in a large sample of working-age PLWBC Being in full-time employment has been associated with benefits such as a structured daily routine, financial stability and social interactions, all of which contribute to reported higher QoL (Waddell & Burton, 2006). Furthermore, emerging evidence indicates that financial toxicity and return to work issues remain among the key concerns in post treatment cancer survivorship care (Zhu et al., 2020) with effective rehabilitation programmes to support return to work still lacking (Algeo et al., 2021).

Another finding is that the majority of the participants in the current sample were women with a breast cancer diagnosis. Several barriers for women returning to work after breast cancer were identified in a recent Irish study (Algeo et al., 2022). The study found that women living with and beyond breast cancer in Ireland were often unaware of their employment entitlements following cancer diagnosis and post treatment. Other studies have reported a similar trend where women returning to work after cancer diagnosis or treatment continue to have poor employment outcomes (Ekenga et al., 2020). This finding highlights the need for increased awareness, particularly for women, of employment rights and entitlements during and after cancer treatment. This information could be provided through work-focused rehabilitation programmes to support those transitioning back to the workplace following completion of their treatment, or when they are ready to. Furthermore, it would be worthwhile to consider incorporating a standalone module on return to work and financial toxicity in CTS and other survivorship programmes in Ireland.

Overall, the current study offers preliminary insights on the interrelations of unmet needs, QoL and overall health in the context of sociodemographic and cancer history following participation in the online CTS programme. However, it must be emphasised that no conclusions can be drawn about the impact of CTS on these outcomes as this study was largely descriptive, exploratory analysis of outcomes after participation, and not an evaluation of effectiveness. Future research is needed to examine the mechanisms through which sociodemographic factors influence unmet needs, QoL and overall health. Understanding these mechanisms could help tailor interventions, such as the CTS programme, more effectively. Moreover, examining the different types of survivorship programmes across diverse healthcare settings could provide broader insights into the most effective strategies for supporting cancer survivorship. Taken together, these findings underscore the value of routine assessments of unmet needs and QoL, even among participants who have completed the survivorship programmes.

# **5.4.1. Study Limitations**

A key limitation relates to the adaptation of the SF-SUNS measure. Although the decision to remove two of the four domains was informed by PPI input and stakeholder consultation to improve contextual relevance, this modification impacted the structural integrity of the tool. This limits comparison to published findings using the full 30-item or 34-item versions. This analysis should therefore be interpreted as descriptive in nature and cannot provide definitive conclusions about the level of unmet needs or the impact of the CTS programme on reducing them. The small sample size and reliance on non-parametric statistical tests limited the ability to conduct more complex multivariate analyses. These methodological constraints reduce the generalisability of the findings and highlight the need for future studies with larger, more diverse samples and longitudinal follow-up.

In addition the cross-sectional design restricts the ability to draw causal inferences from the observed correlations and associations. Other factors outside this study could have contributed to confounding these associations. For instance, the time elapsed between programme completion (up to 2 years prior for some participants) and data collection which assessed a subset of unmet needs and QoL within the last month. This temporal disconnect hinders definitively linking reported needs and QoL to programme participation. Future longitudinal studies are recommended to establish causality and

track changes over time. Further, given the cross-sectional nature of the study and absence of baseline data, causal inferences could not be drawn.

### 5.5. Conclusion

Study 3b explored the prevalence of unmet needs and QoL among PLWBC who participated in the online CTS programme in Ireland. While overall levels of unmet needs were low, persistent emotional and coping related needs remained for some participants. QoL scores were generally moderate to high, and unmet needs were negatively associated with both QoL and overall health. Due to the study's cross sectional design and lack of comparative baseline data, this study is not able to assess impact of the programme on reported outcomes. However, the findings highlight the need for ongoing needs assessment and continuous evaluation of the programme against the needs of the participants is essential to ensure it remains responsive and reflective of PLWBC's needs.

While Study 3a established the high usability of technologies within the CH-delivered CTS, with further analysis of the dataset (the present chapter) showing residual needs, a further question arose. This question, also echoed NCCP staff, CTS programme nurses, and facilitators, was how online CTS compares to in-person delivery, and what factors influence modality preference. Given the online CTS programme's commencement during and following the COVID-19 pandemic, no comprehensive comparison of the two modalities exists. Although a pilot study by Anneka et al., (2021) had previously evaluated the in-person CTS impact, a comparative analysis was lacking. Thus, Study 4, described in the next chapter, aimed to compare both modalities and to explore the factors influencing modality choice.

# Chapter 6

# Study 4

Comparing online vs. In-person cancer survivorship support for psychosocial well-being and quality of life: Exploring choices and modality preferences in the Cancer Thriving and Surviving programme.

#### **Abstract**

**Background:** As outlined in *Chapter 4 and 5*, the CTS programme offers both CH and in-person delivery modalities to support cancer patients post treatment. However, it is unclear whether these different programme modalities result in similar outcomes for participants. Study 4 examined the factors influencing modality choice and differences in participation patterns, psychological well-being and QoL.

**Methods:** The study employed a cross-sectional, post-test design comparing outcomes in participants who completed the in-person and online CTS programme between January and June 2024. Post-test measures included the Functional Assessment of Cancer Therapy-General (FACT-G) to assess QoL and the Hospital Anxiety and Depression Scale (HADS) to assess depression and anxiety. Qualitative data on modality choices were collected using open text responses.

Results: Forty-three participants completed the study with 28% (n=12) having completed the programme online via CH and 72% (n=31) in person. CH participants attended significantly more CTS sessions (p < .05), however no significant differences were found between online and in-person participants in terms of QoL as measured by FACTG, or anxiety and depression as measured by HADS. Participants residing in rural areas and those with a support programme in their locality were significantly more likely to opt for in-person participation. Qualitative findings indicated that social interaction motivated in-person modality preference, while convenience drove CH preference. Lack of viable alternative options was a key influence on modality choice; modality did not impact overall programme satisfaction.

Conclusion: Offering diverse programme formats is beneficial to accommodate individual needs and preferences in cancer survivorship care. Both CH and in-person delivery modalities could support QoL and psychological wellbeing in PLWBC. Understanding the factors driving modality choice can inform targeted outreach and programme development strategies to optimize engagement and reach.

### 6.1. Introduction

Traditional in-person support programmes, often involving group meetings or individual counselling sessions, have long been a cornerstone of survivorship care (Jonas & McManamon, 2024). These programmes provide a space for PLWBC to connect with others, share experiences, receive emotional support, and gain valuable coping strategies. However, access to in-person supports and programmes can be limited by factors such as geographical location, transportation barriers, physical limitations, and time constraints (Bourgeois et al., 2023), among others.

Research comparing CH to in-person counterparts has yielded promising results across various outcome measures. Study 1 found that CH delivered interventions led to reductions in depression and anxiety symptoms. In addition, CH delivered psychosocial interventions have shown promise in improving QoL and cancer-related distress in PLWBC (Beatty et al., 2016; Owen et al., 2005). While some studies have reported no significant differences in psychosocial outcomes between CH and in-person interventions (Stevenson et al., 2019), others have found that CH interventions may lead to greater improvements in certain aspects of QoL, such as physical functioning and social well-being (Abrahams et al., 2017).

Moreover, while evidence suggests comparable efficacy between online and inperson interventions, some research indicates that the choice of modality might be influenced by demographic factors. For instance, younger age and higher levels of education have been associated with a preference for CH (McAlpine et al., 2015b). Additionally, individuals experiencing greater symptom burden or those with limited access to transportation may find CH interventions more appealing (Syed et al., 2013). Overall, the evidence regarding the predictors of modality choice and preference remains limited and inconclusive, underscoring the need for further analysis to better understand these factors (Beatty & Binnion, 2016). The mixed evidence base underscores the need for nuanced and rigorous research that moves beyond simply comparing the efficacy of CH versus in-person delivery. A critical question that remains is how the impact of CH delivery compares to that of traditional in-person programmes within the same context. Additionally, it is unclear what factors, including demographic variables, influence decisions to choose one modality over the other in a dual offering. Understanding these nuances is crucial for tailoring survivorship care to meet the diverse needs and preferences of PLWBC (D. Kumar et al., 2023).

Studies 3a and 3b have illustrated how online CTS delivered via CH is of benefit, however there is a need to see how this compares to the in-person delivered programme. Thus, study 4 aims to: (i) examine differences in participation patterns in both modalities; and (ii) identify factors that may influence the choice of programme modality. The CTS dual delivery approach provides a unique opportunity to compare delivery modalities within the same programme context.

### 6.2. Methods

## 6.2.1. Study design and context.

This study employed a cross-sectional, post intervention design. While initially intended as a pre post design, practical challenges necessitated a change of design to a naturalistic post programme survey across multiple cancer support centres. Specifically, by the time the study commenced in early 2024, most centres had already begun the CTS workshops or were nearing completion. In addition, some centres initially scheduled to deliver the programme online had switched to in person formats. As a result, collection of baseline (pre-programme) data was not feasible and sufficient recruitment for pre-post comparison was unlikely. Based on these logistical constraints and informed by prior experiences of low response rates (as seen in study 3a and b), the research team opted for post intervention comparison across delivery modalities.

### 6.2.2. Recruitment and eligibility criteria.

Participants were recruited in collaboration with the NCCP, which coordinates the national roll out of the CTS programme, described earlier in *Chapter 4*. The project manager in charge of survivorship at the NCCP, where the CTS programme falls, provided a list of community based cancer support centres and organisations scheduled to run the CTS programme between January and June 2024 (most centres close over summer months). These centres are distributed across the country. A total of 18 centres offering the programme were identified, of which 13 agreed to participate in the study. Two centres did not run the programme during the study period, and three did not respond to the requests to participate. Centre managers or programme facilitators served as gatekeepers for recruitment. Eligible participants included PLWBC aged 18 and above who had completed the CTS programme (*either online or in person*) between January 2024 and June 2024. This included individuals who had completed all six sessions of the

programme, as well as those who did not complete all sessions. Centre leaders, in their role as gate keepers distributed the online survey link and study information to eligible participants via email or word of mouth during, or close to the last session of the workshops. The invitation included information about the study's purpose, procedures, and potential benefits and risks.

Participation was voluntary, and all responses were kept confidential. Posters with study information were also displayed across the centres, especially those offering the programme in person. The survey remained open through July 2024 to accommodate late-June programme completers. No a priori power analysis was performed as the study was designed to capture responses from all eligible CTS programme completers within a six-month period across participating centres. This pragmatic sampling approach prioritised feasibility and inclusiveness over statistical power. However, it was acknowledged that the sample size may have limited the ability to detect small to moderate effects between online and in-person delivery groups.

The survey was hosted on Qualtrics platform (Qualtrics, L. L. C, 2020). Ethical approval for this study was granted by Maynooth University Social Research Ethics subcommittee in February 2024 (#SRESC-2024-37827). Participants provided informed consent prior to study completion.

### 6.2.3. Measurements

Upon providing informed consent, participants were asked to complete an online survey or a paper version if requested, depending on their preference. The survey consisted of the following sections. The full questionnaire is appended (*see appendix 5*).

Sociodemographic and disease characteristics: Information on age, gender, marital status, highest education level, employment status over the last three months, and cancer diagnosis details (type, stage, time since diagnosis), residence (urban/rural) and time since active treatment ended was collected. Participants were also asked to rate the accessibility of their local cancer support centre in terms of transportation on a scale of 0-5 (with 0 being "Not accessible" and 5 being "Fully accessible") and to indicate whether their local centre offered the CTS programme (yes/no/unsure). The questions were developed based on those used in previous chapters and refined in consultation with programme facilitators to ensure contextual appropriateness and relevance to the target

population. These included standard items commonly used in psychosocial oncology research, such as age, gender, cancer type, treatment status, and employment.

**Programme modality choice and rationale:** Participants were asked whether they completed the CTS programme online or in-person and were given the opportunity to explain their reasons for choosing their specific modality via an open-text response.

**Programme characteristics and effectiveness:** Participants were also asked to indicate the number of CTS sessions completed and the time of day they engaged with the programme. They were asked to rate various aspects of the programme on a Likert scale, including the time/day of the programme, venue (for in-person delivery) or technology (for online delivery), communication during sessions, the organization and preparation, and the leaders delivering the programme. Additionally, participants endorsed programme's overall impact on their psychological wellbeing, QoL, sense of empowerment, and whether they would recommend it to other people affected by cancer (yes, no, maybe) and why (open text). Participants were also invited to provide any additional comments they had about the programme (open text).

Anxiety and Depression: The HADS (Zigmond & Snaith, 1983) was used to assess for anxiety and depression following completion of the programme. It was selected for its brevity and ease of use, minimising participant burden while ensuring psychometric robustness. Also, as highlighted in study 1, the HADS is a commonly employed outcome measure in the context of CH evaluation. The scale consists of two subscales: anxiety (HADS-A) and depression (HADS-D), each comprising 7 items. Respondents rate how they have felt over the past week on a 4-point Likert scale ranging from 0 to 3. Subscale scores range from 0 to 21 with higher scores indicating greater symptom severity. A review of 747 studies that utilised HADS demonstrated its high reliability. Cronbach's alpha ranged from .68 to .93 for the HADS-A subscale and from .67 to .90 for the HADS-D subscale (Bjelland et al., 2002). Among cancer patients specifically, Cronbach's alpha was 0.85 for the full HADS (all 14 items), 0.79 for the HADS-A subscale, and 0.87 for the HADS-D subscale (Rodgers et al., 2005), making it one of the mostly used measure to screen for anxiety and depression in this population.

Quality of life: FACT-G, Version 4 (Cella et al., 1993) was used to assess participant's QoL. The FACT-G was chosen over longer measures, such as the EORTC QLQ-C30 used in earlier chapters, to reduce respondent burden while retaining coverage of key quality of life domains. Its strong reliability and validity in cancer survivorship contexts further supported its use in this study. The FACT-G is a widely used 27-item self-report measure with subscales assessing multidimensional QoL in PLWBC and comprises of four domains namely physical wellbeing, social/family wellbeing, emotional wellbeing, and functional well-being (Cella et al., 1993). E.g., an example of question for physical wellbeing domain is 'I have lack of energy.' Items are rated on a 5point Likert scale ranging from 0 (not at all) to 4 (very much). Negatively worded items are reverse scored. Subscale scores are summed to get a total QoL score, with higher scores indicating better QoL. The maximum total score is 108. FACT-G has been widely validated and used across cancer populations and has good psychometrics properties (Cella et al., 1995; Overcash et al., 2001). The FACT-G and its subscales have demonstrated acceptable reliability with a reliability analysis showing an average Cronbach's alpha of .88 (subscales ranging from .71 to .83) across 78 published studies (Victorson et al., 2008).

### 6.2.4 Data Analysis

Data analysis was conducted using SPSS version 26. Descriptive statistics were used to summarize participant characteristics, with means and standard deviations reported for continuous variables, and frequencies and percentages for categorical variables. To examine differences between those who participated in the CTS programme online versus in-person, independent samples t-tests for continuous variables (FACT-G and HADS scores) and chi-square tests for categorical variables (demographic and cancer related characteristics) were conducted. Where assumptions for the chi-square test were violated due to small cell sizes (i.e., expected counts <5), Fisher's Exact Test was used instead to provide a more accurate estimate of statistical significance. These bivariate analyses were used due to the modest sample size and the exploratory nature of the study. Statistical significance was determined with a p-value of <.05. The open-text responses were analysed using content analysis, with responses categorized into themes/categories (Hsieh & Shannon, 2005). The frequencies of these themes were then compared across in-person and CH groups to identify the primary drivers behind each modality choice.

### 6.3. Results

# 6.3.1. Response rate and modality of participation.

Across the 13 cancer support centres that agreed to participate in the current study between January and June 2024, and based on centre reports, each workshop typically hosted 8 to 14 participants, suggesting that approximately 104 to 182 individuals completed the programme during this period. However, due to the absence of centralised participant-level data, the precise number of completers could not be confirmed. A total of 51 individuals accessed the survey, and 43 provided complete responses that were included in the analysis. Among the 43 participants, 72% (n=31) completed the CTS programme in person, while 28% (n=12) completed online via CH. In-person participants were drawn from a range of centres across the republic of Ireland.

# 6.3.2. Sociodemographic characteristics.

Participants ranged in age from 37 to 76 years (M=53.6, SD=10.4). On average, participants had completed treatment 11 months before the survey date (M=11.1, SD=9.9). All but one respondent was female (n=42, 98%). The distribution of sociodemographic characteristics is shown in Table 6.1.

**Table 6.1**Differences in Sociodemographic and clinical characteristics of participants by programme delivery modality

Characteristic	Category	Tota	Total Online		In-p	erson	rson Differences		
		n	%	n	%	n	%	$\chi^2$ (df)	p-value
Gender	Male	1	2.3	0	0.0	1	100	n/a	n/a
	Female	42	98	12	29	30	71		
Education Level	Secondary school/other	7	16. 3	1	14. 3	6	85.7	0.77(1)	.380
	Third level and above	36	83. 7	11	30. 6	25	69.4		
Marital Status	Single	8	18. 6	4	50. 0	4	50.0	4.73(4)	.316
	Married	24	55. 8	6	25. 0	18	75.0		
	Divorced	3	7.0	0	0.0	3	100		
	Widowed	3	7.0	0	0.0	3	100		
	Cohabitating	5	11.6	2	40. 0	3	60.0		
Current Occupation	Working Full Time	8	18. 6	2	25. 0	6	75.0	9.95(5)	.077
	Working Part Time	6	14. 0	1	16. 7	5	83.3		

Characteristic	Category	Tota		Online		In-p	erson	Differences	
		n	%	n	%	n	%	$\chi^2$ (df)	p-value
	Unemployed and looking for work	2	4.7	0	0.0	2	100		
	A homemaker or stay-at-home parent	3	7.0	2	66. 7	1	33.3		
	Retired	11	25. 6	6	54. 5	5	45.5		
	Sick/Disability Benefit	13	30. 2	1	7.7	12	92.3		
Residence	Urban	24	55. 8	12	50. 0	12	50.0	13.18(1)	<.001
	Rural	19	44. 2	0	0.0	19	100		
Cancer Type	Breast	31	72. 1	9	29. 0	22	71.0	7.94(9)	.540
	Ovarian	3	7.0	1	33. 3	2	66.7		
	Lymphoma	2	4.7	0	0.0	2	100		
	Pelvic	1	2.3	0	0.0	1	100		
	Lung	1	2.3	1	100	0	0.0		
	Melanoma/skin	1	2.3	0	0.0	1	100		
	Olfactory neuroblastoma	1	2.3	0	0.0	1	100		
	Multiple myeloma	1	2.3	1	100	0	0.0		
	Head and Neck	1	2.3	0	0.0	1	100		
	Endometrial	1	2.3	0	0.0	1	100		
Time Since treatment ended	<1 year	33	76. 7	8	24. 2	25	75.8	2.94(2)	.230
	1-2 years	5	11.6	1	20. 0	4	80.0		
	2-5 years	5	11.6	3	60. 0	2	40.0		
Cancer programme at local centre	Yes	35	81. 4	6	20. 0	29	80.0	12.27(2)	<.001
	No	4	9.3	4	100	0	0.0		
	Unsure	4	9.3	2	50. 0	2	50.0		

Participants based in rural areas were more likely to attend the CTS programme in person compared to those in urban areas ( $\chi^2$ =13.177, df=1, p<.001). Additionally, participants with a cancer programme offered at their local centre were significantly more likely to attend in person, whereas those without or unsure about local programme availability tended to choose the CH modality ( $\chi^2$ =12.267, df=2, p=0.002). In terms of accessibility (transportation wise) of the cancer care centres, participants indicated that on average the centres were fairly accessible (M=4.1, SD=1.2), however, there was a statistically significant difference across modality, with those who attended via CH giving a lower

accessibility rating compared to those who attended in person (CH M=3.5, SD=1.5; inperson M=4.4, SD=1.0; t=2.2. p=.032).

# 6.3.3. Quality of life, Psychological wellbeing and CTS modality

To compare QoL scores between the two CTS delivery modalities, an independent samples t-test was conducted. The analysis included the overall FACT-G score and four subscales: Physical Well-being, Social/Family Well-being, Emotional Well-being, and Functional Well-being. No significant differences in QoL outcomes were found between the two modalities on either the overall FACT-G score or any of the subscales.

Similarly, an independent samples t-test was employed to compare anxiety and depression scores between modalities, as measured by the HADS. No significant differences in anxiety or depression levels were found (Table 6.2).

**Table 6.2**Comparison of Quality of Life and psychological wellbeing between CH and In-person CTS Programme Participants

	Modality		M			
Measure	Online (CH) n=12 Mean (SD)	In-person n=31 Mean (SD)	– Mean Differenc e	t	df	p- value
FACT-G -PWB Score	20.50 (4.42)	18.61 (6.33)	1.89	0.947	41	0.349
FACT-G -SWB Score	18.25 (6.20)	20.02 (5.41)	-1.77	-0.922	41	0.362
FACT-G -EWB Score	17.40 (3.31)	15.90 (4.75)	1.50	0.998	41	0.324
FACT-G -FWB Score	18.67 (4.29)	16.39 (5.95)	2.27	1.204	41	0.236
FACT-G- Overall Score	74.82 (13.67)	70.92 (18.25)	3.90	0.669	41	0.508
HADS-Anxiety Score	8.50 (4.10)	7.77 (4.21)	0.73	0.511	41	0.612
HADS-Depression	4.67 (2.02)	5.90 (3.22)	-1.24	-1.508	32	0.141
Score						

# 6.3.4. Programme's impact on psychosocial wellbeing, QoL and empowerment.

When asked about the programme's effect, a large majority of participants in both modalities reported that the CTS programme improved their psychological well-being, QoL, and empowerment (*Table 6.3*)

**Table 6.3**Programme's impact on psychological wellbeing, quality of life and empowerment.

Question	Response Option	Modality	
		CH n (%)	In-Person (%)
In general, I would say the	Disagree	1 (8.3%)	1 (3.2%)
CTS programme improved my psychological wellbeing	Neither Agree nor Disagree	1 (8.3%)	0 (0.0%)
	Strongly Agree/Agree	10 (83.3%)	30 (96.7%)
In general, I would say the	Disagree	1 (8.3%)	2 (6.4%)
CTS programme improved my Quality of Life.	Neither Agree nor Disagree	1 (8.3%)	2 (6.5%)
	Strongly Agree/Agree	10 (83.3%)	17(88.1%)
In general, I would say the	Disagree	1 (8.3%)	2 (6.4%)
CTS programme empowered me.	Neither Agree nor Disagree	1 (8.3%)	0 (0.0%)
	Strongly Agree/Agree	10 (83.3%)	29 (93.6%)

# 6.3.5 Programme participation and evaluation

The number of sessions attended by participants varied from 4 to 8, with a median attendance of 7 sessions. Notably, the CTS programme consisted of six core weekly sessions. An introductory "Session  $\theta$ " is often included. Some participants may have repeated sessions, resulting in reported attendance of 4 to 8 sessions as seen in prior evaluations in study 3a and 3b. A notable difference was observed between the two modalities: participants in the CH modality attended a median of 8 sessions, while those in the in-person modality attended a median of 6 sessions. This difference in session attendance between the CH and in-person groups was statistically significant, as indicated by the Mann-Whitney U test (U = 96.00, p = .014). Table 6.4 presents a summary of the evaluation responses across the CH and in-person modalities. In-person participants provided high ratings for the venue, with 87.1% rating it as "Excellent." Similarly, a majority of the CH participants rated the technology positively, with 63.6% indicating it was "Excellent."

Communication during the sessions was highly rated across both modalities, with 75% of CH participants and 80.6% of in-person participants rating it as "Excellent." The organization and preparation of the programme also received strong approval, with 75.0% of CH participants and 80.0% of in-person participants rating it as "Excellent." Regarding

the effectiveness of programme leaders, 75.0% of CH participants and 90.0% of in-person participants rated them as "Excellent."

 Table 6.4.

 CTS Programme Participation and Evaluation

Question	Response		Modality
	Option	CH n (%)	In-Person (%)
Γime/Day Sessions	Average	1 (8.3%)	0 (0.0%)
	Good	4 (33.3%)	11 (35.5%)
	Excellent	7 (58.3%)	20 (64.5%)
Venue (In-Person)	Terrible	na	0 (0.0%)
· · · · ·	Good	na	4 (12.9%)
	Excellent	na	27 (87.1%)
Technology (CH)	Average	1 (9.1%)	na
, ,	Good	3 (27.3%)	na
	Excellent	7 (63.6%)	na
Communication	Poor	1 (8.3%)	0 (0.0%)
	Average	1 (8.3%)	1 (3.2%)
	Good	1 (8.3%)	5 (16.1%)
	Excellent	9 (75.0%)	25 (80.6%)
Organization	Poor	1 (8.3%)	0 (0.0%)
-	Average	1 (8.3%)	0 (0.0%)
	Good	1 (8.3%)	6 (20.0%)
	Excellent	9 (75.0%)	24 (80.0%)
Leaders	Average	3 (25.0%)	1 (3.3%)
	Good	0 (0.0%)	2 (6.7%)
	Excellent	9 (75.0%)	27 (90.0%)

Note. na-not applicable

# 6.3.6. Modality choices and preferences

Participants were asked why they chose one modality over the other, with all 41 participants providing responses. For in-person participants, *social interaction* was the leading motivating factor, with many voicing the opportunity to connect face-to-face with others. This contrasts with the CH group, where *convenience and flexibility* were highlighted by the majority of participants. Additionally, 'lack of alternatives' was a leading reason across both modalities with participants indicating that their chosen modality was 'the only available option.' In-person participants also cited outright comfort and preference for face-to-face interactions more frequently, while health concerns, including the impact of COVID-19 and side effects of treatment, influenced the CH group. These findings are summarised in Table 6.5.

**Table 6.5**Reasons behind Modality Choices

	Free	quency		
Category/ Theme	In- Person (n, %)	Online (n, %)	Example Quote (In Person)	Example Quote (CH)
Social Interaction	11 (35%)	0	"I don't think online completion would be effective as it wouldn't include the person-to-person bonding and sharing."	
Preference	6 (19%)	0	"Feel much more comfortable in person."	
Lack of alternatives	9 (29%)	6 (50%)	"It was the only option available."	"Only choice available and distance to centre meant l couldn't do it in person"
Convenienc e/Flexibilit y	1(3%)	5 (42%)	"It was suggested and was within easy reach"	"Saw it was an option. Suits family life much better than being out of the home. Medication leaves me very tired some evenings so an online course much preferable so as no driving necessary."
				"I did not feel 'up to' the commitment of the inperson course. I am not driving at the moment due to side effects of my treatment.
Health/Cov id- 19	0	2 (17%)		"Covid."

### 6.3.7. Reasons for recommending the programme

All participants affirmed that they would recommend the programme. When asked why they would recommend it, participants in both modalities indicated that they valued the support and sense of community the programme provided, as well as the opportunity to connect with others who have similar experiences. Both groups also found the programme empowering and useful in providing tools for managing life after completing cancer treatment. However, in-person participants more frequently emphasized the importance of psychosocial support, while CH participants appreciated the programme's flexibility and accessibility. This is summarised in *Table 6.6* below.

**Table 6.6** *Reasons for recommending the programme.* 

	Frequency		Illustrative Quotes		
Category/Theme	In- Person	СН	In-Person	СН	
Support and community	12 (39%)	5 (42%	"Gives you support and contact with others who understand how you are feeling."	"Because I found great support from other cancer sufferers and the facilitators were excellent."	
Meeting people with similar experiences	8(26%)	3 (25%)	"Nice to meet other people that have been through the same issues as you."	"It's good to meet people in the same situation."	
Empowerment and tools	7(23%)	3(25%)	"Empowers you to take back charge of all aspects of your life."	"Given lots of tools to help physical & emotional well-being."	
Psychosocial support	5(16%)	1(8%)	"For psychological help and a good way to improve the general outlook"	"I felt very supported and great group of ladies with a lot of positivity in the group."	

### 6.3.8. General comments

All participants provided general comments about the programme experience. The analysis of these comments revealed distinct themes between the two groups. Both groups highlighted *Support and Community* and *Programme Content and Structure* as key themes. However, in-person group emphasized *Support and Community* more frequently and provided more detailed critiques regarding *Programme Content and Structure*.

Accessibility was a theme primarily mentioned by CH group. Facilitators and Leaders were appreciated across both modalities, but in-person participants were more likely to mention positive experiences. Lastly, Personal Growth and Confidence was a theme recognized by both groups. Participants in both modalities also highlighted some possible areas for improvement, where they emphasised the need for more interactions amongst themselves. The frequencies of these categories and exemplar quotes are provided in Table 6.7 below.

 Table 6.7

 General comments about the CTS programme

Theme	Frequency		Illustrative Quotes	
	In-Person	СН	In Person	СН
Support and community	11 (35%)	4(33%)	"Wonderful leaders. I met 5 other participants who are friends for life"	"The strength of the programme lies in the formation of a group of people who are in need of connecting with others in a similar situation. Sharing their stories and discussing challenges helps them move forward."
Programme content and structure	9 (29%)	4 (33%)	"The programme is excellent at outlining the effects and effects of having Cancer. I found at times that the content is too prescriptive basic."	"The course content, which was very practical and broken into manageable chunks, helped me focus on small steps I needed to take and set goals for myself. I think it helps that the course facilitators have also been through the cancer experience, there is a shared understanding between all of us that adds to the power of the experience.
Personal growth and Confidence	5 (16%)	2 (17%)	"It gave me confidence in the future and my ability to cope."	"On the whole, it gave me more confidence to deal with my situation."
Accessibility	1 (3%)	3 (25%)		"I would highly recommend online. I would not have been able to avail of this programme 3 years later It made a

Theme	Frequency		Illustrative Quotes	
	In-Person	СН	In Person	СН
				valuable course much more accessible."
Recommendations for improvement	2(6%)	2(17%)	"I have other lifelong illnesses which have been exacerbated by the treatments also. More time needs to be allocated for participants to talk to each other as this was always rushed to ensure we finished on time."  "I thought the leaders time could've been put to better use if there had been more interactive elements. Also, several times the class ran over, I didn't feel there was enough time allowed for group discussion as the course was structured"	I would prefer if there was less about self-management in general and more about how to overcome or live with side effects.  A similar programme for family and friends would also be extremely beneficial.

## **6.4. Discussion**

This chapter examined engagement experiences among participants who completed the CTS programme delivered either online via CH or in-person in Ireland. Findings offer insight into how delivery modality intersects with participant characteristics, programme experiences, and psychological outcomes, while also highlighting implications for survivorship support models within the Irish context. The analysis revealed no differences in post-intervention scores for QoL, anxiety, or depression between participants who completed the programme via CH and those who participated in person. However, while satisfaction was comparable across modalities, there were differences in reasons for engaging in different modalities. Interestingly, those

based in the rural areas were more likely to engage in-person, while urban participants were divided between CH and in-person modalities. These findings are consistent with earlier chapters (*Chapter 3*), where rurality was highlighted as a potential barrier to CH adoption. In addition, CH participants attended a greater number of sessions compared to their in-person counterparts, suggesting that participants in online modality had consistent engagement. These findings align with a growing body of literature demonstrating benefits across modalities in PLWBC as described in Study 1, and challenges traditional biases towards in-person care, particularly in light of increasing demand for remote healthcare solutions (Burbury et al., 2021), and the rising number of PLWBC in need of these services. However, the comparable effectiveness of both modalities should not overshadow the significant influence of contextual and individual factors on modality preference (D. Kumar et al., 2023).

PLWBC based in the rural areas were significantly more likely to opt for inperson participation, suggesting a potential reliance on centralized services. It may also reflect limited internet access in those areas, or a stronger sense of connection and trust in the community based supports. This finding resonates with broader healthcare disparities in Ireland, where access to specialized services, particularly outside of urban centres, remains a pressing concern (P. Walsh et al., 2016). Study 1's finding on the potential of CH technologies to improve accessibility and support is corroborated by this study's findings of a balanced preference for CH and in-person modalities among urban participants, highlighting the role of convenience and flexibility (D. Kumar et al., 2023). While CH solutions are often promoted for their potential to address rural healthcare access barriers (Burbury et al., 2021; Signorelli et al., 2019b), this finding suggests that rural residents may face persistent digital infrastructure challenges or have lower confidence in engaging with online formats. Alternatively, it may reflect a stronger preference for in person community-based services in rural settings (McEvoy & MacFarlane, 2013). These findings underscore the importance of not assuming uniform digital readiness across geographical regions and highlight the need for targeted digital inclusion strategies as part of CH implementation in survivorship care.

The decision to allow participants to self-select their preferred modality is particularly relevant when viewed through the lens of the TAM discussed in preceding chapters. Factors such as perceived ease of use, perceived usefulness, and individual context (e.g. time availability, comfort with technology) may have shaped not only participants' choices but also their experiences and outcomes. This reinforces the idea that

CH is not a one-size-fits-all solution, and delivery mode must align with user preferences, access, and capabilities, a theme echoed in *Chapter 4* regarding programme usability and utility.

Findings underscore the importance of choice and flexibility in survivorship support. While CH may offer logistical advantages, particularly for those managing fatigue, transportation issues, or immunosuppression, its uptake remains contingent on user readiness and system-level supports, as supported by the SEM (McLeroy et al., 1988). It is important to note that the distinction between programme effects and delivery mode cannot be disentangled in this design. The observed associations likely reflect both the intervention's psychosocial focused content, as per the stress buffering hypothesis earlier discussed, or the influence of modality-specific factors such as interaction quality, group dynamics, and digital confidence, as noted in the usability and utility findings in Chapter 4.

The qualitative findings from this study provide a deeper understanding of these preferences and impacts, revealing distinct motivations underpinning modality choice. While in-person group participants emphasized the value of social interaction and the sense of shared experience fostered by face-to-face engagement, the CH group highlighted the convenience and flexibility of accessing support from home, on their own terms. This suggests that CH delivery, beyond its practical advantages, may also resonate with individuals seeking greater autonomy and control over their healthcare experience, potentially mitigating feelings of vulnerability or dependence often associated with cancer survivorship (Schmidt et al., 2022; Stein et al., 2008).

Notably, despite variations in modality preference and engagement patterns, participants unanimously expressed a willingness to recommend the CTS programme to others. This endorsement underscores the perceived value and relevance of such programmes, irrespective of the modality in which it is offered, within the Irish cancer survivorship landscape, aligning with research highlighting the significant unmet needs for psychosocial support among this population (Delemere et al., 2023; O'Connor et al., 2019). This positive sentiment is further supported by the high satisfaction ratings across both modalities regarding programme organization, leadership, and perceived impact on psychosocial well-being, QoL and sense of empowerment.

While both CH and in-person groups emphasized the programme's role in fostering a sense of community and providing practical tools for navigating life after cancer, subtle differences emerged in how these benefits were experienced. In-person

participants more frequently highlighted the strength of the connections forged through face-to-face interactions, echoing findings that emphasize the unique value of in-person support groups in reducing social isolation and promoting a sense of belonging (Welch et al., 2024). Conversely, CH participants particularly appreciated the programme's flexibility and accessibility, suggesting that this modality may effectively mitigate barriers to engagement for individuals facing geographical constraints, logistical challenges or long-term effects such as fatigue, a finding supported by the significantly higher median attendance observed in the CH group. This finding aligns with growing evidence suggesting that CH can broaden the reach of psychosocial support services (Brennan et al., 2022; Delemere et al., 2022). Overall, these nuanced findings underscore the importance of offering diverse programme delivery models to cater to the multifaceted needs and preferences of PLWBC, ultimately promoting greater equity and accessibility in supportive cancer care.

While this study's strength lies in its mixed methods approach, several limitations should be acknowledged. First, the study employed a cross-sectional, postintervention-only design, which limits causal inference and prohibits evaluation of change over time. Without baseline data, it's not possible to determine whether any observed differences are attributable to the CTS programme or pre-existing differences between participants, or if participants were enrolled in other support services. Second, the analysis was limited to bivariate comparisons due to small sample size. While covariates such as time since treatment and sociodemographic factors likely influenced outcomes, the study was not sufficiently powered to conduct multivariate analyses or control for these confounders. This issue was further compounded by the variability in time since treatment completion, which may have influenced psychological adjustment and QoL outcomes. Third, while validated instruments including HADS and FACT-G were used, no data were collected on other services participants may have accessed concurrently. This limits attribution of outcomes specifically to the CTS programme. Finally, the possibility of selfselection bias must be considered. Participants opted into their preferred delivery format, which likely reflects underlying attitudes, motivations, and capabilities. These factors, rather than the delivery mode alone (online versus in person) may have influenced their outcomes, as suggested by the TAM and related adoption frameworks.

#### 6.5. Conclusion

Study 5 offers valuable, if modest, insights into the evolving landscape of delivering cancer survivorship care in Ireland, highlighting the need for flexible approaches that cater to diverse needs and preferences. The findings support a personcentred approach to survivorship care, where both CH and in-person options are made available to accommodate diverse needs and contexts. Future evaluations should adopt longitudinal or experimental designs, integrate covariates, and explore hybrid models of delivery to optimise accessibility and impact. These insights feed directly into the broader aim of this thesis, which is centred around advancing evidence-based, contextually grounded implementation of CH in cancer survivorship care in Ireland.

Studies 1 through 4 have investigated various aspects of CH technologies in relation to their role in supporting psychosocial wellbeing and QoL in PLWBC. However, all these studies primarily employed quantitative or mixed methods cross-sectional approaches, which, while valuable for identifying trends, may not fully capture the nuances of lived patient experiences. Qualitative inquiry, known for its ability to explore and contextualize such experiences, offers a more holistic understanding of complex phenomena. Study 5, presented in the next chapter, addresses this gap by employing a qualitative exploration of PLWBC's experiences with CH in Ireland.

# **Chapter 7**

# Study 5

Connected Health in Cancer Survivorship: A Qualitative Study of Experiences, Benefits, Challenges, and Recommendations in Ireland

#### **Abstract**

**Background:** As described in study 1 and 2, CH technologies are increasingly recognized as valuable tools in cancer care. However, as seen in studies 2-4, their uptake and adoption remain uneven. Study 5 explores the experiences of PLWBC in relation to their interactions with CH technologies in Ireland. The objective is to understand participants' experiences with CH in the context of survivorship care.

**Methods:** A qualitative descriptive design was utilised. Semi-structured interviews were conducted with 15 individuals living with and beyond cancer, who were conveniently recruited to participate in the study. Reflexive thematic analysis was utilised.

Results: Six themes were identified. Access as agency highlighted systemic inequities in digital literacy and infrastructure, shaping engagement with CH technologies. Negotiating holistic support emphasized CH's ability to facilitate emotional and peer support while exposing tensions around maintaining personal connection. Seamless or fragmented care illustrated CH's efficiency in streamlining care while highlighting systemic disintegration that hindered continuity. Empowerment or dependency reflected participants' active roles in self-management and shared decision-making but cautioned against over-reliance to CH and patient burden. Trust and reluctance highlighted privacy concerns, technological hesitancy, and skepticism as barriers, underscoring the need for patient-centered designs. Harnessing the power of knowledge emphasized the role of awareness, digital literacy, and lessons from COVID-19 in fostering CH adoption.

Conclusion: This study offers first-hand insights into PLWBC'S experiences with CH-delivered psychosocial care. These findings complement earlier quantitative chapters by highlighting the interpersonal, contextual, and structural dynamics shaping engagement. Findings underscore CH's promise and associated complexities in cancer survivorship care, advocating for inclusive, patient-centred implementation. These insights can inform the wider discussion on digital health, providing recommendations for integrating CH into cancer survivorship care.

#### 7.1. Introduction

The preceding empirical chapters have quantitatively evaluated the usability, utility, and perceived outcomes of the CTS programme delivered online via CH in Ireland. These investigations (Chapters 4-6) provided foundational insights into how CHdelivered survivorship support programmes, such as the CTS programme may influence psychological wellbeing, unmet supportive care needs and QoL among PLWBC. However, these studies also revealed persistent gaps and limitations, such as issues with digital access, variable engagement, and differing modality preferences, that warranted deeper qualitative exploration. To build on this work and to better understand the lived experiences of PLWBC with CH in respect to survivorship care, this chapter presents a qualitative study focused on the perspectives of PLWBC regarding CH in survivorship care. Further, while previous studies in this thesis employed structured tools and surveys to capture quantifiable outcomes, they were limited in their ability to uncover the nuanced, contextual, and often emotionally complex dimensions of engagement with CH technologies. This study sought to complement and expand upon earlier findings by examining how CH is experienced in real-life settings, exploring its perceived benefits, drawbacks, and potential for enhancing psychosocial support and survivorship care in Ireland.

As noted in previous studies, PLWBC often face a range of physical, emotional, and practical challenges that can significantly impact their overall psychosocial well-being and QoL (Emery et al., 2022; Shapiro, 2018). Further, findings from study 1 demonstrated tangible benefits of CH in improving patient outcomes. For instance, these technologies have been linked to improved medication adherence (Greer et al., 2020), better symptom management (Grašič Kuhar et al., 2020), and increased patient empowerment (Rossetto et al., 2023), all of which contribute to a higher QoL. Wearable sensors can track vital signs and activity levels, providing valuable data to both patients and healthcare providers (Fisch et al., 2016; H. Onyeaka et al., 2021), while mobile applications offer convenient platforms for symptom tracking (Basch et al., 2016), medication reminders (Greer et al., 2020b), access to educational and informational resources (Northouse et al., 2014), and peer and social support (Klemm, 2012). Further, CH can bridge geographical barriers (Brennan et al., 2022; Burbury et al., 2021) and connect PLWBC with HCPs for remote consultations (P. Wang et al., 2016), reducing the need for travel and improving access to care (Awad et al., 2021).

However, despite the promising potential that CH presents, its widespread adoption and use are not without challenges, as seen in study 2. A complex interplay of barriers and enablers can influence the successful integration of these technologies into the lives of PLWBC (Coetzer et al., 2024). One key barrier is the issue of digital (il)literacy (Kemp et al., 2021). Additionally, people impacted by cancer may experience age-related cognitive and communicative changes that can further hinder their ability to engage with these CH tools (Bol et al., 2018; Sharma & Brunet, 2023). Addressing these barriers is crucial to ensure equitable access to the benefits of CH (Coetzer et al., 2024).

Qualitative inquiry is invaluable for exploring and contextualising patient experiences (Renjith et al., 2021). This analytical approach can facilitate a more holistic understanding of complex human phenomena. For instance, a recent qualitative metareview of CH in cancer care identified paradoxes in how current literature views eHealth use, including the mismatch between the complexity of health system problems and the simplistic view of CH as a solution, as well as the tendency to frame barriers as individual deficits rather than systemic issues, thereby misallocating responsibility for improvement (Coetzer et al., 2024). Recent qualitative research on the experiences of patients participating in a telehealth-based rehabilitation programme in Ireland (O'Brien et al., 2023) identified how the telehealth programme supported participants' physical and psychosocial recovery, while also identifying an ongoing need for some in-person care.

Additionally, a recent qualitative analyses of CH experiences among families affected by paediatric cancer revealed a multifaced interplay of barriers and facilitators, highlighting the need for further investigation (Delemere et al., 2022). While these studies continue to offer useful insights on patients experiences with technology, the increasing digitalization initiatives such as the *eHealth Ireland* strategy noted in *Chapter 1 Section* 1.3 (HSE, 2024a), it's important to continually understand participants experiences with the technologies and how it relates to their care.

This study aimed to explore the experiences of PLWBC with CH in Ireland in relation to their cancer survivorship care.

#### 7.2. Methods

The reporting of this study was guided by the COnsolidated criteria for REporting Qualitative research (COREQ) checklist (A. Tong et al., 2007). Ethical

approval was obtained through the Maynooth University Social Research Ethics Sub-Committee in June 2023 (ref no: SRESC-2023-36455).

#### 7.2.1. Participants

Participants were PLWBC who had completed their primary treatment for cancer, aged 18 years and above, and residing in the Republic of Ireland. To participate, one did not need to have any experience with CH in their care and treatment or participated in the earlier quantitative studies. Study 2 noted the need to include non-users in CH research to offer insights into possible reasons for no use and opportunities for improved adoption. Participants were conveniently recruited, through social media pages and circulation of recruitment invitation to cancer centres and through the NCCP quarterly newsletters. Snowball sampling strategy was utilised where necessary where participants were requested to refer other PLWBC who may be interested in participating in the study.

# 7.2.2. Study Design

This study employed a qualitative methodology, involving semi-structured interviews conducted virtually or in-person. The qualitative descriptive design was grounded in a critical realist philosophical framework (Braun & Clarke, 2006), which emphasizes listening to and learning from lived experiences to gain insights into the phenomenon of interest. Epistemologically, this study adopted an interpretive and constructivist paradigm within a phenomenological qualitative approach (Clarke & Braun, 2013). It aimed to gain an in-depth understanding of participants' experiences with CH including but not limited to its benefits, challenges and opportunities for CH in their cancer care, while also accounting for the reflexive influence of the researcher on the analysis.

#### 7.2.3. Data Collection

A topic guide of open-ended questions was used flexibly to guide the interview. Prompts were included to probe answers where necessary (*See Appendix 6 for full details of questions posed*). Questions were open-ended to allow participants to openly discuss their thoughts. The questions were developed by drawing on previous research and incorporating PPI feedback, as well as through discussions with leaders from the NCCP (NCCP, 2024; NCCP, ICS, 2024), some of whom coordinate survivorship programmes in Ireland. Full informed consent was obtained electronically before the interview. Verbal

consent to participate at the start of each interview was also sought. Upon consenting, participants completed a brief demographic questionnaire that captured their age, marital status, highest educational level, employment status, cancer type and treatment received, time since primary treatment ended and their proximity to health centre. This was facilitated via the Qualtrics platform (Qualtrics, L. L. C, 2020). An interview date and time was then mutually agreed based on the participant's preferences, either in person or Via Microsoft Teams. Where interviews were conducted in person (n=1), this took place in a quiet place, in adherence to the ethical and procedural guidelines established by the Maynooth University Department of Psychology for conducting research involving participants.

The interview with the first participant acted as a pilot. The participant was invited to share feedback and suggestions, which were used to refine the questions and probes in the subsequent interviews. Interviews were conducted between June 2023 and January 2024. Both audio and video were recorded for most participants with their consent. All interviews were conducted by IG (PhD researcher) who has experience conducting interviews with patients living with chronic conditions including cancer. Interview durations ranged from 33 minutes to 64 minutes; the average was 45 minutes. IG approached this study from the perspective of a psycho-oncology researcher with nursing and mental health experience, but without personal experience of cancer.

#### 7.2.4. Data Analysis

The study employed the six-step process of reflexive thematic analysis as outlined by Braun and Clarke (Braun & Clarke, 2006, 2021b). This method was selected due to its flexibility. Reflexive thematic analysis is a well-established analytic approach commonly used in qualitative health research (Braun & Clarke, 2021b) as it supports interpretivist perspectives on qualitative data generation. The flexibility of the reflexive thematic analysis approach facilitated a primarily inductive analysis, though some deductive analysis was also applied when examining the themes in relation to the research questions. This analytic approach allowed for an open consideration of participant perspectives while acknowledging their subjectivity and the researchers' own interpretive influence (Braun & Clarke, 2021a). The iterative nature of this method facilitated an indepth exploration of meaning across the dataset, thereby enhancing understanding of the participants experiences (Braun & Clarke, 2023).

Prior to analysis, all interviews were transcribed verbatim and anonymized, and participants were given pseudonyms. Data were analysed using a recursive six step process outlined by Braun and Clarke. Firstly, transcripts were re-read to develop familiarity with the contents. Coding was then completed by IG using MAXQDA 22 with names given to important features of data. The accuracy of codes was confirmed by rereading codes in the absence of data to ensure they held on their own. A sample of three transcripts was then coded by AA (an undergraduate psychology student with no experience in qualitative research). Following this, IG and AA discussed codes and themes developed. When all the coding was completed, IG, RM and DD met to review and discuss the preliminary analysis. Codes were then grouped together to develop preliminary themes and subthemes. Themes were reviewed by re-reading all transcripts to ensure no relevant data was omitted. Finally, themes and subthemes were defined and named. The final phase involved the selection of key quotes to represent each theme and subtheme. Involving multiple coders and collaborators facilitated deeper reflection, examination of underlying assumptions, and a collaborative approach to data interpretation (Braun & Clarke, 2024).

#### 7.3. Results

Initially sixteen individuals expressed interest in taking part. One participant was lost to follow-up; 15 interviews were conducted (14 via Microsoft Teams; one in person). Participants were aged between 44 and 77 years (mean 58 years); 11 were female and 4 were male. Most participants had attained tertiary education, current employment status varied. The majority lived in urban areas and had accessible healthcare, with a mean accessibility score of 4.33 (rated on a scale of 1 to 5). Participants had diverse cancer diagnoses, including breast, skin, ovarian, uterine, prostate, cervical, colon, and lung cancer, with some experiencing recurrence. Most received a combination of treatments, including radiotherapy, chemotherapy, and surgery; duration since primary treatment completion ranged from 1 month to 23 years, although most (n=12) had completed treatment within the past 3 years. The demographic and disease characteristics of the participants, alongside their experience with CH is summarized in Table 7.1

 Table 7.1

 Participant Sociodemographic Characteristics, Cancer History and Experience with Connected Health

Name	Age (Yrs)	Gende r	Edu. Level	Emplo yment Status	Marital Status	Reside nce	Accessibili ty Score (0-5)	Cancer Type	Treatments received	Time since Treatment ended	Used CH? /Examples
Emily	60s	Female	Third level	Retired	Single	Rural	4	Breast	Surgery, Radiotherapy, Chemotherapy	3 Yrs	Yes, Videoconferencing, apps
Megan	40s	Female	Third level	PT Work	Married	Rural	5	Breast	Surgery and Hormone Therapy	1 Year	Yes, Videoconferencing, apps
Sarah	60s	Female	Third level	Retired	Single	Urban	4	Lung	Surgery	3 months	Yes, apps
Laura	60s	Female	Third level	PT Work	Married	Rural	4	Uterine	Surgery	10 Yrs	Yes, conferencing platforms
Mariah	50s	Female	Third level	FT Work	Married	Urban	3	Breast	Surgery, Radiotherapy, Chemotherapy	9.5 Yrs	Yes, Videoconferencing, apps
Jessica	60s	Female	Third level	Retired	Married	Rural	5	Breast	Surgery, Radiotherapy, Chemotherapy	4 Yrs	Yes, Videoconferencing, apps
Emma	40s	Female	Third level	FT Work	Single	Urban	5	Breast	Surgery, Radiotherapy, Targeted therapies, Chemotherapy	1.5 Yrs	Yes
Daniel	40s	Male	Third level	Student	Married	Urban	5	Skin	Surgery	3 Years	Yes, EHRs, apps
Rachel	NP	Female	Third level	Retired	Single	Urban	5	Ovarian & Colon	Surgery, Chemotherapy	27 Yrs for Ovarian & 2.5 Yrs for Colon	Yes, Videoconferencing, apps
Grace	60s	Female	Third level	Retired	Married	Rural	5	Cervical & Kidney	Surgery, Radiotherapy, Chemotherapy	23 Yrs for Cervical and 1 Yr. Kidney	Yes, apps
David	70s	Male	Third level	Retired	Divorced	Urban	5	Prostate	Surgery	One Month	Yes, online physiotherapy

Lucy	50s	Female	Third level	FT Work	Single	Urban	4	Breast	Surgery, Radiotherapy, Hormone Therapy	6 Months	No experience with CH
Brady	50s	Male	Third level	Sick Leave from FT	Single	Urban	3	Squamous cell carcinoma	Surgery, Radiotherapy, Chemotherapy	4 months	No experience with CH
Sam	70s	Male	Third level	Self- Employ ed	Separate d	Urban	3	Colon	Surgery, Radiotherapy, Chemotherapy	1 year	None
Irene	50s	Female	Third level	Sick Leave from FT	Married	Urban	5	Breast	Surgery, Radiotherapy, Targeted therapies, Chemotherapy	One Month	Yes, apps, video conferencing platforms

NP: Not Reported FT: Full time employment PT: Part time Employment

#### 7.3.1. Experiences with CH technologies.

The majority of participants reported some level of engagement (experience) with CH technologies during their cancer care journey. While the focus was on post treatment care, some participants discussed their experiences with CH during their treatment. CH technologies referenced in the interviews ranged from attending and participating in support group and survivorship programs via video conferencing platforms like Zoom, which were widely used for support groups, physiotherapy sessions, and consultations, to various apps and electronic health records that facilitated health monitoring and communication with healthcare providers. For instance, Megan highlighted the utility of her Apple Watch in adhering to exercise guidelines posttreatment, while Emily and Irene found value in online support groups like the CTS programme and the ARC Cancer Support Services. Participants also reported using more conventional communicative tools such as WhatsApp to maintain contact with their care teams, as noted by Samuel, who appreciated the ability to consult with his stoma nurse remotely. However, not all participants had extensive experience with CH technologies; some, like Brady, relied entirely on in-person care. Overall, of the 15 participants, 11 had some experience with CH, highlighting its growing but uneven adoption.

#### **7.3.2. Themes**

Reflexive thematic analysis was used to develop six interconnected themes reflecting participants' experiences, and the benefits, enablers, and challenges of CH technologies. Access as agency highlighted systemic inequities in digital literacy and infrastructure, particularly in rural areas, shaping participants' engagement and emphasizing the need for equitable access. Negotiating holistic support explored CH's role in providing emotional and peer support while revealing tensions in maintaining personal connection within virtual care. Seamless or fragmented care highlighted CH's ability to enhance communication and continuity of care but exposed systemic disintegration, undermining its potential. Empowerment or dependency reflected participants' experiences of self-management and shared decision-making, while cautioning against over-reliance and the labour of self-monitoring. Trust and reluctance revealed how privacy concerns, technological hesitancy, and skepticism slowed adoption, emphasizing the need for transparent, patient-centered design. Finally, harnessing the power of knowledge revealed how raising awareness, enhancing digital literacy, using

local resources like libraries and learning from lived and collective experiences like COVID-19 would be beneficial in fostering CH adoption and meaningful use. Below, these themes and related subthemes are described with illustrative excerpts from the interviews with pseudonyms used. Additional quotes supporting each theme and subthemes are included in *Appendix 7*.

#### 7.3.2.1. Access as agency

A foundational theme across participants was access to CH technologies, which extends beyond physical availability to encompass individuals' ability to engage meaningfully with the technologies. This theme reflected the digital divide and its implications, highlighting the socio-technical interplay of digital literacy, infrastructure, and design as mediators of participants' sense of agency in managing their care. Agency, in this context denotes the inherent power individuals possess to make choices and take action, thereby shaping both their own lives and the social structures surrounding them.

#### a) Literacy as agency

Digital literacy was identified as a fundamental determinant of participants' ability to engage in CH effectively. Digital literacy is not just a skill but a form of power that determines whether participants perceive CH as enabling or alienating. Participants who felt confident in navigating the technology reported feeling empowered and comfortable in using it.

If you understand it, it's easy...it's easy for me to sit back here this morning talking to you. Because I'm feeling relaxed. I'm not worried. (David)

Digital literacy challenges were compounded by generational divides, with older participants expressing difficulty adapting to new technologies.

I suppose we're in transition, because some people of my age and, you know, whatever, older around my age anyway, we're not used to communicating, communicating with people via Zoom and whatever. (Jessica)

# b) Infrastructure as a reflection of equity.

Connectivity and digital infrastructure revealed stark geographic and economic inequities that participants face. Infrastructure gaps exacerbated pre-existing healthcare inequities, making CH a potential amplifier of disparity. While participants with stable broadband felt supported, particularly those in urban areas, those in rural Ireland or underserved areas encountered barriers.

Especially in rural locations, where it's very hard to get coverage and ultimately, you know, yeah, so you're basing it on, like, your kind of mobile data...So like, say, the (Cancer) Thrive and Survive can be over two hours. Yeah, you have to either do it in person or we get the APP digital in the household. (Irene)

Participants with good connectivity experienced no difficulties in engaging in CH.

I [didn't] have any difficulty because I have a good broadband connection. Participants were participating by phone. And I could see that they were coming and going. For these facilities to work a good broadband connection is essential, or good connectivity is essential. (David)

Further, economic constraints were a significant barrier, with participants emphasizing the high cost of devices and subscriptions as limiting access to CH.

..it's not cheap. When you think about if you're paying for other things, and I have my Apple Watch, again, not cheap, I have an iPhone, again, not cheap. And I have the laptop, and none of those things are cheap. (Megan)

#### c) Design for all, or design for some?

Participants valued intuitive, user-centered designs, but these advantages were only realized by those who already had access and literacy.

I think (it's) simple enough (the app), it's very easy to use. Yeah, it's just very intuitive. And it just does it all for you on the watch. And then it sends your trends to the app, or you can look it up yourself or to just send it to your phone every so often (Megan)

Designing for simplicity was reported as insufficient without addressing systemic barriers that exclude certain demographics. Thus, participants emphasised the need to design technologies that people really need, and with the user in mind.

I think it's important to focus on what people want, not designing something that may be wonderful, that nobody needs or wants. Yeah, but if you know, you know, that there are specific needs, in particular communities, or groups of people. (David)

This also includes technologies that are accessible to everyone, including those living with disabilities.

Equitable as in accessible to everybody, regardless of your background, just status your financial ability, your physical ability, and so on. So just. Yeah, I think it should be universally available as well. As all healthcare really should be (Daniel)

# 7.3.2.2. Negotiating holistic support

This theme highlights CH's potential to facilitate holistic support while uncovering the limitations of digital-only care in addressing the psychosocial needs. Participants narratives highlighted the dual role of CH technologies in facilitating holistic support including addressing psychosocial needs, offering emotional support, and fostering connections with peers and HCPs. However, participants also described the limitations of digital modalities, particularly limitations to fully emulate the depth of interpersonal interactions and relational support inherent in face-to-face care. They suggested a hybrid approach as an alternative.

#### (a) Emotional connections or surface-level support?

Participants noted that CH facilitated much-needed emotional and psychological support, particularly during times or periods of isolation and when in-person connected was impossible. Some participants found the support facilitated through CH programmes particularly useful during the early phases of survivorship.

Well, in the early six months. Now, that's when I was on the actual intravenous chemo, and it was very, very strong. I was very kind of vulnerable, obviously, medically, because I was on very strong chemo, and I couldn't go out because of Covid, it's like a treatment, ... So it was good to be able to connect with somebody in the outside world, when you're stuck in the house, because all your life, as you know, it has just gone (Irene)

And it was just I felt like at a time when you're fairly isolated, you're not at work, all of that you're still able to link in with other people. So, I really feel, I really feel that those programmes helped me get through it. (Megan)

Further, participants noted the assurance that comes from knowing that services actually exist, and they can avail of them when needed via the CH technologies. This is particularly in relation to information needs.

So there is a certain comfort in the knowledge that those facilities are there if I feel that I need them and its easier than having to go and research and explore for myself, at least I know a starting point that if I need information from the Irish Cancer Society, I can contact them, and they can point me in the direction of certain groups or apps and so on. You know that there is comfort knowing that they're there, if I feel that I need them. (David)

However, while CH delivered programmes and support served as a lifeline for some, its virtual nature risks reducing support to transactional or impersonal interactions.

.. and so the connection, the personal connection is not there. And, you know, somebody doesn't know me. So, it's very hard to have a genuine conversation about your own health, because I think there's more to the person than, you know, just what presenting, you're presenting in terms of the disease (Jessica).

I appreciate, and I can see the benefits of technology in medicine. But for, for my own personal opinion is that there, there it doesn't compare to actually meeting somebody in person. There's no doubt about that (Brady)

## (b) Virtual peer support: A double-edged sword

Virtual peer groups fostered solidarity, but for some, these spaces became emotionally taxing, especially when group dynamics were not well managed. If the virtual peer support groups are not well facilitated, they could create a paradoxical space where shared experiences can both alleviate and amplify distress.

Some of them were in a very dark place and really did need help. And I don't know, I don't think we had the qualifications. While you're listening to one another, I don't think they had backup support, what you're going through your own, and you really can't take on somebody else's (Emily)

This experience could be made worse if the virtual platform does not offer a safe psychological space for all the participants or if the group dynamics are not well balanced.

And it was facilitated by psychologists actually, our breakout rooms, I was really surprised. I'm a psychologist myself. So, you know, I know this stuff. I was really surprised they, they kind of didn't seem to be in control of it. So, you'd have one person talking a lot, and then another person talking a lot. And then the next week could be the same people. And it was really like they were talking to each other. Under us just like bystanders. And that's not a safe space, psychologically, you don't feel involved in the conversation. And you don't really know who you're talking to (Megan)

..they didn't talk to, like some of them were, they were all different ages, there was one young girl who, because of her cancer, would never have children. And she was like, in her late 20s. So that was horrendous for her. And then there was those that have children growing up, and they couldn't, the children couldn't cope, you know, there was me that past having children. So, it was completely different (Emily)

#### (c) Beyond medicalization: addressing the person, not the disease

While participants appreciated CH as valuable avenue to facilitate psychosocial support, they called for care models that prioritized emotional and practical well-being alongside medical treatment. Some criticised the medical model's narrow scope,

acknowledging that indeed, emotional needs are sometimes more overwhelming than the physical disease itself.

I liked the interaction with the hospital.... Sometimes the medical side of it is the least side that's caused the problem. Sometimes the emotional side of us coping with the change in life, everything like that is, is something that you'd like, but they're just focused on you're getting this much chemo, and that's it, you're out, and they don't have time to talk. (Rachel)

...psychosocial needs, they were met well in terms of support around the ongoing aspects of having cancer, the treatments, you know, the side effects, the fatigue, all have that and the trauma and also the ARC menopause survivorship program was really good and really a lot of experts very good again and all online.....and it was really good. (Megan).

## (d) The hybrid model as a middle ground

Participants advocated for a hybrid approach, combining virtual tools with inperson care to balance efficiency with human connection. They emphasized that CH technologies should complement, and not replace, human interactions, thereby addressing diverse patient needs.

I go back to my own experience, that I was given examples that I could see videos, that I could anticipate what it would be like, that really helps I think, for people to kind of see, well, this is what could work. And I do think that the hybrid combination approach of real person, and online, yeah, would be the best way forward to ally a lot of these fears. (Laura)

#### 7.3.2.3 Seamless or fragmented? The realities of digital care pathways

While participants appreciated the convenience of CH, they also highlighted systemic gaps in integration, exposing a mismatch between the promise and reality of seamless care. CH tools were valued for reducing logistical burdens, such as travel for appointments, and allowed participants to engage with HCPs more flexibly. However, despite their potential, participants also identified significant gaps in the integration of CH systems, highlighting a disconnect between the promise of seamless care and the fragmented realities they encountered. Issues such as uncoordinated EHRs and inconsistent communication across HCPs undermined the continuity and effectiveness of care, highlighting systemic inefficiencies in CH implementation. For instance, participants described scenarios where EHRs were not accessible across healthcare providers, requiring them to act as intermediaries and share information manually. This lack of interoperability undermined CH's potential for improving care continuity.

#### (a) Convenience and flexibility in accessing care

CH was valued in that it reduced logistical burdens and increased access to services.

So basically, most of last year, I was in a lot of pain, and I was quite, I wasn't really able to do much, especially drive. So there was a limited amount of things I could access. So, it was great, really, really good to be able to just log on. So that was brilliant, it was much, much less stressful, much less tiring, but you actually got the same kind of level of support without having to leave the house. (Megan)

However, for others, convenience and connection were noted to exist in tension, with CH often prioritizing efficiency over emotional resonance.

..it was convenient, as I understood the context of COVID. But I would have been happier, had I been able to go to the physiotherapy class. Perhaps, you know, see more in person. It probably would have been demonstrated and have a better opportunity to put questions at that probably, informally talk a little bit more to some of the other men who were involved (David)

# (b) Communication as empowerment

Participants felt empowered by CH's ability to enhance communication with providers, yet this was contingent on their capacity to use these tools effectively. CH technologies can democratize healthcare, but their impact is mediated by individual and systemic competencies.

The main thing from my point of view in my mental state or well-being was to be able to have the language, the terminology, to discuss things with my oncologist or with the nurses that I was a bit old or familiar, that from the research I knew what to call things or how to describe things or. I felt more informed. (Samuel)

#### (c) Consistency and continuity of care

Participants appreciated for the standardization and reliability provided by CH technologies. For instance, CH tools ensured the use of consistent protocols, tests and evaluation measures, reducing subjectivity in care. Participants valued the role of CH in maintaining accurate medical histories, supporting informed decision-making, and minimizing errors. This continuity was particularly reassuring for those navigating complex survivorship needs, as it aligned care with best practices and evidence-based guidelines. While technology's consistency was praised, participants emphasized the need for human oversight to address individual nuances not captured by standardized approaches.

I guess the final thing is the benefit of technology is that we have accuracy and consistency. And standardization. So, a lot of medical care is subjective ... But the tech,

that's fine, they need that as well. But part of the benefit of technology is that things are consistent. So, they're using the same standardised test, the same measures of evaluation. And that puts into context your case history. That is standardised. (Laura)

# (d) Fragmentation despite digital promise.

Participants frequently encountered disjointed systems where CH tools failed to bridge institutional silos, undermining continuity of care.

Well, one thing I found surprising over the years was how hospitals have technology and have all.. yet they do not have your records [together], like I've got records in XX clinic. My operation, my procedure for my cancer removal took place in YY. XX and the YY do not talk to each other. It's like starting off afresh. (Samuel)

In the midst of technology advancements, the lack of integration of services was reported as particularly very frustrating.

I think that is one of the most frustrating things in the whole health service, that blood tests or anything done in one area, it should be a relatively simple matter that that information will be available in some network or whatever (David)

The integration of various health services into a single platform was seen as beneficial for comprehensive care. Participants recommended a centralised patient information platform in the form of an app that would serve as a 'one stop shop' to ensure integrated care.

I showed up for appointments that I was told were made when they hadn't been made. I should have cardiac scan done, and cardiologist hadn't heard anything about me. You know, things like that. Yeah, so I think yeah, if they had a patient portal or an app, it means that firstly, you could see what has been scheduled what hasn't, and chase what hasn't or what's been missed or done wrong (Mariah).

#### 7.3.2.4 Empowerment or Dependency? The ambiguities of digital autonomy

This theme highlights the dual-edged nature of digital autonomy in CH technologies. Participants reported that CH positioned them as active agents in their care, but this empowerment came with hidden labour and the risk of over-reliance. While these tools empowered participants to take control of their care, they also shift a significant portion of care responsibilities onto individuals, potentially amplifying emotional and cognitive burdens to some.

#### (a) Self-monitoring as liberation or labour

CH enhanced self-management through self-monitoring tools which enabled participants to track their health, but this also shifted caregiving responsibilities onto patients. While empowering, self-monitoring risks burdening patients with tasks traditionally managed by providers.

I started noticing being very tired or easily bruising rather than trying to wait sometimes months to get a doctor's appointment. I could make an appointment, I do it online and actually take the camera and show the doctor, look, this is the bruise that's appearing on my arm. Or I could do it, they sent me like home diagnostic tests, you know, where you can do samples of urine and samples of blood, and then send that in. (Laura)

# (b) Decision-making as empowerment or pressure

CH technologies facilitated informed decision-making, but participants faced challenges balancing newfound autonomy with the weight of medical decisions. This suggests that while CH democratizes care decisions, it may also complicate the emotional and cognitive demands on (or for) patients.

And then looking at the possibility of it reoccurring or how prone might my colon be to developing more cancerous polyps and discussing that, being able to discuss my findings with the oncologist and say, ask questions, and informed me to ask questions that I felt were pertinent to my case. (Samuel)

#### 7.3.2.5 Trust and reluctance: narrowing the digital divide

This theme explores the barriers that hinder the CH adoption among PLWBC. It encapsulates the various obstacles participants face, from technological hesitancy to privacy concerns. Participants' willingness to adopt CH was mediated by trust, skepticism, and systemic inequities, revealing barriers to widespread acceptance. Resistance to CH was perceived to reflect the broader anxieties about technological and healthcare systems rather than individual shortcomings.

# (a) Tech hesitancy as resistance

Participants resisted CH due to fear, unfamiliarity, and perceived complexity, compounded by the stress of managing illness.

Well, I think this or the fear, first of all, lack of familiarity. And when people are accessing these technologies, they're probably stressed and worried because of whatever condition they have. If there are additional technological problems, that adds to the stress. (David).

In some cases, this hesitancy was informed by the belief that virtual health may mask the actual symptoms and lack the personal touch.

I think that technology can mask a lot. It's like, if we see any other form of safety, look at social media, people only show the part/good pictures of themselves. You know, so you, and people want their doctors to like them, they want them to think they're good patients. So they might put the best vote no, everything's fine. (Laura)

## (b) Privacy as a precarious trade-off

Concerns about data privacy and security deterred adoption, revealing a trust gap in digital health systems overall. These privacy concerns underscore the fragile nature of trust in digital healthcare.

So, from my point of view, I wouldn't really trust it that much. Even though I trust the phone for other things, I trust it to get me to destination as they say, alright, use it for google maps. But in terms of health, I'm not sure I. Yeah, you know, I can I sometimes I think it's a bit intrusive. (Jessica)

# (c) Dependency on technology: A new vulnerability?

Participants criticized over-reliance on CH, fearing it could replace meaningful human interactions and create dependency. Participants noted that CH's reliance risks fostering dependency while eroding the interpersonal relationships that underpin holistic care.

You know, the danger, I think, though, of these online platforms, too, is that for a lot of people, they become a substitute for support they have in real life. So, and some people are really needy, they need a lot of attention. And in action, it falls into such a stream, it's almost like a psychological dependency. And that's not good. (Laura)

#### 7.3.2.6. The power of knowledge and awareness.

This theme emphasizes the foundational role of knowledge and awareness in enabling meaningful engagement with CH. Participants reported that you cannot engage if you do not know about it. They identified gaps in information dissemination, the need for targeted education, and the role of collective experiences like COVID-19 in accelerating CH adoption. Participants insights further revealed the interplay between individual capability, systemic support, and societal influences in shaping awareness. Awareness was contextualised as not simply about providing information; but about creating opportunities for individuals to perceive the relevance and utility of CH within their unique contexts. Enhancing digital literacy reflected a systemic responsibility to

address digital divides, not just as a technical deficit but as embedded inequalities shaped by socioeconomic, geographic, and health-related factors.

## (a) Raising awareness to overcome the unknown

Participants described how limited awareness of CH services hindered their ability to benefit from them. Despite the availability of resources, participants often felt these were not adequately promoted or accessible.

I think also Awareness. Like, you know, if we started with the research, if you can get direct correlations to show the benefits of the technology, the potential for technology, I think, then it's easier to get more people on board and involved, get more projects started. And, you know, I think that's, that's the kind of the first mountain to climb. (Daniel)

#### (b) Enhancing digital literacy as an empowerment tool

Digital literacy was framed as a critical enabler of CH engagement. Participants advocated for tailored workshops, such as rural library initiatives, and personalized training to equip users with the skills needed to navigate CH technologies confidently.

As you embark on your treatment, and now I know the focus is that you don't want to be learning new skills really, when you're sick and trying to, but at least there should be that that support. Or even when you're finished your treatment you would do a course on bringing you up to speed with technology. And if you can't afford it, that your local library that it's accessible there. And so making all those connections (Emma)

Participants further highlighted the need for tailored educational resources that address generational differences in learning styles and the financial realities of underserved populations

I'm 44, and the digital, there's already a digital divide between me and the school leavers. In terms of how they consume information and their attention span and, you know, so that they go for the short videos (Mariah)

#### (c) The role of lived experience in awareness campaigns

Authenticity was highlighted as crucial in promoting CH. Participants suggested that campaigns led by individuals with lived experience (of using CH in their care) could foster trust and relatability, bridging gaps between service providers and users. Including voices of lived experience in awareness efforts challenges

hierarchical communication approaches, placing individuals impacted by CH at the centre of educational strategies.

You have to have a public campaign. And you have to have real people who have experienced talk about it, I think they don't, there's no point in the Department of Health and the minister talking about it, if he hasn't the lived experience, nobody cares what he has to say. (Emily)

#### d) COVID-19 as a litmus test

The COVID-19 pandemic was a turning point, rapidly normalizing digital tools in healthcare. It served as a collective experiment, demonstrating the potential of CH while also exposing gaps in preparedness and equitable implementation. This highlights the importance of maintaining momentum post-pandemic to institutionalize CH within healthcare systems. Participants noted how the crisis underscored the feasibility and necessity of CH, fostering broader acceptance and integration.

A lot of stuff was online. And there's a lot of resources. Now there are things like support groups that are online. There's a phone service where they ring you up and talk to you about any issues you're having, or they'll give advice and so on. So, now it's a bit better. I think it's definitely COVID is causing us to transition to embrace this technology bit more. (Daniel)

## 7.4. Discussion

This study explored the experiences, benefits, challenges, and opportunities associated with connected health in post treatment cancer survivorship care. Six themes were identified, offering nuanced insights into CH technologies role in supporting cancer survivorship. The findings underscore the potential of CH in survivorship care but also highlight barriers and tensions that require systemic attention within the Irish context. While these findings point to the potential of CH to significantly enhance accessibility to care, facilitate psychosocial and peer support, and empower patients through improved self-management, benefits are tempered by persistent barriers such as access and equity gaps. Further, findings highlight the need for a user centered approach in the design and implementation of CH technologies, ensuring that they complement, rather than replace, the empathy and personalized care that are of critical importance to patients.

While this is the first qualitative analysis of the experience of CH technologies among adult PLWBC in Ireland, findings echo and align with previous research. For

example, in the context of families of paediatric cancer in Ireland, Delemere et al., (2022) stressed the need to tailor CH interventions to individual needs and empower patients through knowledge, while also acknowledging barriers such as trust, rapid technological advancements, and accessibility challenges. Similarly, O'Brien et al. demonstrated the benefits of a CH rehabilitation programme in supporting physical and psychosocial recovery in upper gastrointestinal cancer, but also highlighted the continued importance of in-person care alongside digital interventions (O'Brien et al., 2023).

The varied engagement with CH among our sample reflects the ongoing digitalization efforts within the Irish healthcare system (HSE, 2024a), where digital literacy and infrastructure continue to shape patient experiences. While participants reported engaging in technologies such as video conferencing and general well-being apps, their engagement was generally limited to non-cancer specific applications, echoing findings from a recent systematic review that highlighted the limited availability of cancer-specific apps overall (D. J. Lu et al., 2021). Furthermore, participants reported limited engagement with technologies such as EHRs, despite their established role in cancer care globally (Fisch et al., 2016). This limited uptake underscores the slow pace of digital health adoption in Ireland, which is surprising in the context of national digital commitments (HSE, 2024a). Prioritization of integration of foundational CH technologies, such as EHRs, to improve patient care and outcomes in the Irish context is needed.

Access to CH was identified as a foundational theme, highlighting inequalities shaped by disparities in digital literacy, connectivity and economic constraints. Limited broadband access, particularly in the rural areas restricted engagement, as did the cost of devices and internet services. Older participants reported difficulties in adapting to new technologies, reflecting a generational divide and mirroring broader trends in digital health (Chikomba et al., 2023; Coca et al., 2022), where rural-urban and socioeconomic disparities persist, as highlighted in recent work exploring access to services among men living with prostate cancer in Ireland (Gordon et al., 2024). This resonates with the SEM model described in *Chapter 1*, where structural factors such as internet access and digital literacy were identified as determinants of CH engagement. The finding that some participants lacked the tools or skills needed to fully participate in CH supports calls for equity-focused digital health strategies in Irish survivorship care. Moreover, this mirrors *Chapter 6*'s finding that rural residents overwhelmingly preferred in-person delivery, potentially reflecting infrastructural limitations and reinforcing digital exclusion.

Addressing these challenges requires enhancing broadband infrastructure and providing targeted training, especially for older individuals less familiar with CH. Furthermore, echoing previous research emphasizing self-efficacy in technology adoption within cancer care (Chapter 3), participants' comfort and confidence with technology influenced their engagement. Moreover, the TAM identifies user-friendliness and intuitive CH platforms as essential to improve adoption (Lun et al., 2024).

In Ireland, amidst ongoing digitalization efforts, targeted interventions like subsidized devices and app subscriptions, broadband expansion in rural areas, and tailored digital literacy programmes are crucial for realizing the potential of digital health. This aligns with research emphasizing the importance of digital literacy and reliable infrastructure for successful CH implementation (Golinelli et al., 2020; Kemp et al., 2021).

CH technologies demonstrated value in addressing emotional, psychosocial and information needs, particularly during periods of isolation through virtual support groups and survivorship programmes such as the CTS and the ARC. By offering a sense of connection and access to professional resources, these technologies addressed emotional needs crucial in the initial survivorship phase, when patients often face physical limitations and grapple with the emotional impact of diagnosis and treatment, potentially hindering their engagement with the outside world. The provision of psychosocial support through CH platforms aligns with the increasing recognition of psychological well-being's importance in overall health outcomes (Gao et al., 2010; O'Connor et al., 2019) and resonates with global efforts to integrate such support into cancer care, particularly in underserved areas (P. Wang et al., 2016). However, participants in the current study noted that virtual interactions often lacked the depth and "personal touch" of in-person engagements, highlighting a tension in digital health, specifically survivorship care: balancing the efficacy of CH platforms with the relational depth required for holistic care.

There were also concerns around psychological safety spaces, a prerequisite for authentic engagement in virtual spaces (O'Donnell et al., 2024). While certain aspects of in-person care cannot be fully replicated, CH remains a viable option for delivering psychosocial supports (study 1) as demonstrated in other studies (Delemere et al., 2022; O'Brien et al., 2023) with some participants finding comfort simply in the availability of these supports. Moreover, it is likely that some of interventions, originally designed for in-person delivery, may lack comprehensive adaptation for CH delivery. A recent study highlighted considerations for effective digital adaptation, including end-user

involvement throughout the adaptation process (Cooney et al., 2024). Understanding the original intervention design, the context of its digital application, and the unique motivational needs of digital intervention recipients are crucial for successful implementation.

Participants appreciated CH's ability to enhance convenience, improve communication with HCPs, and facilitate remote consultations. This underscores the value that participants placed on the convenience and accessibility provided by CH, and echo findings from study 5 where convenience was a key motivation to CH. This is particularly beneficial for individuals facing physical mobility challenges or those required to travel long distances to access care and support. This issue is particularly relevant in the Irish context, where public transportation infrastructure remains underdeveloped in many areas, leading to significant reliance on private vehicles. According to the National Travel Survey 2019, private cars accounted for 73.7% of all journeys (as drivers or passengers), while public transport represented just 4.8%, underscoring the heavy dependence on private cars for mobility in Ireland, more so in rural areas (Social Justice Ireland, 2022). This "forced car dependency" (Carroll et al., 2021) poses substantial challenges for PLWBC, who may be unable to drive due to the physical effects of cancer, treatment side effects, or fatigue. Additionally, practical issues such as limited availability of parking near healthcare facilities further exacerbate barriers to accessing care.

Frustrations with systemic fragmentation in the health service, such as the lack of integration between EHRs across healthcare providers was noted in this study. This disjointedness undermined CH's potential to streamline care and reduce patient burden, particularly in survivorship care, where multidisciplinary coordination is essential (Elnahal et al., 2013). These findings suggest the need for centralized interoperable digital platforms that enhance continuity of care. Advancing efforts to integrate CH technologies within existing healthcare infrastructure, such as through the national eHealth framework (HSE, 2024a), could address these fragmentation issues and improve patient experiences in Ireland.

CH technologies empowered participants to monitor their health, adhere to treatment recommendations, and engage in shared decision-making. For example, wearable devices were valued for their ability to track activity levels and support adherence to exercise regimens. However, participants also expressed concerns about the potential burden of over-reliance on self-management tools, particularly in the context of

complex health needs as is the cancer in cancer. This finding reflects broader debates in healthcare regarding the risks of shifting care responsibilities disproportionately onto patients (Lupton, 2013, 2014). The tension between empowerment or dependency offers a nuanced view of patient agency. For some, CH enabled greater self-management and involvement in decisions, aligning with constructs in the TAM, such as perceived usefulness and perceived ease of use, as discussed in *Chapter 3*. However, the data also illustrate that empowerment through CH can slide into *responsibilisation* if systems shift the burden of care without adequate support, as described in *Chapter 1*, *section 1.3* on healthcare digitalisation. This concern is echoed in Chapter 5, where unmet needs persist, even after participation in structured support services. Qualitative data in this chapter suggest that CH interventions must be carefully framed and supported to avoid burdening patients or reducing care to self-monitoring and digital check-ins.

Thus, effective integration of CH technologies in survivorship care requires striking a balance between empowering individuals and providing adequate professional support, ensuring that CH complements rather than replaces human care. Hybrid models, for instance, that allow for both CH and in-person care were emphasized by participants. Hybrid approach integrates the strengths of both in-person and virtual care (Al-Razouki & Smith, 2022). This model enables HCPs and patients to achieve desired outcomes through tailored approaches that suit diverse circumstances and care settings The effectiveness of hybrid care models hinges on optimizing clinical outcomes, minimizing staff burden, and enhancing patient experiences (Akbarbegloo et al., 2020). The central challenge lies in finding the optimal balance and mix between CH and in-person care, requiring ongoing development and refinement of care pathways to ensure effective implementation that meets diverse patient needs while maintaining high-quality care.

Despite mixed experiences and evident benefits, several barriers to the adoption of CH in cancer care were raised. Trust emerged as a central determinant of CH adoption, with privacy concerns, technological hesitancy, and skepticism about the impersonality of digital care acting as significant barriers. Participants were wary of data security risks and the intrusive nature of certain CH tools, which limited their willingness to engage fully. This reflects challenges identified in Chapter 3's analysis of HINTS data, where adoption of CH technologies was influenced not only by demographics but also by psychological factors such as self-efficacy. Moreover, this study's inclusion of three participants with no prior CH experience provided valuable contrast, illustrating that

hesitancy often stems from more than just digital skill deficits, it is also shaped by beliefs, values, and past experiences with healthcare systems.

This concern is particularly relevant in the Irish context, where recent data breaches within the health service have likely heightened distrust in digital platforms (Gallagher, 2021) but also globally where personal data privacy has been a central topic of debate in the widely expanding artificial intelligence space (Bartlett, 2021; Oladoyinbo et al., 2024). These concerns highlight the importance of transparent data governance, user-centered design, and clear communication about the benefits and limitations of CH. The need for strong privacy frameworks and regulatory measures is well-established in the literature (Sharma, 2019), particularly given that personal data protection is a fundamental right in Europe (Voigt & Von Dem Bussche, 2017). Thus, fostering trust will require collaboration between policymakers, HCPs, and technology developers to ensure that CH technologies are secure, inclusive, and aligned with patient needs. Technophobia, often rooted in a lack of familiarity (Khasawneh, 2018) was unsurprising, given that many of the study's participants were older and may not have had prior exposure to such technologies. Moreover, "techno-scepticism", where over-reliance on technology could potentially lead to psychological dependency were raised, underscoring the need to see CH as a supplement to, rather than a replacement for, in-person care. These findings suggest that while CH holds significant promise, both personal and systemic barriers must be addressed to fully realize its potential.

Participants reported limited awareness of CH options, which hindered adoption despite their potential benefits. Knowledge and awareness emerged as critical enablers of CH engagement, emphasizing the need for effective dissemination of information about available technologies. Participants' increased exposure to CH and digital tools during this period contributed to greater acceptance and comfort, findings that align with earlier arguments in *Chapter 1 and Chapter 2* regarding the pandemic as accelerant for digital transformation globally, and in Ireland *(Chapter 3)*. However, the findings also reinforce that awareness alone is insufficient; targeted training, clear communication, and accessible platforms are essential to meaningful and equitable adoption of CH. Tailored educational efforts, including digital literacy workshops, utilising local library and community-based initiatives, were suggested as solutions to bridge these gaps. This aligns with the importance of context-sensitive education in healthcare, particularly in addressing the generational digital divide (Coca et al., 2022). While COVID-19 pandemic was highlighted as a pivotal moment that normalized CH technologies, sustaining this

momentum requires deliberate efforts to integrate CH into routine care, particularly in the Irish context, where community engagement has historically played a vital role in public health initiatives (McEvoy & MacFarlane, 2013).

Moreover, engaging patients and the public in this awareness campaigns process ensures that the resulting technologies are inclusive, accessible, and effectively tailored to the needs of their users. This approach is not only a best practice in design (Abras et al., 2004; Omaghomi et al., 2024) but is also essential for creating CH solutions that truly address patient needs while maintaining a personal and empathetic touch in care delivery. The involvement of caregivers, including family members, emerged as vital, especially for those patients who struggle to engage with digital tools independently. Caregivers are integral in holistic survivorship care (Darley et al., 2021; Maguire et al., 2018).

#### 7.4.1. Strengths and limitations

This study used a qualitative descriptive design, appropriate for the broad aim of exploring experiences and perspectives in a naturalistic and low-inference manner. While most participants had direct experience with CH, three did not. Their inclusion allowed for a more holistic understanding of barriers to CH engagement and aligned with the study's aim to explore both experiences and perceptions. Importantly, participants who had not used CH technologies shared their reasons and recommendations to enhance future usage. The inclusion of participants from urban and rural settings, with varying levels of digital literacy, added depth to the findings. A single semi-structured interview guide was used across all interviews, though probes were adjusted depending on CH experience. Limitations include the small sample size, lack of triangulation with HCP's perspectives, and reliance on self-reported data. However, the study provides a rich, contextualised understanding that complements the broader quantitative findings of this thesis. In addition, most participants had tertiary education and urban healthcare access, potentially limiting generalizability to less advantaged populations. Future research should include larger, more diverse samples to further explore the intersection of CH technologies and social determinants of health.

Given that most interviews were conducted via technology (Ms Teams) it is likely that participants were already more comfortable with CH. Furthermore, advertisement for the study was mainly through digital platforms, and this may have excluded the perspectives of individuals lacking access to these technologies, and thus the potential bias of using technology to study technology.

#### 7.5. Conclusion

This qualitative study provided valuable insights into the lived experiences of PLWBC in Ireland regarding their engagement with CH technologies. Through six interrelated themes, it highlighted the dynamic and complex ways in which CH can support or hinder psychosocial wellbeing and survivorship care. The findings underscore the need for equitable digital infrastructure, patient-centred design, and systemic integration of CH into survivorship care pathways. When viewed alongside earlier chapters, this study offers a complementary perspective that informs the future implementation of CH interventions tailored to the unique needs, preferences, and contexts of cancer survivors in Ireland. The study underscores the significant promise that CH technologies hold in improving cancer survivorship care by facilitating psychological support, empowering patients, and enhancing care continuity. However, realizing CH's full potential requires overcoming systemic (e.g., cost, connectivity), demographic (e.g., digital literacy), and relational (e.g., depersonalization) barriers that hinder equitable access and adoption. Patient-centric, inclusive strategies are crucial for addressing these challenges. In Ireland, integrating CH within existing healthcare frameworks, engaging communities, and addressing disparities in access and digital literacy could foster a more inclusive and effective survivorship care model. Prioritizing equity, trust, and relational care within CH technologies will likely better equip PLWBC to navigate the complexities of survivorship.

Upon completing the studies, an informal narrative synthesis approach was utilised to integrate findings from all the studies. The overarching aim was to summarize key learnings and identify trends and insights aligned with the study objectives. To begin, the researcher thoroughly reviewed each study to enhance familiarity and extract the main findings. These findings were then consolidated into a single document, which was subsequently analysed to identify areas of overlap, divergence, and emerging trends. The following final chapter presents a detailed discussion of this synthesis, highlighting key conclusions, offering recommendations, and identifying potential areas for future research.

# **Chapter 8**

**Discussion, Recommendations and Conclusion** 

#### **8.1. Discussion Overview**

This thesis explored the role of connected health technologies in supporting the psychosocial well-being and quality of life among people living with and beyond cancer. Drawing on six studies, including a systematic literature review and meta-analysis (Chapter 2, study 1), an analysis of population level survey data from the US (Chapter 3, study 2), a cross sectional study evaluating a CH delivered cancer survivorship programme (CTS) in Ireland, presented as two distinct chapters (Chapter 4 and 5, study 3a and 3b respectively), a post-programme participant-reported outcomes comparative study of online versus in person CTS (Chapter 6, study 4), and a qualitative study of PLWBC experiences (Chapter 7, study 5), this thesis examined how CH is used, its potential benefits, barriers and facilitators to implementation, and the contextual factors to its uptake in cancer survivorship in Ireland. This chapter synthesizes key findings in relation to the three overarching research objectives and considers implications for research, practice and policy while acknowledging the methodological and conceptual strengths and limitations of the included studies.

# 8.2. *Objective* 1. To examine how CH technologies may support psychological wellbeing and QoL among PLWBC

The first objective of this thesis was to examine how CH technologies may support psychosocial wellbeing, including anxiety, depression, and QoL among PLWBC. Findings across the studies in this thesis suggest that CH interventions may support aspects of psychosocial wellbeing and QoL, though causal conclusions cannot be drawn due to the largely observational and cross sectional designs employed in the quantitative studies.

Study 1, a systematic literature review and meta-analysis, synthesised international evidence and found that CH interventions produced moderate improvements in depression and anxiety symptoms compared to standard care. Further, thematic synthesis revealed that CH may enhance other aspects of psychosocial outcomes through improved information access, peer support, and self-management. In the Irish context, usability and acceptability of CH delivered survivorship interventions, as explored in Study 3a, were found to be high. Participants reported high satisfaction and perceived benefits in psychological wellbeing, QoL and self-management. This aligns with international literature in regard to CTS (National Library of Medicine, 2013; Risendal et

al., 2014), showing that well designed CH tools can promote engagement and autonomy in survivorship care. Yet, further analysis of this data, Study 3b revealed that unmet needs such as stress management and self-identity remained after participation in the programme, and QoL scores showed variation. However, given the absence of baseline data, it is not possible to attribute these outcomes to the CTS intervention. The findings instead speak to the persistence of psychosocial needs among PLWBC, suggesting that while CH may facilitate support, it cannot replace the broader system level responses to survivorship needs. When compared to in person delivery, as in Study 4, participants in both delivery modalities showed broadly similar levels of anxiety and depression and QoL domains, though individuals self-selected in modalities, thus limiting interpretation of comparative impact of delivery mode. Importantly, online participants valued the convenience that CH technologies offered. In addition to broadening participation, CH delivery of the CTS programme offered a crucial access point for individuals who might have otherwise been excluded due to logistical, geographic, or health-related barriers. As reported by participants in the qualitative study (study 5), several participants noted that without the option to participate remotely, they would not have been able to engage in the programme at all, whether due to travel distance, post-treatment fatigue, caregiving responsibilities, or other constraints.

These findings collectively demonstrate that CH appears to offer opportunities to support PLWBC by facilitating access to psychoeducational content, peer support and self-management strategies. These mechanisms align with Cohen's stress buffering hypothesis (Cohen & Wills, 1985), which posits that social and informational support can mitigate psychological distress, a top concern in cancer survivorship (Gao et al., 2010; Thakur et al., 2022), amidst the rising number of PLWBC in Ireland and globally (Bray et al., 2024). The findings also add to the growing adoption of technology to enhancing access to psycho oncological care (Shaffer et al., 2023), and align with WHO's global strategy on digital health (WHO, 2021a).

Overall, while CH holds promise, it cannot be seen as replacement for in person care or as universally suitable. For maximal benefit though, CH interventions should be integrated into broader survivorship pathways, tailored to users' digital literacy, emotional needs and cultural context. These findings underscore calls for flexible and adaptable survivorship interventions that can be tailored to the evolving needs of individuals across the cancer continuum. This is particularly important given that participants in this thesis, especially those in Study 3b, reported varying psychosocial and

practical needs. As such, survivorship care cannot be static, and digital interventions must be designed with responsiveness and adaptability in mind. Emotional labour associated with self-monitoring and digital navigation (as discussed in study 5) must be considered.

# 8.3. *Objective 2*. To identify factors influencing adoption and utilization of CH among PLWBC.

The second objective of this thesis was to identify the factors that influence the adoption and utilization of CH technologies among PLWBC. Understanding these factors is important to effectively implement these solutions in cancer survivorship care. Based on the findings from Study 2's secondary analysis of HINTS data and Study 4's post programme online versus in person CTS comparison, and qualitative accounts from study 5, the socioecological model lens was used to organise the multilevel factors influencing CH adoption.

# a) Individual level factors

Studies 2 and 5 suggest factors such as age, education, digital confidence, and health literacy influenced engagement with CH technologies. Younger, higher educated, and those digitally confident were more likely to engage with CH tools. In contrast, older PLWBC faced significant challenges related to digital literacy and technology adoption.

#### b) Interpersonal level factors

Study 3a highlighted the importance of peer support as a motivating factor for participation in the CTS programme. Participants valued the ability to connect with others who shared similar experiences, particularly through online support groups. Encouragement from peers, caregivers and HCPs, as explored in Study 5 played a role in shaping participants' attitudes towards CH. Positive reinforcements from peers and HCPs encouraged engagement, especially among hesitant users. However, the same study found that for some PLWBC, in-person interactions offered more meaningful social support than virtual ones, suggesting that face-to-face contact retains a unique value that CH technologies cannot fully replicate. In addition, the study found that if the online groups are not well facilitated, sharing of individual experiences could be emotionally draining to some of the participants. This highlights the importance of considering interpersonal dynamics and virtual psychological safety (O'Donnell et al., 2024) in CH implementation, ensuring that CH provides opportunities for meaningful social connections.

#### c) Organizational level factors

The availability of support programmes at local community cancer centres and the delivery preferences of programme coordinators influenced modality access (Study 4). Notably, rural residents were more likely to attend in person sessions, either due to connectivity limitations or the desire for person to person interactions. This finding challenges the assumption that CH inherently increases access in rural areas and reinforces the need for tailored community level implementation strategies. Additionally, interviews with PLWBC in Study 5 revealed that inconsistent integration of CH technologies by HCPs led to fragmented care experiences, emphasizing the need for organizational-level buy-in and consistency in promoting CH use among PLWBC. Indeed, prior work has reported that HCPs play a key role in adoption of CH technologies (Leigh & Ashall-Payne, 2019; Weik et al., 2024). The training provided to both patients and HCPs influenced the successful adoption of CH technologies. Participants indicated that clear guidance on using CH technologies and platforms facilitated their engagement, while insufficient training contributed to anxiety and reluctance. Further, findings from the open text responses in study 3a showed that participants appreciated the supports received by the CTS programmers, and this included technical supports and provision of hardcopy reading materials following the session completion. This points to the need for structured education and support initiatives within healthcare organizations to improve both patient and provider readiness to use CH.

#### d) System level factors

Broader digital infrastructure gaps, policy priorities and digital health disparities shaped both CH availability and uptake. Systemic barriers noted across the studies included limited rural broadband, fragmented data systems, and inequities in digital health literacy. Study 5, for instance, revealed that fragmentation in digital care pathways within the health service, such as the lack of interoperable EHRs, created significant barriers to continuity of care, that ironically CH is meant to address. In some cases, participants often had to manually relay information between HCPs and hospitals, which added to their burden, thereby limiting seamless integration of CH into their care. Considering the need for multidisciplinary teams in survivorship care, this finding calls for an urgent effort to address the clear lack of communication between different HCPs and hospitals.

Overall, these findings highlight the importance of system-wide digital integration to facilitate coordinated, patient-centered care, which is particularly relevant

to the Irish healthcare context (Delemere et al., 2022; Walsh et al., 2021), where fragmentation in services can undermine care quality. These findings underscore the importance of addressing infrastructural disparities to ensure equitable access to CH technologies across Ireland, particularly given the ongoing national healthcare digitalisation efforts. Notably, the 'Digital for Care' framework (HSE, 2024a), launched by the HSE sets out a national roadmap for digital transformation in healthcare. The framework aims to strengthen governance, interoperability, digital inclusion, and secure infrastructure across all care levels. With strategic pillars focused on person-centred care, equity of access, and integration of digital tools into clinical workflows, this framework has the potential to address many of the systemic gaps identified in this thesis. While slow implementation has already been pointed out (Burke et al., 2018; Thomas et al., 2021), this national commitment aligns well with the findings of this thesis, which highlight the need for patient-centred design, and interoperability to embed CH technologies meaningfully into survivorship care pathways. Failure to address these inequities amidst digitisation efforts may exacerbate the existing inequities, a phenomenon akin to what was described in the introduction chapter as the 'power of technology to empower and disempower' individuals. This remains a key concern in healthcare digitalization globally (Fareed et al., 2021; Helsper, 2017; S. Jiang & Liu, 2020b).

This multilayered understanding underscores that CH adoption is not solely an individual choice, but embedded within broader structural, policy and healthcare system dynamics. The SEM lens helps clarify how access and engagement are shaped by intersection of personal agency, service availability and systemic supports. Overall, efforts to promote CH integration must extend beyond technical training or tool provision. Digital inclusion policies must address infrastructure, education and equitable service design. Programmes such as the CTS should remain flexible to allow in person and CH options, ensuring user choice without widening disparities. This thesis reinforces the need for equitable CH rollout, acknowledging intersectional factors such as age, geography, literacy and socioeconomic status.

# 8.4 *Objective 3*. To explore barriers and facilitators to CH implementation in Irish survivorship care.

The final objective of the thesis was to explore barriers and facilitators to the implementation of CH in Irish cancer survivorship care. This objective was primarily explored through the qualitative study (Study 5) and supported by earlier chapters. While

<u>Davis et al.</u>, (1989)'s Technology Acceptance Model was utilised in the framing of this objective, particularly through the concepts as perceived usefulness and ease of use, this model is not applied rigidly. Instead, it provides a helpful lens to interpret the individual and systematic barriers, facilitators, influencing engagement with CH.

# 8.4.1 Barriers to CH implementation

## a) Digital divide and infrastructure gaps

The digital divide emerged as recurrent factor to CH adoption and use in Studies 1, 2, 4 and 5. Structural challenges such as limited broadband access, especially in the rural areas, and disparities in digital literacy and affordability of CH tools continue to hinder equitable access. Study 2 highlighted that older individuals with lower education levels and SES, and those from rural areas were less likely to engage with CH due to barriers related to access and literacy challenges, Study 4, found that rural participants opted for in person delivery, suggesting infrastructural and perhaps cultural barriers to CH use. Study 5 also emphasized the challenge of connectivity in rural areas, limiting access to CH services for individuals who would otherwise benefit from them. These findings reflect broader health inequities globally (as in the US, as seen in study 2) and Ireland (study 5), which have also been reported in other studies (Fareed et al., 2021a; S. Jiang & Liu, 2020), where disparities in digital access impact individuals' ability to engage in CH delivered interventions.

#### b) Technological hesitancy and burden

In study 5, participants expressed hesitancy to CH, stemming from privacy concerns, data security and technological fatigue. Some found the effort in logging in, troubleshooting and staying online engaged to be emotionally draining, highlighting a perceived lack of ease of use, and pointing to a form of emotional burden previously described. While in most studies self-management was highlighted as a beneficial aspect of CH technologies, Study 5 underscored the emotional labour associated with CH use, which was experienced by many participants as an additional burden rather than a benefit. Participants reported feeling overwhelmed by the expectation to monitor their health continuously, interpret data, and make informed decisions without adequate professional support. This highlights a fundamental challenge in digital health interventions. While self-management benefits in chronic disease management cannot be overemphasised, ensuring that CH does not inadvertently increase patient burden by shifting excessive responsibilities to individuals requires consideration in CH implementation.

From a sociotechnical point of view, continued debate is ongoing on these paradoxes of digital health, and the need for their careful consideration implementation of digital health solutions (Coetzer et al., 2024; Lupton, 2014). For example, while CH tools can empower patients by enhancing access to information, promoting self-management, and enabling more flexible care as seen in this thesis, other work has suggested that they may also introduce new burdens, such as the emotional labour of self-monitoring, managing multiple platforms, or increased anxiety due to frequent symptom tracking (Lupton, 2013; Scott Duncan et al., 2022).

Similarly, while CH promises greater efficiency and convenience in healthcare delivery, it can also erode personal connection and introduce feelings of isolation, especially when face-to-face support is replaced entirely by virtual formats as reported in recent research (Padalkar et al., 2024; Sinha et al., 2020). Moreover, while CH has the potential to improve access and equity, it can unintentionally widen the digital divide, particularly for older adults, individuals with limited digital literacy, or those in rural areas lacking adequate infrastructure. These tensions were evident in the current thesis, particularly in the qualitative findings of Study 5, where some participants found CH empowering and flexible, while others viewed it as impersonal or inaccessible. Addressing these paradoxes requires intentional design and implementation strategies that are sensitive to diverse user needs and must ensure CH is used to complement, not replace, human-centred care.

As argued in earlier in *Section 8.1.1*, CH should not be seen as a monolithic intervention, and it is essential to distinguish between its different functional applications, particularly in terms of their user demands and psychosocial impact. For instance, monitoring-oriented CH tools, such as remote symptom tracking, wearable health monitors, or self-reported outcome dashboards, may increase patients' sense of control over their health but also come with significant emotional labour (Lupton, 2013). For instance, these tools could heighten anxiety through constant awareness of one's health status, foster hypervigilance, and transfer a considerable amount of responsibility and burden onto the patient (Fiske et al., 2020; Scott Duncan et al., 2022). In contrast, social support—oriented CH programmes, such as the online CTS sessions, emphasize peer interaction, shared experiences, and facilitated group-based support. These modalities tend to be less burdensome and more empowering, particularly for individuals seeking connection and validation during survivorship, as seen in Study 3a and Study 4, where participants in the online CTS frequently cited the value of shared learning, emotional

support, and normalisation of fears within the CTS programme, which contrasts with the often solitary and data-driven nature of monitoring-based CH (Fiske et al., 2020; Lupton, 2013). Thus, acknowledging this distinction, findings from this thesis underscores the need to tailor CH implementation strategies based on the nature of the intervention, target population, and psychosocial demands. This also reinforces the argument that CH should be integrated thoughtfully into care pathways, ensuring that tools used to support health do not inadvertently become sources of distress.

#### c) Limited choice and availability

As reported in Study 4, several participants did not actively choose online or in person as a modality, in that it was their only available option ('it was the only option available'). In this context, availability, not preference, drove the modality choice, limiting autonomy and potentially influencing satisfaction. Thus emphasising the need for dual offering.

# d) Fragmented care and limited integration

Participants in study 5, noted the lack of integration across services. CH platforms, and digital health tools in general were described as standalone tools rather than part of a coherent care pathway. This fragmentation hindered their perceived usefulness and made it harder to sustain engagement.

# 8.4. 2. Facilitators to CH engagement

## (a) Perceived benefits and usefulness

Many participants viewed CH technologies as useful in supporting self-management, enhancing access to psychosocial support, and overcoming barriers particularly during and after the COVID-19 pandemic. High technology usability was reported in study 3a. This study found that technologies used to access the CH delivered CTS were highly usable, which contributed to positive experiences and enhanced engagement among participants. In Study 5, participants described CH as empowering and beneficial to their psychological wellbeing and QoL. However, while many found CH technologies intuitive, others still encountered usability issues, underscoring the importance of co design with end users and PPI.

#### (b) Flexibility and Convenience

Flexibility was a recurring theme in that it was as major facilitator of CH use. In study 4 those who opted for the online CTS programme often cited the convenience of participating from the comfort of their home and fitting sessions around their schedules.

This flexibility was particularly beneficial for those with mobility challenges or other constraints that made attending in-person sessions difficult. Indeed, some participants indicated they would not have accesses survivorship support without the online option. The ability of CH to enhance accessibility to care aligns with Ireland's national digital health strategy (Burke et al., 2018; HSE, 2024a), which aims to reduce barriers to care for underserved populations. These perceived benefits align with the TAM concept of perceived ease of use, which influence intention to use technology, such as the CH.

# (c) The role of families and caregivers, and HCPs

Family and caregivers played a crucial facilitative role in supporting PLWBC throughout their engagement with CH technologies. Their support was multifaceted, ranging from technical assistance with new technologies, particularly for older adults with limited digital literacy, to logistical support, such as managing support with childcare, enabling participation in CH programmes without added stress (study 3a). As noted earlier, this underscores the pivotal role of families and caregivers in survivorship care (Maguire et al., 2018; PDQ Supportive and Palliative Care Editorial Board, 2010), highlighting the importance of their active involvement in the design and implementation of CH to ensure comprehensive and effective support. Moreover, the endorsement and recommendation of CH by HCPs appeared to build trust and legitimacy, especially for those uncertain about digital tools. In study 2, HCP encouragement was associated with higher engagement in CH tools.

## (d) Supportive programme design

Positive user experiences with the CH delivered CTS programme (Studies 3a, 4 and 5) were enhanced when delivery was structured, user friendly, and well facilitated. Experiences of facilitator warmth and competence were notable findings from study 5, suggesting the key role of facilitators in helping mitigate any technological barriers.

# (e) Increased digital familiarity post COVID-19

In Study 5 participants linked their willingness to engage with CH to their increased digital exposure during the pandemic. This echoes wider literature noting the pandemic as a digital catalysis for health care engagement (Burbury et al., 2021; Golinelli et al., 2020a).

In summary, CH implementation depends on service and system level readiness. Staff attitudes, institutional buy in and funding models were all identified as key barriers or enablers. Without systemic alignment, even the most user-friendly of the CH technologies may fail to reach or benefit those most in need.

#### 8.5 Recommendations

Based on the collective insights from this thesis, the following recommendations are proposed for policy, future research, policy and implementation to optimise the role of CH in cancer survivorship, particularly in the Irish context. However, given the methodological limitations of quantitative studies and their limited generalisability, these recommendations should be considered tentative. Broadly, the recommendations highlight the need to ensure that national digital health strategies incorporate survivorship-specific needs and equity considerations, especially for underserved populations such as rural PLWBC.

## 8.5.1. Recommendations for policy and service development

# a) Integrate CH into the national survivorship programmes

Findings from this thesis highlight the utility of CH in enhancing access, self-management and psychosocial wellbeing. Policy makers should formally integrate CH into survivorship models of care, ensuring alignments with Sláintecare principles and National Cancer strategy goals for equity and innovation. The digital health framework 2024-2030 (HSE, 2024a) is a positive start in this regard, and aligns with the European Commission's goal in shaping Europe's digital future (European Commission, 2024).

## b) Support for hybrid delivery models.

Findings from study 4 and 5 suggest that offering both in person and CH options enables choice, personalisation and responsiveness to different individual preferences and contexts. As one participant highlighted in study 5, 'it's always good to have the choice' in the form of hybrid care models that combine the best of both CH technologies and inperson support. Such an approach would leverage the scalability and accessibility of digital solutions while preserving the empathy and relational depth provided by face-to-face care. A hybrid model aligns well with Ireland's broader healthcare vision (Burke et al., 2018; HSE, 2024b), ensuring that all patients, during and post treatment, receive personalized, person-centred care. Personalised, person centred care is some of the core ingredients of CH (Pattichis & Panayides, 2019). Thus, national guidelines should aim to support flexible, person centred delivery models in cancer survivorship services.

# c) Prioritise equitable access and digital inclusion.

Widespread CH adoption risks exacerbating existing health disparities if infrastructure, literacy and access gaps are not addressed, as seen in Study 2 and Study 5. Investments in digital literacy programmes and broadband infrastructure, particularly for rural based, older and socioeconomically disadvantaged groups is urgently needed to promote equitable access to CH. One example is to implement community-based digital literacy training, particularly aimed at older adults. Partnering with libraries (as suggested in study 5), community centres, and healthcare organizations can help deliver these programmes and enhance patients' digital literacy and confidence in using CH tools.

## 8.5.2. Recommendations for practice and programme implementation.

# d) Monitoring and evaluation of the implementation in real world settings.

To ensure CH technologies remain responsive to the evolving needs of PLWBC, ongoing evaluation is essential, and is a key emphasis in the global digital health strategy (WHO, 2021a). Use of implementation science frameworks such as the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework (Glasgow et al., 1999; Holtrop et al., 2021) is recommended to guide scale up, track engagement and assess long term outcomes and sustainability of CH interventions, such as CTS, in survivorship settings. Additionally, establishing mechanisms for continuous patient feedback is crucial for identifying and addressing gaps in CH interventions, guiding iterative improvements and enhancing the relevance and quality of CH technologies. Furthermore, longitudinal research should assess the long-term impact of CH technologies on survivorship outcomes, particularly their effectiveness and 'active ingredients' in supporting psychological well-being and QoL over time, given the changing needs across the cancer continuum (Cochrane et al., 2022; Sodergren et al., 2019).

# e) Co designing and 'patient-centric-ness' in CH

Drawing on qualitative findings (Study 5, Ch.7), CH technologies should be co designed with PLWBC and adapted to individual, cultural contexts, and cancer experiences. This aligns with the growing recognition for the importance of PPI in guiding research and with some funding and guidelines available such as those from the PPI Ignite Network (PPI Ignite Network, 2024), to ensure responsiveness to their needs, preferences, and challenges. Flexibility in delivery format, content, pacing, and access options can enhance acceptability. Furthermore, prioritizing accessibility for all users,

including those with physical and intellectual disabilities or limited digital skills, is essential. Simplicity, intuitive navigation, and with a multicultural orientation, should be emphasized to enhance usability for diverse populations.

# f) Enhance training and support for facilitators.

Implementation success depends on the facilitator confidence (study 5), digital skills, and adaptability. Ongoing training and structured supports should be provided to those delivering CH programmes, such as CTS to maintain programme fidelity and engagement. Simultaneously, HCP endorsement of CH technologies should be encouraged, given their significant influence in adoption (Leigh & Ashall-Payne, 2019). Training programmes should familiarize HCPs with these technologies and their potential benefits, thereby empowering them to confidently recommend them to patients. Furthermore, offering incentives, perhaps to hospitals, can encourage HCP integration of CH technologies into their practice, ensuring active support of patient use.

# g) Improved awareness of available technologies

Participants in study 5 noted that they did not know of the existence of CH tools and technologies for their survivorship care. Thus, there is need for heightened awareness campaigns of available technologies. This can be achieved through PPI campaigns, leveraging 'technology ambassadors' and PLWBC with lived experience of using technologies.

#### 8.5.3. Recommendations for research

#### h) Conduct longitudinal and controlled studies

To address the limitations of cross sectional design as applied in some studies in this thesis, future studies should use longitudinal, randomised or quasi experimental designs to assess the causal impact of CH on survivorship outcomes, including psychosocial wellbeing, QoL and unmet needs over time. Additionally, future work is needed to compare the effectiveness of hybrid, digital-only, and in-person care models in addressing survivorship needs, particularly across different groups (e.g., urban vs. rural, older vs. younger participants). A comparative study in Ireland, for example, where the healthcare landscape includes both urban centres like Dublin and rural areas with limited access to specialised care, could help determine the optimal model for improving survivorship outcomes across varied contexts. Beyond the post treatment phases where this research was largely framed, research should examine CH's role from diagnosis through survivorship, including transitions in case, survivorship planning and palliative

phases. Given the ongoing digital transformation in the Irish healthcare system (HSE, 2024a), such studies could contribute to understanding the sustainability of CH interventions within the Sláintecare framework.

# i) Include digitally excluded and marginalised populations

This thesis highlighted disparities in CH adoption based on demographic factors like age, education, and income. Further research should proactively include groups historically underrepresented in CH studies, such as people with low literacy, ethnic minorities, traveller populations, and those with severe mental illnesses, to ensure inclusivity and relevance. Notably, Ireland is becoming increasingly culturally diverse, and research is needed to explore how cultural factors influence CH adoption and effectiveness in cancer survivorship. Understanding cultural differences in technology acceptance, from a multicultural orientation framework, health beliefs and seeking behaviours, and communication preferences could inform the development of culturally sensitive CH interventions that promote the principle of 'cultural humility'. For instance, evaluating the perspectives of traveller communities on the use of CH technologies could help identify culturally tailored strategies to enhance engagement.

# j) Explore integration of CH technologies with healthcare systems

Fragmentation in care pathways was frequently reported by participants in Study 5, particularly the lack of system-wide integration and data interoperability. Future research should explore best practices for integrating CH technologies within the HSE. For example, evaluating initiatives like Ireland's National Electronic Health Record (NEHR) project, a flagship pillar in the 'Digital for Care' 2024-2030 framework (HSE, 2024a), could provide insights into how CH platforms can be linked with broader healthcare infrastructure to ensure seamless information sharing and coordinated care. Such research could also include exploring successful integration models from other EU countries that have overcome similar challenges.

# k) Cost-benefit analysis of CH Implementation in survivorship care

Further research should conduct a cost-benefit analysis of implementing CH technologies in cancer survivorship care. This analysis should consider both the direct costs (e.g., technology, training) and indirect costs (e.g., time spent on digital literacy development) against the benefits, such as improved patient reported outcomes and reduced healthcare visits. For the Irish context, assessing the economic impact of CH technologies could guide decisions on resource allocation under the Sláintecare

programme, especially in reducing unnecessary hospital visits and optimizing outpatient care.

# l) Advance psychometric and theoretical development

There is need for research to validate adapted tools for CH formats, e.g. the modified SF SUNS instrument used in study 3b, and to further apply and refine theoretical models such as the stress buffering hypothesis and the socioecological model to digital survivorship interventions.

# m) Artificial intelligence (AI)

AI, a rapidly evolving technological advancement, offers opportunity to enhance CH technologies and patient experience in cancer survivorship care. Prior research, including a recent RCT demonstrating the effectiveness of an AI-driven *AI-TA* app aimed at reducing psychological symptoms in young breast cancer patients, supports this potential (L. Jiang et al., 2024). Future research should explore AI's capacity for personalized interventions, predictive modelling of patient needs, and enhanced decision-making for HCPs. For instance, AI-powered tools like chatbots and predictive analytics could improve patient engagement and identify at-risk individuals. Such research, however, must prioritize design justice and PPI principles to ensure equitable and responsive AI solutions (Zidaru et al., 2021). Additionally, as has been highlighted in this research, ethical considerations surrounding data privacy, algorithm validation, and professional training require careful attention for responsible AI integration into healthcare. Table 8.1 summarises the key findings and recommendations and stakeholders responsible.

 Table 8.1

 Summary of key findings and recommendations for relevant stakeholders

Study	Summary Findings	General Recommendations	Stakeholders
2, 4 and 5	Access to digital infrastructure in rural areas	Invest in expanding broadband infrastructure in	Policy Makers/HSE
	is limited, affecting CH adoption	rural areas to bridge the digital divide and ensure	
		equitable access to CH technologies.	
2 and 5	Younger, well-educated, higher SES PLWBC	Develop targeted community-based digital literacy	Policy makers, HCPs
	are more likely to adopt CH, while older	programs for older adults to ensure equitable access	
	PLWBC face barriers due to digital literacy.	to CH technologies.	
4 and 5	CH technologies facilitate access to	Adopt a hybrid care model that integrates CH with	Policy makers, HCPs
	psychosocial supports, but relational support	in-person support to provide a balance between	
	is lacking	convenience and relational, emotional care	
1 and 5	CH promotes self-management, with a risk of	Provide personalized guidance and support to	HCPs
	increased emotional burden on some	reduce the burden of self-management, ensuring	
	participants	CH tools complement, rather than replace, human	
		care.	
3(a), 4 and 5	HCPs play a crucial role in promoting CH,	Train HCPs on the benefits and use of CH	Policy makers, HCPs
	but lack of training affects adoption	technologies, empowering them to effectively	
		endorse and support CH use among PLWBC	
3(a)	CH usability is generally rated high, but	Co-design CH tools with end users (PLWBC) to	Tech developers,
	participants need ongoing support to use the	ensure they are intuitive, accessible, and responsive	HCPs, PLWBC family
	technologies effectively		and caregivers

Study	Summary Findings	General Recommendations	Stakeholders
		to the diverse needs of PLWBC. Include families	
		and caregivers	
3a, 3b, 4 and 5	Participants value peer support and social	Incorporate interactive features in CH tools, such as	Tech developers,
	interaction, which are sometimes lacking in	virtual support groups or real-time chats with	HCPs
	CH-only models.	HCPs, to enhance emotional and relational support	
5	Irish Healthcare system fragmentation limits	Develop interoperable digital platforms that	Policy makers, Tech
	CH integration, with participants facing	facilitate seamless communication and data sharing	developers
	challenges in continuity of care	between healthcare providers to improve care	
		continuity	
3b	PLWBC often have unmet needs in	Integrate tailored emotional support services into	Tech developers,
	emotional domains, such as stress	CH tools, such as digital counselling and guided	Policy makers
	management and coping with body image	mindfulness programmes, to address psychosocial	
	changes	needs comprehensively	

# 8.6. Conceptual guide for supporting the use of CH in cancer survivorship care

Drawing upon findings across the six studies presented in this thesis, this section proposes a preliminary conceptual guide for informing the integration of CH technologies into cancer survivorship care. Rather than offering a prescriptive implementation framework, this guide distils emergent themes from the studies and existing literature into a multi-level structure, organised according to three interrelated layers. This aligns with the SEM used earlier to analyse factors influencing CH adoption in objective 2 and 3.

#### 8.6.1. Individual-Level Considerations

Findings across studies underscored the importance of recognising heterogeneity in PLWBC's needs, preferences, and capacities in relation to CH. Key individual-level factors to consider include:

- **Digital literacy and confidence.** Some PLWBC reported high comfort with CH (Study 5) while others expressed confusion, anxiety, or reluctance due to lack of familiarity or access. This suggests that tailored onboarding and digital support may be critical.
- Preference and perceived relevance. Study 4 and Study 5 both highlighted that
  programme modality choice was shaped not just by convenience but also
  perceived appropriateness. For some, CH was seen as empowering and flexible;
  for others, it lacked human connection or was inappropriate due to personal
  values.
- *Psychological readiness and burden*. The qualitative accounts in Study 5 cautioned against over-reliance on CH, with some participants reporting a sense of burden in managing their care digitally. This highlights that the emotional labour associated with self-monitoring applications should not be underestimated.
- Access and infrastructure. Rural participants disproportionately opted for inperson delivery possibly due to connectivity limitations (Study 4). CH rollout must be preceded by infrastructural investment to prevent digital exclusion.

# 8.6.2 Healthcare Provider and Organisational Considerations

The attitudes, capacity, and workflows of HCP and cancer support centres play a significant role in shaping CH access and delivery. Key considerations include:

- Awareness, training, and readiness. As noted in Study 1 and Study 5, some HCPs lacked knowledge about CH options or expressed concerns about their efficacy. Structured education, guidelines, and peer-learning opportunities could enhance HCP engagement.
- *Integration with existing services*. Fragmentation of care was a recurring theme in the qualitative accounts. Participants emphasised the importance of CH being embedded within broader person-centred care systems, rather than existing in silos.
- *Referral pathways and gatekeeping*. The process by which PLWBC were invited to CTS varied across centres (Study 4 and Study 5). Consistent, equitable referral mechanisms, particularly where modality choice exists must be clearly defined.

# 8.6.3. System-Level Considerations in CH implementation.

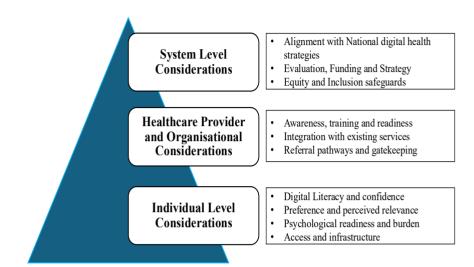
At the policy and health system level, several structural supports are required to enable meaningful and sustainable CH integration in survivorship care:

- *Alignment with national digital health strategies*. Ireland's recently launched Digital Health Framework (HSE, 2024a) outlines goals to promote equitable access, interoperability, and person-centred eHealth. CH survivorship initiatives must align with and draw support from this broader digital infrastructure
- *Evaluation, funding, and sustainability*. Current CH programmes, including CTS, require structured support for ongoing evaluation, capacity-building, and equitable funding mechanisms, especially for rural centres (Study 3b, Study 5).
- *Equity and inclusion safeguards*. Study 2 and Study 5 identified concerns around digital exclusion of older adults, those with lower socioeconomic status. National policies must mandate inclusive CH design and outreach strategies.

Figure 8.1 summaries the conceptual guide outlining these factors in a multilevel approach.

Figure 8.1

Conceptual guide for supporting the use of CH in cancer survivorship.



# 8.7. Summary of Limitations and Strengths

This thesis offers several methodological and conceptual strengths, while also acknowledging important limitations that shape the interpretation of results. While each study's limitations and strengths have been included in the specific chapters, this section provides an overview of overarching limitations and strengths.

#### 8.7.1 Limitations

Firstly, the absence of longitudinal or experimental designs across the quantitative empirical studies is a primary limitation. The cross-sectional nature of these studies inherently restricts the ability to draw causal inferences regarding the impact of CH interventions on key outcomes of interest, specifically psychological well-being and quality of life. Furthermore, the sample may be influenced by selection bias, given the reliance on voluntary participation and self-report methodologies. A further concern is the limited control for confounding variables. Specifically in Studies 3a/b and 4, potentially influential variables such as time since treatment, use of other support services, or comorbid conditions were not accounted for. These unmeasured variables may have influenced the observed outcomes and should be rigorously considered in future research, as recommended earlier in section 8.5.3.

Secondly, the modest and non-randomized sample sizes in Studies 3a/b, and 4, the small sample sizes and the lack of random assignment to intervention modalities (online vs. in-person) diminish statistical power and consequently limit the generalizability of the findings. Thirdly, the use of modified tools and associated psychometric constraints impacted certain analyses. For instance, in Study 3b, the adapted version of the SF-SUNS, though co-designed with stakeholders, involved the removal of several domains. This precluded the use of standard cut-offs and inhibited domain-level comparisons. Fourth, the variability in CH definitions and modalities across the studies also presented a challenge. While CH was broadly conceptualized as an umbrella term encompassing diverse technologies and interventions, reflecting real-world diversity, this broad scope also complicates the isolation of specific effects attributable to individual CH components. Finally, contextual factors related to the COVID-19 pandemic (when the majority of the studies were conducted) may influence the long-term applicability of some findings. While the pandemic undeniably accelerated the adoption of CH technologies,

and digital health overall, it also introduced temporary factors, such as lockdown restrictions and increased digital acceptance, which may not persist. This transient context could potentially limit the ongoing relevance of certain findings in future post-pandemic scenario.

# 8.7.2 Strengths

Despite the limitations, this research demonstrates several key strengths, the overarching one being that it is the first body of work in Ireland to explore CH in the context of survivorship programmes such as CTS using a multi-methodological approach. Through integrating a systematic review, secondary survey analysis, cross-sectional evaluations and qualitative inquiry, this thesis offers a rich and triangulated understanding of the role CH in supporting individuals living with and beyond cancer. This comprehensive design facilitated the exploration of both broad population-level trends and in-depth individual experiences.

Secondly, the integration of PPI into the thesis improved the relevance of the research, responding directly to a societal need. Stakeholders and PPI members were consistently involved in critical stages, such as tool development, and the interpretation of findings. This involvement ensured alignment with person-centred principles and enhanced the relevance of the research to end-users and practical contexts ensuring real-world impact and policy relevance, particularly within Ireland's Sláintecare initiative. Each of these studies have been presented at the annual Irish Association for Cancer Research (IACR) meetings and also to the cancer centre leaders and facilitators.

Thirdly, the timeliness and originality of this research are also notable. Research presented in this thesis directly addresses the rapidly evolving field of digital health within post-COVID survivorship care, an area where empirical evidence remains scarce, particularly within the Irish context.

Fourth, the national relevance of this work is underscored by the recruitment strategies employed. Several studies (e.g., Study 4) involved participants from multiple cancer support centres across Ireland, thereby enhancing the generalisability and practical applicability of the findings for Ireland's national cancer survivorship strategy.

Finally, the focus on health equity and access was maintained throughout the studies. This was demonstrated by nationwide recruitment drives, including participants residing in rural areas or possessing low digital literacy, thereby highlighting an important equity consideration pertaining to the adoption and impact of CH interventions. While

not prescriptive, the suggested conceptual guide can stimulate discussion and further work on CH integration in cancer survivorship, grounded in data and stakeholder engagements.

#### 8. 8. General Conclusion

#### 8.8.1. Conclusion

This thesis set out to explore the role of CH technologies in supporting the psychosocial well-being and quality of life of people living with and beyond cancer, with particular focus on survivorship in the Irish context. In doing so, it addressed critical gaps in evidence and practice concerning how CH is perceived, implemented and experienced by PLWBC in Ireland. Drawing on a multi method approach, including a systematic literature review, population level secondary data analysis, mixed methods evaluation of a CH delivered cancer survivorship programme in Ireland, and in depth qualitative accounts, this thesis has demonstrated that CH technologies hold substantial promise in expanding access to supportive survivorship care, enhancing self-management and addressing psychosocial concerns in cancer. Importantly, it has shown that while CH can empower PLWBC and offer meaningful benefits, its uptake and accessibility are not even, but deeply influenced by individual, interpersonal, technological and system level factors.

Across the studies, CH emerged not simply as a technological solution, but as a relational, contextual and dynamic mode of care delivery. It enables new forms of engagement, support and agency, more so when designed with empathy, equity and adaptability considerations. Yet, the findings also caution against overly optimistic assumptions about digital transformation. Issues related to digital exclusion, trust, infrastructure, and implementation capacity remain pressing concerns. In line with ecological and stress buffering frameworks, and some nuances from technology acceptance models applied throughout this work, this thesis underscores the importance of embedding CH within broader supportive environments. Such environments should acknowledge PLWBC's lived realities, context, preferences and evolving needs.

As Irish and global healthcare system move towards greater digital integration, the insights presented in this thesis can inform the development of more responsive, inclusive and person centred survivorship services. In sum, while CH is not a panacea, it is a vital and timely component in modern survivorship care delivery. With thoughtful implementation, codesign with PPI principles, and continued research, it has the potential

to narrow access gaps, enhance quality of life and transform survivorship journal for all diverse and rising population of people living with and beyond cancer, in Ireland and globally.

#### 8.8.2 Contributions to the field.

The findings from this research make several contributions to the field of cancer survivorship care, particularly within the context of the Irish healthcare system. They provide evidence that CH technologies may be beneficial in supporting psychosocial outcomes for people affected by cancer by facilitating access to care and supports. The proposed CH conceptual guide provides a structured approach to multilayered considerations in implementing CH in cancer survivorship. This research strongly aligns, while offering preliminary empirical evidence, with Sláintecare, Ireland's healthcare reform strategy which aspires to enhance accessibility of care, particularly for those in underserved areas, through remote consultations and virtual support.

Although not a direct empirical contribution, this thesis made a deliberate effort to adopt people-centric terminology when referring to people living with and beyond cancer. As outlined in the introduction, section 1.8 this approach aligns with the increasing focus on efforts to 'deweaponize' cancer language and promote person-centred care. Informed largely by PPI contributions, the thesis intentionally avoided terms such as "cancer survivors," "fighters," and "battling cancer" in favour of language that emphasizes the individuality and lived experiences of people impacted by cancer. This conscious choice contributes to ongoing discussions about the importance of respectful and empowering terminology in cancer survivorship discourse.

In summary, CH technologies hold substantial promise for supporting people living with and beyond cancer, facilitating accessibility to survivorship care and improving psychosocial wellbeing and QoL outcomes. However, the success of CH in achieving these outcomes relies heavily on addressing the identified barriers. The research underscores the importance of collaborative efforts among policy makers, HCPs, technology developers, and PLWBC to create an environment where CH technologies can be fully optimised. Future research, as outlined in the proposed areas for further exploration, will be essential for ensuring that CH technologies are continuously improved, adapted, and implemented in ways that are equitable and meet the evolving needs of those affected by cancer in Ireland and beyond.

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### Appendices

### APPENDIX 1

### Coding frame for Study 1 with final agreed themes

Final agreed Theme/Cluster	Code/codes (Intervention components/Target)	Code description
Psychosocial Support and Rehabilitation	Psychological counselling	CH delivered interventions incorporating guided psychological therapy (e.g., CBT, mindfulness, yoga)
	Emotional wellbeing support	Targeted emotional support for distress, anxiety, or depressive symptoms
	Rehabilitation support	Interventions promoting coping, recovery, or reintegration into everyday life
Psychoeducation and Information Support	Educational modules	Structured content on cancer, symptoms, treatment side effects, examples include the interactive health communication platforms such as the IHECs,
	Information delivery/literacy promotion	CH tools used to deliver relevant health or care- related information building PLWBC' knowledge, confidence, and understanding in managing their health
Symptom Monitoring and	Digital symptom tracking	Use of platforms or apps to record and monitor symptoms e.g. app based symptom tracker
Self-Management	Automated feedback or alerts	CH systems that provide real-time responses or clinician alerts
	Self-management support	Interventions designed to empower individuals to manage symptoms such as fatigue, pain, etc.eg fatigue logs, pain monitoring tools
Peer and Social Support	Online/virtual peer groups	Virtual platforms facilitating communication between PLWBC such as community message boards, WeChat groups
	Shared experiences	Emphasis on connecting through lived experience
	Moderated/facilitated communities	Structured or guided peer interactions (for example with a facilitator or nurse). E.g. facilitated social support groups
Health Coaching and Physical Activity Training	Behavioural coaching/change	Goal setting and accountability support delivered digitally and general support for sustained improvements in diet, movement, or general wellbeing
	Exercise/PA tracking	CH tools supporting structured or semi- structured physical activity, examples include the daily steps tracking, exercise prompts etc

### Information and Consent Form for Study 3a/b



### **Information Sheet**

**Purpose of the Study.** I am Isaiah Gitonga, a PhD Candidate, in the Department of Psychology, Maynooth University. As part of the requirements for my PhD, I am undertaking a research study under the supervision of Dr Rebecca Maguire and Prof Deirdre Desmond.

This research is conducted with the financial support of Science Foundation Ireland under Grant number 18/CRT/6222.

This study will explore your experiences with the online one or more of the wellbeing support programmes which you participated in, as well as the extent to which this programme met your needs as a cancer survivor. Hearing from you as a cancer survivor will help policy makers and service providers, such as the **National Cancer Control Programme (NCCP)** to design and deliver services that better support the wellbeing and quality of life of those living with and beyond cancer.

What will the study involve? The study will involve completing a survey, which is expected to take 15-20 minutes in total.

Who has approved this study? This study has been reviewed and received ethical approval from Maynooth University Research Ethics committee. You may have a copy of this approval if you request it.

Why have you been asked to take part? You have been asked because you are a cancer survivor and have participated in one or more of the wellbeing support programs currently available for cancer survivors. These include the Life and Cancer Enhancing Survivorship (LACES) and Cancer Thriving and Surviving Programme (CTS).

**Do you have to take part?** No, you are under no obligation whatsoever to take part in this research. You are invited to take part in this study if you feel comfortable doing so. It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, you will be asked to click a box indicating your consent at the outset of the survey after reading the information sheet. You can view a copy of the information sheet using the link provided. If you decide to take part, you are still free to stop at any point. You can also skip any question that you do not want to answer. The survey is anonymous and therefore you will not be able to withdraw your data once you complete the survey.

### What information will be collected?

The survey questionnaire will involve five sections. These five sections will be as follows;

- Section 1: You will be asked some questions about your sociodemographic characteristics (your Age, Sex, Education level, Location) and your cancer diagnosis (Cancer type and Years since diagnosis and time since completion of treatment)
- Section 2: You will be asked about your experiences with the online survivorship support programs you received from the National Cancer Control Programme.
- Section 3: You will be asked questions about the usefulness, ease of use, effectiveness, reliability, and satisfaction with technology while participating in the programs.
- Section 4: You will be asked about the extent to which participation in the online programs met your needs as a cancer survivor.
- Section 5: Finally, you will be asked about your physical, psychological, and social functions after participation in the online survivorship support programs.

This information will be collected from you privately via the Qualtrics platform. No identifying information will be collected from you.

Will your participation in the study be kept confidential? Yes, all information that is collected about you during the course of the research will be kept confidential. All electronic information will be encrypted and held securely on MU PC or servers and will be accessible only to Isaiah Gitonga, Dr Rebecca Maguire or Professor Deirdre Desmond.

It must be recognized that, in some circumstances, the confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances, the University will take all reasonable steps within the law to ensure that confidentiality is maintained to the greatest possible extent.

What will happen to the information which you give? All the information you provide will be kept at Maynooth University in such a way that it will not be possible to identify you. On completion of the research, the data will be retained on the MU server. After ten years, all data will be destroyed (by the primary researcher.).

What will happen to the results? The research will be written up as a research paper for submission to an appropriate peer-reviewed journal and presented at national/international conferences. Isaiah Gitonga will also use the results as the basis for a chapter in his PhD thesis. The results will also be combined with information from a range of sources to inform future design and delivery of connected health interventions for cancer survivorship. A copy of the research findings will be made available to you upon request.

What are the possible disadvantages of taking part? It is possible that this topic may be an emotional one for you and completing questions about the experience of cancer and the interventions may cause some distress. If this occurs and you would like to stop taking part in the survey, you will be free to do so.

What if there is a problem? If you experience any distress in the course of completing this survey, you may contact the patient support services at Phone: 1800 200 700 or Email: <a href="mailto:supportline@irishcancer.ie.">supportline@irishcancer.ie.</a> You may contact my supervisors Dr Rebecca Maguire (Rebecca.Maguire@mu.ie) and Prof Deirdre Desmond (deirdre.desmond@mu.ie) if you feel the research has not been carried out as described above. You will also be provided with details of support services should you need them.

**Any further queries?** If you need any further information, you can contact me at <a href="mailto:gitonga.isaiah.2021@mumail.ie">gitonga.isaiah.2021@mumail.ie</a> or at Maynooth Department of Psychology, John Hume Building, Maynooth University, Maynooth, Co. Kildare.

### Thank you for taking the time to read this

### **Consent Form**

If you agree to participate, please tick each statement below:	
I have read and understood the nature and purpose of the study	
I am participating voluntarily.	
I understand the limits of confidentiality as described in the information shee	et 🗆
If during your participation in this study you feel the information and guidel that you were given have been neglected or disregarded in any way, or if you are unhabout the process, please contact the Secretary of the Maynooth University Ethics Committee at <u>research.ethics@mu.ie</u> or +353 (0)1 708 6019. Please be assured that concerns will be dealt with in a sensitive manner.	happy

For your information the Data Controller for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at <a href="mailto:ann.mckeon@mu.ie">ann.mckeon@mu.ie</a>. Maynooth University Data Privacy policies can be found at <a href="https://www.maynoothuniversity.ie/data-protection">https://www.maynoothuniversity.ie/data-protection</a>.

### **NCCP Study Support Letter**



Social Research Ethics Sub-Committee Maynooth University An Clár Náisiúnta Rialaithe Ailse Urlár 3, Teach Óstaí an Rí, 200 Sráid Pharnell Baile Átha Cliath DO1 A3Y8, Teil: +353 1 828 7100

National Cancer Control Programme 3<sup>rd</sup> Floor, King's Inns House, 200 Parnell Street Dublin 1 DO1 A3Y8, Tel: +353 1 828 7100

May 3oth, 2022

RE: Letter of Support for proposal: Utility and perceived benefits of connected health technologies in cancer survivorship

To whom it concerns,

This proposal provides an opportunity for the National Cancer Control Programme (NCCP) to collaborate on research that will evaluate the impact of new initiatives designed to reach and support cancer patients in the post treatment period. We are particularly keen to see the impact of connected health and identify gaps in the cohorts of cancer patients we reach. The survivorship programme of the NCCP of the HSE (NCCP) wishes to express our support for this application and our commitment to collaborate should the proposal be approved.

Yours sincerely

Ms. Louise Mullen

National Lead for Cancer Survivorship National Cancer Control Programme

OX. E. Wullen

### **Study 3 CTS Survey Questions and Instruments**

### A Sociodemographic and Health Questionnaire

- i. What is you Age in Years?
- ii. What is your gender identity (Male/Female/Nonbinary or Third gender/Prefer not to say)
- iii. What is the highest level of education completed (No level of schooling/primary/secondary/post-secondary school training/third level education)
- iv. What best describes your employment status over the last six months? (Working FT/Working PT/Unemployed and looking for work/A home maker or stay at home parent/student/retired/ others (please specify)
- v. What is your ethnic group (White/Asian or Asian British/ Black or African or Caribbean)
- vi. What type of cancer had you been diagnosed with? (e.g. *breast, colon, prostate etc*)
- vii. What best describes where you live? (*Urban/Rural*)
- viii. How many years ago were you diagnosed?
  - ix. How many years since you completed your cancer treatment?
  - x. What type(s) of treatment did you receive? (Surgery/chemotherapy/radiotherapy/immunotherapy/others: please specify)

## **B\_** Experiences and Perceived benefits of online survivorship Programmes

In this section we want to know the extent of your engagement with the telehealth delivered wellbeing support programs and the perceived benefits. Telehealth system is a term used to describe healthcare services that are delivered through an online/virtual platform, such as zoom/WhatsApp/Teams or other audio/videoconferencing platforms

- 1. Which online survivorship programme did you participate in?
  - Life and Cancer Enhancing Survivorship (LACES)
  - Cancer Surviving and Thriving (CTS)
  - Other (Specify)
- 2. How many online sessions did you complete in total ?
- 3. Please tell us the date you completed your last session (month/year)
- 4. What was the main motivation for participating in the telehealth-delivered well-being support programmes?
- 5. Rate your agreement with the following statements;
  - Participation helped improve my psychological wellbeing {(1) Strongly disagree; (2) Disagree; (3) Neither agree nor disagree; (4) Agree; (5) Strongly agree.]

- Participation helped in improving my Quality of life {(1) Strongly disagree; (2) Disagree; (3) Neither agree nor disagree; (4) Agree; (5) Strongly agree.]
- Participation helped me to tale more control of my health and wellbeing {(1) Strongly disagree; (2) Disagree; (3) Neither agree nor disagree; (4) Agree; (5) Strongly agree.]
- 6. Regarding programme components.
  - Which of the following programme components did you find most useful as pertaining to your **psychological wellbeing**?
    - Self-management
    - Mental health and
    - Nutrition/Diet
    - Family, finance, and work-life
    - Confidence, body image, and intimacy
    - Self-management
    - Available supports near me.
    - Other (Please specify
  - Which of the following programme components did you find most useful as your **Quality of life**?
    - Self-management
    - Mental health and
    - Nutrition/Diet
    - Family, finance, and work-life
    - Confidence, body image, and intimacy
    - Self-management
    - Available supports near me.
    - Other (Please specify
- 7. Overall, what aspects of the programme did you like the most? Please elaborate
- 8. Did you encounter any barriers to participating in the programmes? Please explain
- 9. Did you receive any supports to complete the programme? Please elaborate.

### Section C- TELEHEALTH USABILITY QUESTIONNAIRE (TUQ)

# Please respond to the questions based on your experience with online survivorship programmes

#	Statements	N/A		1	2	3	4	5	6	7
1.	Telehealth improved my access tohealthcare services.		DISAGREE							AGREE
2.	Telehealth saved me time traveling to ahospital or specialist clinic.		DISAGREE							AGREE
3.	Telehealth provided for my healthcare need.		DISAGREE							AGREE
4.	It was simple to use this system.		DISAGREE							AGREE
5.	It was easy to learn to use the system.		DISAGREE							AGREE
6.	I believe I could become productive quicklyusing this system		DISAGREE							AGREE
7.	The way I interacted with this system is pleasant.		DISAGREE							AGREE
8.	I liked using the system.		DISAGREE							AGREE
9.	The system is simple and easy tounderstand.		DISAGREE							AGREE
10.	This system is able to do everything I wouldwant it to be able to do.		DISAGREE							AGREE
11.	I can easily talk to the facilitator using thetelehealth system.		DISAGREE							AGREE
12.	I can hear the clinician clearly using thetelehealth system.		DISAGREE							AGREE
13.	I felt I was able to express myself effectively.		DISAGREE							AGREE
14.	Using the telehealth system, I can see thefacilitator as well as if we met in person.		DISAGREE							AGREE
15.	I think the visits provided over the telehealth system are the same as inpersonvisits.		DISAGREE							AGREE

16.	Whenever I made a mistake using the system, I could recover easily and quickly.	DISAGREE 🗆 🗆 🗆 🗆 🗆 AGREE
17.	The system gave error messages that clearlytold me how to fix problems.	DISAGREE 🗆 🗆 🗆 🗆 🗆 AGREE
18.	I feel comfortable communicating with the facilitator using the telehealth system.	DISAGREE 🗆 🗆 🗆 🗆 🗆 AGREE
19.	Telehealth is an acceptable way to receivehealthcare services.	DISAGREE 🗆 🗆 🗆 🗆 🗆 AGREE
20.	I would use telehealth services again.	DISAGREE 🗆 🗆 🗆 🗆 🗆 AGREE
21.	Overall, I am satisfied with this telehealthsystem.	DISAGREE 🗆 🗆 🗆 🗆 🗆 AGREE

### **SECTION D: Unmet Needs of PLWBC**

We know that your unmet needs may change over time. In the current survey, we want to know only about the level of unmet needs after completing the online wellbeing support programmes. An **unmet need** is a need that you have not been able to satisfy.

For each statement, Select the choice that best describes your level of Unmet Need. Use this as the guide

**No unmet need** – This is not a problem for me as a result of having cancer now or in the past.

**Low unmet need** – I need a small amount of help with this problem but was not able to get it.

**Moderate unmet need** – I need a moderate amount of help with this problem but was not able to get it.

**High unmet need** – I need a high amount of help with this problem but was not able to get it.

**Very high unmet need** – I need a very high amount of help with this problem but was not able to get it.

A. Unmet Information Needs: This part of the survey is about unmet needs that relate to finding information IN THE LAST MONTH.

	No Unmet Need	Low Unmet Need	Moderate Unmet Need	High Unmet Need	Very High Unmet Need	Decision Notes
For each statement, place an X after the choice that best describes your level of unmet.						
1. Finding information about <b>community</b> support services complementary or alternative therapies	[]0	[]1	[]2	[]3	[]4	YES
2. Dealing with fears about cancer spreading recurring	[]0	[]1	[]2	[]3	[]4	YES
3. Dealing with worry about whether the treatment has worked	[]0	[]1	[]2	[]3	[]4	YES

B. Unmet Work and Financial Needs: This part of the survey is about unmet needs you may have had about your job and finances IN THE LAST MONTH.

	Unmet	Unmet	Unmet	Very High Unmet Need	
For each statement, place an X next to the choice that best describes your level of unmet.					

[]0	[]1	[]2	[]3	[]4	N/A
[]0	[]1	[]2	[]3	[]4	N/A
[]0	[]1	[]2	[]3	[]4	N/A
[]0	[]1	[]2	[]3	[]4	N/A
[]0	[]1	[]2	[]3	[]4	N/A
[]0	[]1	[]2	[]3	[]4	N/A
[]0	[]1	[]2	[]3	[]4	N/A
[]0	[]1	[]2	[]3	[]4	N/A
	[]0 []0 []0 []0	[]0 []1  []0 []1  []0 []1  []0 []1	[]0 []1 []2  []0 []1 []2  []0 []1 []2  []0 []1 []2  []0 []1 []2	[]0 []1 []2 []3  []0 []1 []2 []3  []0 []1 []2 []3  []0 []1 []2 []3  []0 []1 []2 []3  []0 []1 []2 []3	[]0 []1 []2 []3 []4  []0 []1 []2 []3 []4  []0 []1 []2 []3 []4  []0 []1 []2 []3 []4  []0 []1 []2 []3 []4

C. Unmet Needs for ACCESS and Continuity of Care: This part of the survey is about unmet needs that relate to medical care IN THE LAST MONTH.

	Unmet		Unmet	High Unmet Need	Very High Unmet Need	
For each statement, place and X next to the choice that best describes your level of unmet need.						
12. Having access to cancer services close to my home	[]0	[]1	[]2	[]3	[]4	N/A

13. Getting appointments with specialists quickly enough (oncologist, surgeon, etc.)	[]0	[]1	[]2	[]3	[]4	N/A
14. Getting test results quickly enough	[]0	[]1	[]2	[]3	[]4	N/A
15. Having access to care from other health specialists (dieticians, physiotherapists, occupational therapists)	[]0	[]1	[]2	[]3	[]4	N/A
16. Making sure I had enough time to ask my doctor or nurse questions	[]0	[]1	[]2	[]3	[]4	N/A
17. Getting the health care team to attend promptly to my physical needs	[]0	[]1	[]2	[]3	[]4	N/A

D. Unmet Coping, Sharing and Emotional Needs: This part of the survey is about unmet needs that relate to your relationships with others and your emotional health IN THE LAST MONTH.

	No Unmet Need	Low Unmet Need	Moderate Unmet Need	High Unmet Need	Very High Unmet Need	
For each statement, place an X next to the choice that best describes your level of unmet need.						
18. Telling others how I was feeling emotionally	[]0	[]1	[]2	[]3	[]4	YES
19. Finding someone to talk to who understands and has been through a similar experience	[]0	[]1	[]2	[]3	[]4	YES
20. Dealing with people who expect me to be "back to normal"	[]0	[]1	[]2	[]3	[]4	YES
21. Dealing with people accepting that having cancer has changed me as a person	[]0	[]1	[]2	[]3	[]4	YES

22. Dealing with reduced support from others when treatment has ended	[]0	[]1	[]2	[]3	[]4	YES
23. Dealing with feeling depressed	[]0	[]1	[]2	[]3	[]4	YES
24. Dealing with feeling tired	[]0	[]1	[]2	[]3	[]4	YES
25. Dealing with feeling stressed	[]0	[]1	[]2	[]3	[]4	YES
26. Dealing with feeling lonely	[]0	[]1	[]2	[]3	[]4	YES
27. Dealing with not being able to feel 'normal'	[]0	[]1	[]2	[]3	[]4	YES
28. Trying to stay positive	[]0	[]1	[]2	[]3	[]4	YES
29. Coping with having a bad memory or lack of focus	[]0	[]1	[]2	[]3	[]4	YES
30. Dealing with changes in how my body appears	[]0	[]1	[]2	[]3	[]4	YES

Protocol source: <a href="https://www.phenxtoolkit.org/protocols/view/321201">https://www.phenxtoolkit.org/protocols/view/321201</a>

### **NB:** YES- ITESM INCLUDED

NA: ITEMS EXCLUDED AS THEY WERE CONSIDERED NOT APPLICABLE IN THE CONTEXT OF CTS/LACES AND RESERCH OBJECTIVE THAT TARGETED UNMET INFORMATION NEEDS AND COPING, SHARING AND EMOTIONAL NEEDS. SLIGHT WORDING CHANGES WERE DONE TO ITEMS 1 AND 2.

<u>SUMMARY. ITEMS IN SECTION A AND D WERE RETAINED. WHILE B AND C WERE EXCLUDED</u>

#### **STUDY 4 Data Collection Tools**

### Sociodemographic Questionnaire

- 1. Age [18-24. 25-34, 35-44, 45-54, 55-64, 65+]
- 2. Gender identity [Female, Male, Non-Binary, Prefer Not to Say]
- 3. Education [ No level of schooling, less than secondary school/ high school, High school diploma or equivalent, some college or vocational training, bachelor's degree, master's degree or higher, Prefer Not to Say]
- 4. Current marital status
- 5. Occupation [Unemployed, Student, employed (full time), Employed (part-time), Prefer Not to Say]
- 6. Residence (Urban, Rural, Other)
- 7. Cancer Diagnosis (List)
- 8. Time since active treatment ended (Yrs)
- 9. Access to primary treatment centre (not accessible very accessible)
- 10. Does your local cancer support center deliver the cancer thriving and surviving programme? (yes/no/not sure)
- 11. What was your main goal in participating in the CTS program? (open text)

### **Open Ended Questions**

Thank you for providing feedback to assist in evaluating this CTS Programme; it is much appreciated. Please take some time to provide some feedback by responding to the following questions.

- 1) Information about the CTS Program you have been attending.
  - a. Location [Online or in person. (If in person, indicate the venue)]
  - b. Why did you select this modality\_\_\_\_\_
  - c. Time of sessions
  - d. How many workshop sessions did you attend? (Please circle) 1 2 3 4 5 6 7
- 2) Please rate the following aspects of the workshop by circling one number for each item below where 1 = Poor and 5 = Excellent
  - a. The time/day sessions were held? 1 2 3 4 5
  - b. The venue (for in person) for the sessions 1 2 3 4 5
  - c. The mode of delivery 1 2 3 4 5
  - d. Communication 1 2 3 4 5
  - e. Organization and preparation 1 2 3 4 5
- 3) In general, I would say the CTS supported my psychological wellbeing [ (1) Strongly disagree; (2) Disagree; (3) Neither agree nor disagree; (4) Agree; (5) Strongly agree.]
- 4) In general, I would say the CTS program supported my Quality of life [ (1) Strongly disagree; (2) Disagree; (3) Neither agree nor disagree; (4) Agree; (5) Strongly agree.]
- 5) In general, CTS programme empowered me [ (1) Strongly disagree; (2) Disagree; (3) Neither agree nor disagree; (4) Agree; (5) Strongly agree.]
- 6) Would you recommend CTS program to other people affected by cancer? Yes No

		i.	If Yes, why
		ii.	If No, why
	.1		,

7) Any other comments\_\_\_\_\_

### **STUDY 5: Qualitative Interview Guide**

Study Title: Exploring the needs, barriers, enablers and perceived utility of connected health in supporting cancer survivorship care.

*Pre-interview (3-5minutes)* 

Thank you for your time today.

As you may be aware, this study will involve an interview to discuss your perspectives on advantages, disadvantages and opportunity of connected health in supporting psychosocial wellbeing and quality of life in people living with and beyond cancer, otherwise known as survivorship care. Connected Health is the use of smart technologies, like sensors, telehealth (e.g., apps on a mobile phone to monitor health) or electronic health records, within healthcare. This may also include engaging in online programmes relating to cancer. It differs from other technologies in that a two-way flow of information is used. Information is gathered, analysed and then fed back to the individual.

Over the next 30-60 minutes, I will ask you about perspectives on this subject. Firstly, your experiences in using connected health in cancer survivorship care. Secondly, I will explore the needs that connected health can support (or is supporting). Thirdly we will discuss any barriers and facilitators to usage of connected health. Finally, we will explore the perspectives on how connected health can be improved to better support psychosocial needs and overall quality of life in people living with or beyond cancer. Findings from this study will provide recommendations on how connected health can be optimized to support psychosocial wellbeing and quality of life in people living with and beyond cancer.

Before commencing this interview, I would like to remind you the interview will be recorded to ensure that all information is properly captured and for transcription to occur. Overall, there is no risk to participation in this study. All interviews will be anonymized with pseudonyms used. Once the interview has been transcribed, the recording will be deleted. If at any point during this interview, you wish to no longer continue, please let me know and we will stop the interview.

We shall now begin.

[Begin recording]

### **Interview Questions**

- 1. Please tell me about your **experience with connected health** in relation to cancer care and support.
- 2. Do you think connected health technologies are useful in **meeting your needs** as a cancer survivor (or person living with/beyond cancer)?
- 3. What barriers or limitations are there to the use of connected health?
- 4. How do you think connected health can be improved to better support cancer survivorship care?

### **Additional Illustrative Quotes**

Theme	Subtheme	Illustrative Quote
Access as agency	Literacy as agency	I think, particularly, like my cancer which was prostate cancer, which is a cancer affecting men, probably over 60, some who may not be very familiar with technology, who may have never used technology in their lives, like I come from an office background. I'm used to using computers (David)
		I guess, confidence as well in the technology. You know, the confidence in your ability on how to use it (Mariah)
	Infrastructure as a reflection of equity	You know, we can level the playing field more if we support people to access those health technologies, because I certainly found them absolutely super and far preferable to in person. In fact, in a lot of cases. (Megan)
		Probably the most important things would be the broadband and Wi Fi connection, obviously, and if you're living in rural Ireland, it's horrendous (Emily)
		As I said, it's, I don't think the apps necessarily are a problem. It's more access to technology. (Emma,)
		digital poverty, not everybody has access to a smartphone or an iPad, whatever (Emily)
		Well, you know, the big thing is having access to the equipment. Yeah. So for example, like, I'm talking to you on a laptop, and looking at a phone, I actually have a spare computer here. But for some people, they may not have anything, they might have to go to the library to use a public access machine. (Laura)
		Well, if they don't have access to it. For sure that like there's a cost involved in Internet access and good phones or laptops or whatever. So there's a huge cost. (Emma)

Theme	Subtheme	Illustrative Quote
	Design for all, or design for some?	if you're accounting for deaf people, you're putting a transcript anyway, that addresses issues for people who prefer text to video. So, you know, but I think yeah, the NALA principles are a great starting (Mariah)
		Anybody that has an intellectual disability can be quite difficult. So yeah, so I think it is, well, it's probably going to be more time consuming. They're going to have to give more time to this interaction. (Emily)
		The government should look at some kind of subsidized and payment towards broadband access to equalize access to broadband, then even if you have no laptop, okay, or whatever, you still have broadband access to connectivity to be able to avail of these supports (Megan)I think that if you make it really simple at the very, very beginning, you get comfortable with it. Yeah, well, then you can, you can have a small system that you can add on things as needed (Rachel)
		An app has to have a good UI. Also has a good clear user interface. Okay, to get what you want it to do can't take more than a number of clicks, if you have to go drilling through menus and options and things like that. It just makes it difficult. It should be visually simple, uncluttered and appealing, (Daniel)
Negotiating holistic support	Emotional connections or surface-level support?	I have done I think Thrive and Survive, I think, was the name of one of the meetings I attended, and I, I go for a bit of counselling as well with the counsellor. So I think they're fantastic, to be honest with you (Brady)
		Really. I mean, there's forums, online forums and stuff. And you know, all of that. I think they're really helpful. And then they would have been very helpful in my time, when you're trying to figure everything out and demystify everything, (Emma)
	The hybrid model as a middle ground	I think some of them actually, if they lived in near one another would have connected and met up because we were from all over I think they could have started off with a one to one, and then gone online. I think that in-person is really important and then, of course, after that you've made the connection. (Emily)

Theme	Subtheme	Illustrative Quote
Seamless or fragmented? The realities of digital care pathways	Convenience and Efficiency in accessing care	Illustrative Quote  I mean, it can be part, I think, hybrid is the word of the of the century is, so I think, maybe works better than not meeting your consultant or somebody at all. (Jessica)  when people are sick, they're very vulnerable. Yeah. And that level of human connection, actually, I think can help you in your recovery. Yeah, so it's all online, the person may not recover as much as if they had some human contact. So I think a hybrid model when the one that works the best. (Laura)  I think my need for connectedness was really important in the first six months, but is lessened, but it wasn't eliminated. But it just changed. It became more a hybrid approach, you know, after that initial stage for me, because you have to reintegrate back into your life (Samuel)  And that you can be in bed and have your consultation in your own home. (Emily)  you could sit on the couch and wrap the blankets around wherever you want to and take part everybody else was just very much relaxed (Megan)  But then because of the convenience factor, it's easier to go to go there, and then you also have the comfort of your own of your own home. You don't have to go out during the winter into the cold. And then travel and session a probably cold, strange room with a load of strangers. If you're a home wrapped up on the couch, I think you go into it more relaxed, because you're comfortable. (Mariah)
		home wrapped up on the couch, I think you go into it more relaxed, because you're comfortable.

Theme	Subtheme	Illustrative Quote
		illnesses may have restricting conditions, perhaps they're in wheelchairs, perhaps, you know, they're, they're not able to get out of the house for one reason or another, perhaps they have a combination of conditions or so on that, you know, technology may keep help to keep those people in touch (David)
	Consistency and continuity of care	to be able to go on and say, okay, I have that appointment and you'd be able to, you know, view all your bookings and appointments that you've done with the hospital. And because sometimes when you look back and you're talking about it, because when, when was that? Oh, God, I can't remember, you know, just different information, like, you know, to kind of keep it all together, I suppose. And a banquet of, of the information. (Lucy)
		Anyway, it's up to the smart boys to develop the app to try and use what I told you, if you had an app on your phone, that had an app on your phone that has all your health information, you know, kind of a health sign app. And if that was nearly compulsory, that in the minute just not going to your GP, or you're going to anyone, it would cut out, it would cut a lot of costs. (Grace)
Empowerment or Dependency? The ambiguities of digital autonomy	Fragmentation despite digital promise.	a huge source of frustration for people, particularly for older people if they gave you this information last week, why do you need it again? have you no system for recording and be able to locate me anywhere in the system and know by history without having to spend an hour additionally bringing you up to speed (David)
		in today's modern age, how come we do not have something like a credit card or full bank card that has all the medical information on issued that I can scan on anywhere I go having the protocols permission by the GDPR (Brady)
		I think an app could help. Instead of me finding out the information and reserves that have app, an app, a health app, that lists all the kinds of alternative treatments, all the medical treatments that so like, so if I had say, lymphedema, I don't know. But if I had lymphedema, then I would know that acupuncture is not suitable for me. So instead of some friends saying go to acupuncture, I find a great, you have an app that lists all these things, and say, look, this would be suitable. (Rachel)

What I would find beneficial is if I could have reports and investigations that we personally if they were available to me online or so what I find a big difficulty at even something as simple as getting my bloods done. If I get my bloods done in a not available to my GP. He can't log in and see my blood results and vice versa you find the consultants I work with. (Brady)  Self-monitoring as liberation or labour  If you had the tracker to track your side effects, and kind of read them, the sever you'd actually be able to present a printout for your consultants, and you said, we about this, and okay, if you're not going to help me, who do I talk to about, you help support you in your communication with your consultant. (Mariah)  Decision-making as empowerment or pressure  But I think, you know, having a certain level of participation and using the technic that, that that really helps rather than, you know, it's Well, when I go into the dominutes, he's going to tell me everything's okay. So, they think it's having them be people say, for example, if I had, if I was recovering from, say bone cancer, which	
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pressure minutes, he's going to tell me everything's okay. So, they think it's having them b	
$\gamma = 1$	oe aware. So,
painful. And even with the treatment stuff, so but if I could monitor and say, Loo	k, you know, I
went for a walk for two kilometres today because I felt good, right? (Laura)	
But the other thing is that it allows people to be more involved in their care. So, of the big thing. (Laura)	I think that's kind
And I suppose solutions is more information. And something about enabling and people to take a bit of responsibility for their own health, and also as well as that way of navigating through (Grace)	
So those, those girls are building an app and a patient app. And so, I'm on the potential that. So I was suggesting that it would be nice if I was able to record each of my then when I'm supposed to take it, and the app would alert me. (Mariah)	
Trust and Privacy as a So, to be very clear, how long your data is going to be kept, where it's going to b	be kept, what you
reluctance: precarious trade-off know, how was going to be protected? That's a big one, (Laura)	

Theme	Subtheme	Illustrative Quote
narrowing the digital divide		Now obviously there's issues with GDPR and yeah, and things like that, that if you want to talk to somebody privately, are you making sure that the other person has left the room so they can speak in private, this kind of stuff. (Brady)
	Dependency on technology: A new vulnerability?	I think, particularly, let's say my cancer was prostate cancer, which is a cancer affecting men, probably over 60, some who may not be very familiar with technology, who may have never used technology in their lives, like I come from an office background. I'm used to using computers and so on (David)
		But I would imagine for a lot of people who are, say 40, 50 plus an age, they may not have access to the technology that they need, they may not understand it. (Laura)
		and if you're an older person or a person with limited capabilities, and if it goes wrong, they can't troubleshoot it, they can't manage it (Mariah)
	Tech hesitancy as resistance	But I think yeah, so to the total reliance on it and the expectation assumes that everyone can or will automatically benefit. The benefits from us are not realistic. (Emma)
		we're not used to communicating, communicating with people via zoom and whatever. The, and so the connection, the personal connection is not there. And, you know, somebody doesn't know me. So, it's very hard to have a genuine conversation about your own health (Jessica)
		I appreciate, and I can see the benefits of technology in medicine. But for, for my own personal opinion is that there, there it doesn't compare to actually meeting somebody in person. There's no doubt about that (Brady)
		I was a little scared, because, you know, I prefer a person adopted what, once I saw the videos, and they explained to me that the doctor is actually using it's like a game almost. (Laura)
		I suppose there's a bit of a bit of resistance and fear and not a lot of people, but I've had people say to me, I'm no good with technology, but they don't really, it's because they haven't been exposed to you know, much. (Sarah)

Theme	Subtheme	Illustrative Quote
The power of	Raising awareness	I suppose you're going to have to have some kind of a campaign, I think around it, to highlight it,
knowledge and	to overcome the	that it's available. And that it's, it's becoming the norm, that it's more convenient. It'll be more
awareness	unknown	accessible for a lot of people if you have mobility problems or whatever. (Emily)
		Well, I think it's stuff. It's, it's not widely known about, you know, what technology is there? What? Because, you know, what we've discussed? I haven't heard of any of it, really? So I think that's the biggest barrier is information. Education. (Daniel)
		I wasn't even aware of anything. And I suppose from talking to the consultants, the nurses or the doctors, nobody suggested any kind of technical platforms or apps to use (Lucy)
		It's an unmet need. Yeah. Like how I knew from ARC from the last from the very first time 27 years ago ARC was there, but I didn't access it because I didn't know if it was for me. It was like your Nobody said yes, it is for you (Rachel)
		It and wouldn't, I think it would be good to make, you know, to start earlier, even in schools. And you know, maybe teach children about this stuff, you know, and kind of like, look, you know, this is a cancer, this is the technology we have I (Daniel)
		I would imagine the best way you can educate people is definitely through the education system like the schools, but I think also through media, media change, there is need to change the conversation, like, every conversation, and media is about blaming someone for something, every conversation is about blaming, rather than enabling. (Grace)
		There are courses there for the elderly. The active retirement courses there. The libraries do courses. So they're out there. But it's up to the individual. Each individual is responsible for their own well-being of their health. (Samuel)

Theme	Subtheme	Illustrative Quote
	Enhancing digital literacy as an empowerment tool	Better training and education just in using it. You know, and maybe, you know, as I say, I find the YouTube clips good, but then you have to know how to get into YouTube. But if you buy a new appliance, oftentimes kitchen appliance or something using If so, but I'm just thinking, should there be things like to like technology Days or bring your device. You know, I don't know if they're doing it to the library or town where we live or, you know, technology town, whatever. I don't know (Sarah)
		But maybe there is a need for a national strategy to help, there must be something you knew when I'm talking about like saying James has this huge emphasis on pre op classes, post op classes, etc. So, in a sense, that's very good, and you're getting people fitter. So, what perhaps would be the equivalent that you could do in relation to technology. Or is a fact that people learn about technology when they need to. (Sarah)
		But also, maybe there are skills that they, the professionals, need to develop, yes, to make patients or clients more comfortable with the technology and, you know, the process and not like, if you can't manage this, you can't have anything. (Jessica)
		Yes. Well, I presume the patient in order for it to start the patient requires a certain level of digital literacy and faith in the whole thing, and you know, just the technology. But I also think that professionals need to learn to develop whatever ways to make the patient feel confident, yes, this can work. (Jessica)
	COVID-19 as a litmus test	So, and while I was sick and through COVID and everything I think I even got more involved because of zoom. You could get involved in global research. (Emily)
		Post COVID-there has been a lot of digital digitalization efforts and how was that world not only in Ireland, but everywhere. Not only in healthcare, but even in society, in libraries everywhere. (Emma)
		you know, after a while, people get used to anything, which is what happened during COVID.  That, you know, people who never had zoom meetings or team meetings ended up having them

Theme	Subtheme	Illustrative Quote
		and, you know, all of a sudden, people can think of all the advantages more than the disadvantages. So, I presume the same works with telehealth, you know, it'll become like that over time (Jessica)
		Technology is exploding. Okay, so then there's the spark ignite, the innovation program with the doctors in the HSE, and there's going to be so many things that spin out of that. (Mariah)
		I'm happy. I think the only thing is kind of like the like this kind of technology. When we look at what's happened technologically in the last 20 years, like a lot of the stuff that we're going to be using in the next decade, it it's, it's really just in its infancy now and it is going to develop at a rapid rate and the tools that we can use (Daniel)