Long title:

The Feasibility and Acceptability of ExerciseGuide UK: A Web-Based Platform for Personalised Physical Activity Programmes and Educational Resources for Individuals Living with and Beyond Lung Cancer: A Mixed Methods Thesis.

Short title:

Feasibility and Acceptability of a web-based platform for those Living with and Beyond Lung Cancer: a mixed methods thesis.

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PhD by Thesis

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Abstract

Background: Lung cancer has a high incidence and mortality rate, particularly in older adults (65y+). Physical activity can improve the physical and psychological health of these patients. A virtual exercise and education programme could address barriers to engaging with technology and improve health outcomes.

Purpose: Determine the feasibility and acceptability of a website providing personalised physical activity programmes and education for those diagnosed with lung cancer.

Methods: This doctoral research was comprised of three primary components: 1) a systematic review, 2) development of ExerciseGuide UK and usability assessment, and 3) a mixed-methods study examining of the feasibility and acceptability of ExerciseGuide UK for those living with and beyond lung cancer (LWBLC).

Results: Systematic review findings suggest that online supportive care programmes for people LWBLC may be feasible and acceptable, though the field is within its infancy. The mixed-methods feasibility and acceptability demonstrated that ExerciseGuide UK appears feasible for a subset of lung cancer patients, however, it is important to focus on improving accessibility for those with limited digital access and literacy. Overall, ExerciseGuide UK was well received, and participants regarded it as a useful supplement to current cancer treatment.

Conclusion: ExerciseGuide UK demonstrated low-moderate feasibility and moderate acceptability among those living with and beyond lung cancer. Collaboration with patients contributed insights that were crucial to the study. The key next stages will be to maximise equitable access to digital platforms and interventions, increase support for those who experience breathlessness and continue evaluations through larger trials. The foundation for incorporating digitally delivered, personalised supportive care into lung cancer routes has been set forth in this thesis.

Declaration of Authorship

"I confirm that this work is original and that if any passage (s) or diagram (S) have been copied from academic papers, books, the internet or any other sources these are clearly identified by the use of quotation marks and the reference (s) is fully cited. I certify that, other than where indicated, this is my own work and does not breach the regulations of HYMS, the University of Hull or the University of York regarding plagiarism or academic conduct in examinations. I have read the HYMS Code of Practice on Academic Misconduct and state that this piece of work is my own and does not contain any unacknowledged work from any other sources. I confirm that any patient information obtained to produce this piece of work has been appropriately anonymised".

Publications and presentations

Publications:

1. **Curry J,** Roberts H, Smith A, Riley D, Pearson M, Forbes CC. Developing and testing the ExerciseGuide UK website for people with lung cancer: reflections on the added value of patient and public involvement within a doctoral degree. Research Involvement and Engagement. 2022;8(1):66. (1)
2. **Curry J,** Lind M, Short CE, Vandelanotte C, Evans HEL, Pearson M, et al. Evaluating a web-based computer-tailored physical activity intervention for those living with and beyond lung cancer (ExerciseGuide UK): protocol for a single group feasibility and acceptability study. Pilot and Feasibility Studies. 2022;8(1):182. (2)
3. **Curry J,** Patterson M, Greenley S, Pearson M, Forbes CC. Feasibility, acceptability, and efficacy of online supportive care for individuals living with and beyond lung cancer: a systematic review. Supportive Care in Cancer. 2021. (3).

Invited Speaker Presentations:

1. Involve Hull, Patient and Public Involvement Event. Moving for better health. 2023.
2. Exercise Oncology: Understanding the Benefits and Challenges of Physical Activity for Those Living with and Beyond Cancer. Hull and East Riding Living with and Beyond Cancer conference. Oral presentation. 2023.
3. Enhancing Wellbeing for Cancer Survivors: The Intersection of Exercise Oncology, Digital Technology, and Behaviour Change. Royal Marsden Oncology Physiotherapist Society. Online. 2023
4. Wolfson Palliative Care Research Centre & University of Technology Sydney's Creating Connections Palliative Care Conference (Virtual); E-health online support for people living with and beyond lung cancer. 2022.
5. National conference of UK ALK-positive patients and families. The Benefits of Exercise for Lung Cancer. 2022.

Poster Presentations:

1. **Curry J**, Roberts H, Smith A, Riley D, Pearson M, Forbes CC. (2023). The development and testing of a website (ExerciseGuide UK) for people with lung cancer: reflections on the added value of patient and public involvement within a doctoral degree. Presented at the Perspectives on Exercise in Clinical Populations in Manchester, UK. Poster.
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3. **Curry J**, Roberts H, Smith A, Riley D, Pearson M, Forbes CC. (2023). The development and testing of a website (ExerciseGuide UK) for people with lung cancer: reflections on the added value of patient and public involvement within a doctoral degree. Presented at the Annual meeting of the International Society for Behavioural Nutrition and Physical Activity, Uppsala, Sweden. Chaired Poster Session.
4. **Curry J**, Evans HEL, Lind M, Short CE, Vandelanotte C, Pearson M, Forbes CC. (2023). Digital Personalised Physical Activity and Education Program for Lung Cancer Patients: Feasibility and Usability. Presented at the Annual meeting of the American College of Sports Medicine, Denver, Colorado, United States. Thematic Poster. (Nominated for best poster).
5. **Curry, J**., Lind, M., Short, CE., Vandelanotte, C., Evans, HE., Pearson, M., Forbes, CC. (2022). Examining the usability of a web-based tailored physical activity intervention for those living with and beyond lung cancer (ExerciseGuide UK). Presented at the Annual International Journal of Behavioral Nutrition and Physical Activity. Virtual Short Oral.
6. **Curry, J**., Lind, M., Short, CE., Vandelanotte, C., Evans, HE., Pearson, M., Forbes, CC., (2022). Examining the usability of a web-based tailored physical activity intervention for those living with and beyond lung cancer (ExerciseGuide UK). Presented at the i3 Creating Connections Conference

between Wolfson Palliative Care Research Centre & University of Technology Sydney. Virtual Poster.

7. **Curry, J**., Patterson, M., Greenley, S, Pearson M, Forbes CC (2022). Feasibility, acceptability, and efficacy of online supportive care for individuals living with and beyond lung cancer: a systematic review. Presented at the i3 Creating Connections Conference between Wolfson Palliative Care Research Centre & University of Technology Sydney. Virtual Poster.
8. **Curry, J**., Patterson, M., Greenley, S, Pearson M, Forbes CC (2021). Feasibility, acceptability, and efficacy of online supportive care for individuals living with and beyond lung cancer: a systematic review. Presented at the Hull York Medical School Postgraduate Research Conference. Virtual Poster
9. **Curry, J**., Patterson, M., Greenley, S, Pearson M, Forbes CC (2021). Feasibility, acceptability, and efficacy of online supportive care for individuals living with and beyond lung cancer: a systematic review. Presented at the NCRI 2021 Festival. Virtual Poster.

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work, dedication, and determination. Her memory continues to inspire my pursuit of knowledge and education.

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Chapter 1 Introduction to Physical Activity and Online Technology within Lung Cancer

Cancer can be described as the uncontrollable growth and division of cells within the body, which can invade nearby tissue or spread throughout the body. When a cancer spreads to a different part of the body from where it originated, it is known as cancer metastasis (4, 5).

Cancer is a leading cause of death internationally and is accountable for approximately 9.6 million deaths worldwide in 2018 (6). Breast, prostate, lung, and bowel are the most common forms of cancer among men and women, accounting for 53% of all new cancer cases within the UK (7).

Globally, the UK ranks within the top 10% of cancer incidence (i.e. how many new cases develop in a population over a specified period of time), with one person diagnosed with cancer every two minutes (7), equalling over 360,000 new cancer cases diagnosed each year. Therefore, this disease exerts a substantial burden not only on the healthcare system but also on the wider society.

The mortality rate from cancer is a clear indicator of its impact, with around 167,000 deaths each year attributed to the disease. This equates to approximately 460 deaths each day, making cancer responsible for more than a quarter of all deaths in the UK (8). Lung cancer, despite being the third most common cancer in terms of incidence, is the leading cause of cancer death, underscoring the particular severity of this cancer type and the challenges associated with its treatment and management (9).

However, there is a wider impact beyond direct health outcomes. Cancer also places a significant economic burden on the UK. This includes direct healthcare costs related to diagnosis, treatment, and supportive care. The psychological and social effects of cancer are profound, affecting not only those diagnosed with the disease but also their families, friends, and communities. The emotional impact of a cancer diagnosis can lead to anxiety, depression, and a decrease in quality of life (10).

The burden of cancer in the UK highlights the critical need for effective prevention, early detection, and treatment strategies, as well as comprehensive supportive care services to address the physical, emotional, and social needs of those living with and beyond cancer. Additionally, it underscores the importance of ongoing research into all aspects of cancer care, from the development of innovative treatment approaches to the exploration of how digital technology can be leveraged to improve outcomes for patients.

Building on the understanding of the substantial burden cancer places within the UK, it becomes vital to explore ways beyond standard medical intervention. The complexity of cancer, spanning from diagnosis through long-term management or palliative care, necessitates a holistic approach to treatment. This is where the concept of supportive care emerges as a cornerstone in the continuum of cancer care. Supportive care encompasses a broad spectrum of services designed to meet the physical, emotional, and social needs of patients and their families, aiming to improve the quality of life for those affected by cancer. As the focus shifts to the intricacies of supportive care, it is important to recognise its role not just as an adjunct to traditional cancer treatments, but as an integral component of comprehensive cancer management.

Before discussing supportive care, it is important to understand the terminology behind an individual diagnosed with cancer. There are many terms for individuals who have received a cancer diagnosis; cancer survivor, cancer patient, fighting a battle with cancer, living with cancer, and living with and beyond cancer. In this thesis, the term living with and beyond cancer will be used throughout. Those living with and beyond cancer may be any individual who has received a cancer diagnosis in their life. The impact of cancer does not cease post-treatment. Henceforth, those who have received a lung cancer diagnosis up until death will be referred to as those LWBLC.

1.1 Supportive Care

Within oncology, supportive care is dedicated to mitigating and managing the adverse impacts associated with cancer and its various treatments. This crucial aspect of cancer care encompasses the comprehensive management of both physical and psychological symptoms and side effects across the cancer trajectory, from the moment of diagnosis through the treatment phase and extending into follow-up and post-treatment care. The overarching goal of supportive care is to enhance the quality of rehabilitation, facilitate the prevention of secondary cancers, support individuals in their survivorship journey, and ensure compassionate end-of-life care, as outlined by the Multinational Association of Supportive Care in Cancer (MASCC) (11). Integrating this with the core objectives, alleviating physical discomforts such as pain, nausea, and fatigue, and addressing the emotional and psychological toll of cancer by offering counselling, stress management, and psychological support, supportive care serves as a cornerstone in the holistic treatment of cancer patients. It extends its reach further by providing social and logistical support, including facilitating access to support groups and community resources, and navigating the logistical barriers of treatment access. This ensures that patients are not only supported in managing the physical and emotional aspects of their disease but are also afforded dignity, comfort, and a comprehensive wellbeing framework that acknowledges the multifaceted challenges they face. Supportive care thus becomes a vital component of the cancer care continuum, emphasising the need for a compassionate, holistic approach that values and addresses the varied needs of patients and their families throughout the cancer journey. Due to this, supportive care in cancer is widely accepted as a critical aspect of the cancer journey (12) and a recurring key feature in the NHS Long Term Plan (LTP) for improving cancer outcomes and inequalities (13). The European Society for Medical Oncology published a position paper encouraging a holistic approach to patient-centred care, including personalised supportive care within the cancer pathway, from diagnosis onward (14).

1.2 Provisions of Supportive Care

The provision of supportive care in oncology, while recognised as essential, faces significant challenges that impact its accessibility and integration into standard cancer care. One of the key issues is the disparity in access to supportive care services (15). This variance is not just a geographical issue affecting individuals in different regions but also a demographic one, with notable differences in availability and utilisation among various patient groups. Factors such as socioeconomic status, age, ethnicity, and even the type of cancer diagnosis can influence a patient's access to supportive care services, leading to inequities in the quality of care and outcomes (16, 17). Such disparities underscore the need for targeted efforts to ensure that supportive care is accessible to all who need it, irrespective of their location or background.

Furthermore, the integration of supportive care into the standard cancer care pathway presents another layer of complexity. Despite its recognised value, supportive care often struggles to find its place as a core component of cancer treatment, frequently viewed as an optional or secondary consideration rather than an integral part of patient pathway. This perception may impact the allocation of resources, including funding and training for healthcare professionals, necessary to implement effective supportive care.

Addressing these challenges requires focused efforts from healthcare systems, policymakers, and the medical professionals to re-evaluate and redesign cancer care delivery. By prioritising equitable access and integrating supportive care as a fundamental aspect of cancer treatment, a greater move towards a more compassionate and comprehensive care model that appropriately meets the needs of all patients. Acknowledging the challenges inherent in the provision of supportive care in cancer highlights the pressing need to explore and models of supportive care in oncology.

Addressing the challenges in the provision of supportive care is a vital step. The next critical step involves exploring the various modalities through which this care can be delivered. From traditional face-to-face to the rapidly emerging field of eHealth, each modality offers unique advantages and opportunities to enhance the accessibility and effectiveness of supportive care in oncology. Understanding how best this can be used to meet the diverse needs of those living with and beyond cancer will create a key shift towards a more inclusive and adaptable approach to cancer care.

1.2.1 Supportive Care Modalities within Cancer

An increasing body of literature highlights that timely access to supportive care may increase QoL, survival, and positively impact the health economy (18, 19, 20). Though the benefits of supportive oncology care are known, care is provided via multiple oncological disciplines in the absence of a supportive oncology speciality. Figure 1 **Error! Reference source not found.**illustrates the ‘Supportive Care Umbrella’, detailing the patchwork of supportive care.

Exploring one domain stated in the Supportive Care Umbrella, palliative care has evolved over the past five decades from a mere philosophy to a professional speciality (21).

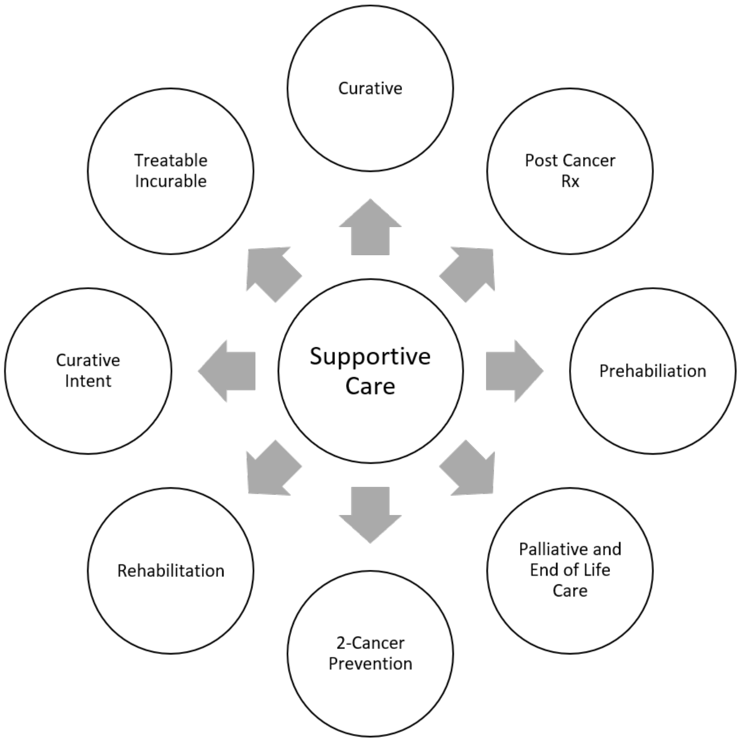


Figure 1: Supportive Care Umbrella, adapted from Berman et al., (22)

Historically, supportive care has been face-to-face (including telephone), supplementary written resources or online-based approaches. However, the yearly disproportional rise in cancer prevalence is not matched by an increase in resources, adding to the healthcare system's inability to provide adequate care to an increasing number of patients (23). Face-to-face engagement is often the most common within cancer care, though the integration of online support has increased. Online technology can minimise time spent in ambulatory care and supplement oncological staff's limited time during face-to-face visits (24).

1.2.1.1 Face-to-face

Communicating and distributing information with patients and carers in person is a standard mode of delivering supportive care information to those living with and beyond cancer.

Face-to-face communication is a highly valued method of supportive care by those living with and beyond cancer and carers when engaging with trained healthcare professionals who can emotionally engage with patients and convey information. Though effective communication skills are essential within supportive oncological care, communication skills are reported poor by patients and carers (25). However, NICE suggests oncological professionals may feel their training is insufficient regarding several aspects of communication, such as exploring complex treatments, sensitive listening, and end-of-life discussion (25).

In addition to face-to-face supportive care, the rapidly emerging realm of online supportive care is revolutionising supportive care while reducing several health inequalities.

1.2.1.2 Online

Using online mediums to deliver supportive care is an emergent area of healthcare research (26). Globally, there is an increasing number of individuals who are using smartphones, attracting the attention of healthcare professionals, researchers, and policymakers due to the extensive capabilities of such devices (27). Furthermore, reviews indicate that those living with and beyond cancer find mobile and internet-based interventions feasible and acceptable (28, 29). Internet and mobile-based applications for those living with and beyond cancer have attracted the attention of psycho-oncological researchers, proposing exploration of using the internet and mobile-based platforms to deliver psychosocial interventions within cancer populations (28, 29, 30).

However, the application to other domains of supportive care, such as physical activity is less explored within oncology.

1.3 Physical Activity and Exercise

Physical activity and exercise are commonly used interchangeably yet describe explicit concepts (31, 32). Physical activity is characterised as any bodily movement caused by skeletal muscles resulting in energy expenditure (31). Exercise refers to a subcategory of PA, wherein physical activities are carried out in a planned, structured, and repetitive manner with the aim of improving or maintaining physical fitness (31).

Physical fitness is defined as a set of traits that are health or skill-related (31). More modern definitions have characterised physical fitness as a physiological state that enables individuals to meet daily living or athletic performance demands, or both (33). In this thesis, the terms pertaining to PA and exercise will be used. Though, the clarification of PA by Warburton and colleagues (2006) will be employed regarding physical fitness.

Exercise has rapidly emerged as a key component of comprehensive cancer care. Recognised by leading health organisations, including the NHS, American College of Sports Medicine (ACSM), and the Clinical Oncology Society of Australia (COSA), exercise is recommended for its general health benefits and specifically for its role in cancer care. ACSM guidelines, updated with newly identified research, support exercise for those living with and beyond cancer, promoting adherence to the 2008 Physical Activity Guidelines for Americans (34). These guidelines stress the importance of adapting exercise routines to accommodate the specific health status and treatment side effects experienced by those living with and beyond cancer. This adaptation helps mitigate the physical impacts often associated with cancer treatments and advocates for maintaining some level of physical activity as a key component of recovery and long-term health management (35). Though, the field is still relatively new, exercise oncology has rapidly developed as a global specialised field, focusing on integrating exercise within the cancer pathway. The benefits of exercise across various levels of cancer care, biological, psychological, and quality of life, are unequivocally supported within the literature (36, 37, 38). Systematic reviews have shown that regular physical activity contributes to reduced mortality and reduces many of the adverse effects of cancer treatment, such as fatigue, depression, and decreased physical function (39, 40). Despite the strong foundation of evidence supporting the guidelines, their implementation has been sporadic, hindered by a lack of specific training for oncology professionals on how to integrate exercise effectively into treatment plans (41). However, the benefits are not solely limited to the treatment phase.

The positive impacts of exercise extend well into the post-treatment phase, often referred to as the survivorship phase. Research suggests that tailored exercise programmes can improve physical endurance, muscle strength, and overall psychological well-being, thereby enhancing individuals' quality of life (42, 43). Furthermore, consistent physical activity has been linked with reduced risks of cancer recurrence and a lower risk of developing secondary health issues related to cancer and its treatment, such as lymphedema and osteoporosis (44, 45). These findings underscore the value of incorporating regular physical activity as a standard part of cancer survivorship care, adapted to the survivors' specific health and recovery needs (46).

Despite a strong evidence base highlighting the exercise benefits for various cancers, specific research on those living with and beyond lung cancer is notably limited (47). Those LWBLC often experience more severe declines in physical function due to, such as the aggressive nature of their treatment, the disease's impact on respiratory function and age. This highlights a critical research gap and illustrates a clear need for targeted interventions that address the unique challenges that LWBLC faces. Identifying and implementing effective exercise programmes for this group could substantially enhance active treatment-related outcomes, post-treatment recovery, and quality of life, providing a vital area for future research and programme development (48).

Integrating digital technology into exercise oncology offers an innovative and promising opportunity for enhancing exercise interventions' delivery, effectiveness, and implementation. Digital tools, including telehealth platforms, websites, mobile health applications, and wearable fitness trackers, provide personalised, adaptable, and scalable solutions. This approach leverages the growing evidence supporting digital interventions in managing non-communicable diseases, such as diabetes and cardiovascular diseases (49, 50, 51) and extends these benefits to cancer care. Though there is progress in some domains, applying such technologies in the context of specific cancers, such as lung cancer, is still developing and requires focused research.

Digital devices facilitate real-time monitoring and feedback, empower patients to manage their health actively, and improve adherence to prescribed exercise programmes. For example, wearable devices can track physical activity levels and physiological outcomes, providing patients and healthcare providers with direct insight into the safety and effectiveness of exercise programmes. Additionally, mobile apps can deliver customised exercise content tailored to the needs and limitations of individual patients, enhancing the accessibility and personalisation of care. Lastly, tools such as websites can provide a larger platform which can be accessed via computers and laptops, which may promote accessibility for older users who may have limitations due to visual or dexterity conditions (52).

The potential of these technologies is more comprehensive than individual patient care. These tools can reach underserved populations, address geographical and organisational barriers, and provide continuous support and motivation for patients throughout their cancer journey (53). By integrating these digital tools, exercise oncology can exceed traditional boundaries, offering more inclusive and comprehensive care solutions (54).

Incorporating exercise into cancer care may offer a wide range of benefits that extend beyond immediate improvements in physical health to enhance psychological well-being and overall survival rates. As the field of exercise oncology continues to grow and expand, future research must explore innovative ways to implement and sustain exercise interventions, particularly through digital technologies, to ensure all cancer patients can access the vast range of benefits physical activity offers.

1.4 Digital Technology

As highlighted throughout the introduction, digital technology may provide a innovate way of addressing some of the barriers faced within supportive care and physical activity access. Since COVID-19, digital technology within healthcare saw exponential growth, but it is important to understand what is meant by ‘digital technology’. There are varying terms used, such as eHealth, mHealth, and Telemedicine. It is important to distinguish what they mean, as sometimes they are misapplied and used interchangeably.

Within healthcare, electronic health (eHealth) covers a wide range of technologies, including computers, laptops, telephones, mobile phones, and wireless communications to healthcare providers and patients, and translates the management of care and education (55, 56). Mobile health (mHealth) is a subtype of eHealth, focusing more on innovative and portable devices used for health and information services (55, 57). Telemedicine is another common term used in digital healthcare and is categorised as a subtype of eHealth. Telemedicine is expressed as health care services delivered at a distance (not in their standard location) (55).

Though there has been a rapid growth in technology in the past five years, the integration of policies surrounding the integration of technology into healthcare setting, including oncology supportive care is not new.

1.4.1 Policies Surrounding Cancer and Digital Technology

In 2015, an independent task force developed a UK national cancer strategy to improve the experience throughout the cancer pathway (58). An accelerated approach to enhancing the support of those living with and beyond cancer, offering advice on weight control, exercise, smoking cessation, and reducing alcohol consumption (58). The five-year plan (2015 – 2020) recommended the importance of the outcomes that matter to patients. Digital technology has been consistently noted in the strategic plan as an opportunity that requires further development and could support the transformational delivery of care and increase reach (58). Furthermore, the 2015 – 2020 cancer strategy highlighted the benefits of PA post-cancer treatment and discussed the substantial evidence indicating individuals should engage in a PA programme after treatment. However, the strategy highlighted the lack of advice and opportunities available to those post-cancer treatments while underlining the importance of advice surrounding PA and lifestyle behaviour (58). A recent strategy has been developed based on the 2015 strategy by the NHS, the Long-Term Plan (LTP), for cancer outcomes (13).

The LTP, developed by the NHS in 2019, details the 10-year plan to improve cancer outcomes in the UK (13). The NHS LTP highlighted the importance of increasing PA capacity and its impact on the physiological and psychological QoL among those living with and beyond lung diseases (13). The NHS LTP aims to explore new rehabilitation and self-management support models for those living with lung conditions, such as lung cancer (13). Tailored health and well-being support should be accessible to all who have received a cancer diagnosis. No two cancer patients are the same and require individualised treatments and recoveries (58). Personalised care may allow individuals to utilise and maximise digital and community-based support (13).

The NHS's current strategy aligns with the longstanding National Institute for Clinical Excellence (NICE) guidance for improving supportive care for adults with cancer (25). NICE has stated that PA can positively impact an individual's physical and emotional health (25). The utilisation of digital technology to deliver PA through an online platform presents a contemporary approach to overcoming health inequalities, such as accessibility to those living in rural or remote areas or difficulty travelling (59). In February of 2021, the Secretary of State for Health and Social Care in the UK further supported digital technology, highlighting the development and implementation to improve patient and staff care (60). Though, policies presented by elected government parties and their officials must be taken with caution. Due to the transient shift in elected UK government ministers and parties. The European Cancer Patient Coalition aligns its values with UK policies emphasising the value and benefits digital technology can bring, particularly to the increasing numbers of those affected by cancer (61).

Digital technology has been a priority in UK health policies for several years. The importance of digital technology remains at the forefront of the LTP for the NHS and internationally policies. Furthermore, the NHS LTP suggests that physical inactivity and smoking are significant health concerns within the UK, and have been labelled as priorities (13). The intersection of digital technology and PA are central to this doctoral research and thus align with the NHS LTP on multiple key priorities. However, where digital technology fits within lung cancer supportive care is yet to be discussed.

Breast, prostate, lung, and bowel cancer remain the four most common cancer types within the UK (8), with lung cancer continuing to be the leading cause of cancer-related mortality internationally (62). Nonetheless, lung cancer research outputs are less frequent than their counterpart's cancer (63, 64). Over the last decade, the allocated funding for lung cancer has increased by 118% (2009 – 2019) (65). Though, funding allocated to control, survivorship and outcomes research has decreased over the decade (65).

Documents and policies clearly demonstrate that digital technology will play a substantial role in healthcare in the near future. Though digital technologies must be appropriately developed, adapted, and assessed before larger-scale implementation.

This doctoral research builds on the LTP within healthcare and the evident inequality within survivorship lung cancer research. Though, it is important to explore the literature behind the intersection of digital technology and physical activity.

1.5 Digital Technology and Physical Activity

Several systematic reviews have consistently supported the application of web-based PA interventions in paediatrics to elderly populations (66, 67, 68). A systematic review of mixed cancer cohorts, by Haberin et al. (2018) reported that various delivery methods to promote PA are utilised, including web-based applications, mobile technology, and e-mails. Though web applications were the most popular (26), it is unclear whether web-based or mobile-based platforms are superior to one another. Ester et al. (2021) found that when examining the current evidence for eHealth PA interventions for those living with and beyond cancer, the two most common forms of technology used were wearable devices (61%) and websites (48%) (69). Other technological approaches reported were SMS text messaging (28%), mobile applications (27%), and email (22%). Supplemental telephone contact was also used in 37% of the studies (69). However, of the 67 studies included, three examined lung cancer independently, 29 were a mixed/any group, and 24 were breast cancer (69). Furthermore, none of the studies examining lung cancer were conducted in the UK, with one being in the USA, one in the Netherlands, and one in Australia.

1.5.1 Non-communicable diseases

eHealth is used widely across various non-communicable disease groups. Non-communicable diseases (NCDs) can be defined as a chronic disease often over a more extended period due to environmental, behavioural, physiological, and genetic factors (70). Common NCDs are diabetes, chronic respiratory diseases, cardiovascular diseases, and cancers. Given that the literature regarding lung cancer and digital health is limited, evidence can be drawn from NCDs to illustrate themes that may be applied to those LWBLC. The literature surrounding the NCDs highlighted above will now be delineated.

1.5.1.1 Diabetes

Diabetes is categorised by hyperglycaemia (abnormally high blood sugar level) due to defects in insulin secretion, insulin action, or both (71). For those living with diabetes, PA is a crucial component of disease management and is associated with physical and psychological benefits (72). Like those LWBLC (48, 73, 74), the literature indicated that those living with diabetes do not participate in and have difficulty maintaining regular PA (75). Cancer and diabetes have shown barriers that can make PA participation and adherence difficult, such as limb pain, peripheral neuropathy, and limited endurance (76, 77, 78). eHealth has shown promise in the diabetes population with cost-effectiveness, personalisation, and a wide range of delivery (79). All benefits are applicable to those living with and beyond cancer. Evidence supports the utilisation of online PA programmes tailored for those living with diabetes (80, 81) and goal-setting strategies to promote PA (82).

1.5.1.2 Respiratory Diseases

Chronic respiratory diseases (CRDs) impact breathing and airflow, such as in the airways and lungs (83). Common CRDs include pulmonary hypertension, occupational lung disease, chronic obstructive pulmonary disease (COPD), and asthma. COPD and lung cancer both report high symptom burden, reduced QoL, dyspnoea, and reduced physical capacity (84, 85). COPD and lung cancer also share similar molecular and physical characteristics (86, 87) Digital technology and eHealth resources have been used in respiratory patients' care, including teleconsultations, telemonitoring, and pulmonary rehabilitation (PR) (88) and has been acknowledged by the European Commission for the potential eHealth and telemedicine bring to managing CRDs such as COPD (89). Interestingly PR has been shown to reduce symptom burden and improve exercise capacity, self-efficacy, knowledge, and health status (90, 91, 92, 93, 94, 95). Furthermore, PR has been shown to reduce hospitalisation and healthcare costs (96, 97, 98, 99). A systematic review and meta-analysis illustrated that when compared to comparator groups (e.g. ordinary care, exercise training and/or education), eHealth utilisation may lead to increased PA levels among those with COPD (84).

Bryant et al. (2019) and Lundell et al. (2015) convey the importance of eHealth concerning health inequalities and barriers to access to PR, including lack of transportation and geographic location, limited family support, and health conditions (84, 100). These barriers are echoed in other non-communicable diseases, most notably lung cancer. With online technology addressing these health inequalities and barriers within CRD populations and mutual symptom burdens, eHealth may be highly applicable to lung cancer and transcend solely PR.

1.5.1.3 Cardiovascular Diseases

Cardiovascular disease (CVD) is an overarching term for a number of diseases linked to the cardiovascular system. CVDs include peripheral arterial disease, cerebrovascular disease, venous thromboembolism, rheumatic and congenital heart disease, and coronary heart disease (101). Not only does PA provide a risk-reducing benefit for primary (102) and secondary CVD (103), PA can result in a reduced risk of hospitalisation, reductions in early mortality, and increases in QoL (104). Comparatively, these are also reported benefits within the cancer population.

A systematic review exploring healthcare delivery remotely during the COVID-19 pandemic reported that all included papers (n=9) highlighted the importance of eHealth for access to services during quarantine (103). Laustsen and colleagues (2020) highlight that an eHealth cardiac rehabilitation programme for those living with ischaemic heart and heart valve disease reported significant improvements in mean change from baseline to 12 months in muscle strength (0.5 N/m/kg (CI: 0.1–0.9) $p = 0.011$), endurance (0.3 Watts/kg; CI: 0.2–0.4; $p = 0.000$), power (0.4 Watts/kg; CI: 0.2–0.5) $p = 0.000$), and health reported QoL (five points; 2 – 8) (105). Furthermore, Neubeck and colleagues express that cardiac rehabilitation has a longstanding history of positive impacts. Maintaining such programmes for those with CVD is important (Neubeck et al., 2020), and online technology can facilitate such demand.

1.5.1.4 Cancer

The utilisation of online platforms is not novel within oncology care and support. There are several ways online technology can contribute to the delivery and management of cancer care.

Fitness bands and trackers have become increasingly popular in recent years. Fitness trackers have been used within oncological care to promote healthier behaviours by promoting PA. Additionally, fitness trackers provide real-time information on health-related indices such as heart rate, blood pressure, and sleep, which healthcare professionals have used during check-ups and follow-up periods (106). Virtual reality has been employed in cancer care in hospitals and homes. Wint et al. (2002) explored pain levels during lumbar punctures in adolescents and showed that the virtual reality group observed lower pain scores, though not significant (107). Additionally, virtual reality has been used to engage patients in treatment adherence (108).

Moreover, digital technology can provide symptom monitoring and reporting. McCann et al. (2009) used questionnaires on patients' mobile phones throughout chemotherapy treatment for lung, breast, and colorectal cancer patients, reporting improved symptom management and communication levels between patients and oncology professionals (109). Interestingly, within digitally delivered exercise within oncology, of the four most prevalent cancers (breast, prostate, colorectal, and lung), lung cancer seems to be less explored (110), presenting a key gap in the published literature.

1.5.1.4.1 Exercise, Digital Technology, and Lung Cancer

Digital technologies may enhance patient empowerment and integration of data across the entire cancer care pathway. As previously stated, lung cancer is typically diagnosed in older adults. Given the recent increase in older adults accessing the internet (111), eHealth may be a feasible and acceptable modality to deliver supportive care.

Ciani et al. (2019) describes the development of a telehealth application to promote symptom monitoring. Additional work incorporates PA with symptom monitoring for telehealth applications (112). Electronic follow-up with lung cancer patients successfully and significantly ($P < .001$) detected first relapse compared to routine surveillance between scheduled visits (113). Researchers in Italy developed a web-based self-management system, providing tailored care for those living with and beyond cancer. However, amendments were made to target those LWBLC due to lung cancer's healthcare and financial burden (114). With the known benefits of PA for those LWBLC, researchers have explored integrating PA delivery with online technology (26, 115). The evidence for PA and digital delivery for those LWBLC is limited.

A systematic review regarding social support and QoL indices for those living with and beyond cancer suggested that support from healthcare professionals and providers is associated with QoL's physiological and psychological constructs (116). Those

LWBLC do not regularly access or use supportive care services and resources (117). Online technologies such as eHealth and mHealth platforms can enhance symptom monitoring and management within a patient's home environment, aiding the mitigation of barriers associated with reduced access (118).

Historically, lung cancer is under-researched and less visible than other highly prevalent cancer types (119, 120); therefore, exploring other prevalent NCDs is imperative to ascertain comparable information on the utilisation and uptake of digital technology and PA. Since the inception of the *Journal of Cancer Survivorship* (from 2007 to 2020), 854 articles have been published, and n=6 (0.8%) of those articles explored lung cancer independently (119). The frequency of breast, colorectal, and prostate cancer was substantially higher, with 190 (24.8%), 45 (5.9%), and 36 (4.7) articles respectively (119). In a scoping review, conducted by Satter and colleagues (2023), examining the state of research, feasibility, safety, acceptability, and outcomes of remotely delivered exercise interventions utilising technology for older adults with cancer, 15 studies were reported on. Of those 15, only one study reported on lung cancer, with the primary sites being prostate cancer with nine studies (60%) and a mixed cohort of breast, prostate and colorectal with three studies (20%) (121). Once again demonstrating research into lung cancer is lacking in compared to other prevalent cancer types.

1.5.2 Summary of eHealth and Non-Communicable Diseases

Electronic health platforms and devices have been shown to offer a vast range of benefits for those living with and beyond cancer, CVDs, CRDs, and diabetes. Digitised supportive care can provide tailored advice based on an individual's characteristics and symptoms. Across various non-communicable disease groups, eHealth has been shown to provide support via remote monitoring, remote consultations, education, providing resources, socialisation, and the delivery of programmes such as PA. General and digital PA interventions are feasible and safe among those living with and beyond cancer (122, 123, 124), specifically lung cancer (3, 125, 126, 127, 128). The internet is regularly used by a wide array of patients and health care professionals to provide support throughout their disease pathway; being a vital resource and using internet-based methods has been demonstrated as valuable for encouraging individuals with cancer to self-manage aspects of their health and lifestyle. (129, 130). Mass data storage is simple, and content can be updated easily to ensure up-to-date standards (131). Several studies have reported the benefit of accessibility, reach, and convenience through online or computer-mediated communication because it can mitigate temporal and geographical barriers (132, 133, 134).

1.6 The Gap in Knowledge

As lung cancer begins to be highlighted as a gap in knowledge, it is important to have a deeper look into the specifics of lung cancer and its impacts. It is evident that while traditional supportive care approaches have been beneficial, they do not fully address the evolving needs of patients. A notable gap in our current approach is the underutilisation of digital platforms for exercise-based supportive care. In a time where technology plays a vital role in supportive health management, the absence of such interventions for those LWBLC highlights a key gap in our care strategies. This gap not only limits patient access to potentially life-enhancing resources but also highlights the need for research aimed at integrating these technological solutions into everyday care practices.

1.7 Lung Cancer Treatments and Side Effects

1.7.1 Preliminary Symptoms

Lung cancer often presents with unexplained cough, weight loss, anorexia, fatigue, chest pains, and/or shortness of breath (135, 136). Cancer-related treatments may exacerbate these pre-diagnosis symptoms and possibly lead to the development of additional symptoms. The impact of treatments is discussed below in Table 1. It is recommended that a clinician offers an urgent (within 14 days) thoracic x-ray if an individual is experiencing two or more symptoms and is 40 years or older. (135). Clinical signs of the development of lung cancer are supraclavicular lymphadenopathy, thrombocytosis, and persistent or reoccurring chest infection (135).

1.7.2 Treatments

The magnitude of physiological and psychological impairments varies based on cancer type, stage, and treatment (137, 138). An overview of the impairments from common cancer treatments (e.g., surgery, radiotherapy, chemotherapy, hormone therapy, and targeted therapy) are provided in Table 1.

Radiotherapy limits the rate at which cancer cells can divide and proliferate by damaging the genetic material of Deoxyribonucleic Acid (DNA). Through the process of cancerous cells being irradiated through radiotherapy, surrounding tissues and organs may be affected. Side effects such as lung or cardiac tissue fibrosis can negatively affect QoL through reductions in cardiopulmonary function (139, 140). Radiotherapy is used at every stage of clinical advancement in SCLC and NSCLC (141). It is not without short- and long-term symptoms though radiotherapy can be used in both curative and palliative methods.

Surgery to remove one or more lobes of the lung (lobectomy), entire lung (pneumonectomy), or removal of a small portion of the lung (segmentectomy) are the three types of lung surgeries for those living with lung cancer. The impairments' extent depends on the type of surgery and the associated complications.

Whereas radiotherapy and surgery are typically used to treat cancer locally, chemotherapy works systemically to stop rapidly dividing cells. Due to chemotherapy acting systemically, both cancerous and noncancerous cells can be damaged. Healthy cells are exposed to the same toxicities cancerous cells are, which can lead to several impairments and long-term symptoms (142).

Though radiotherapy, surgery, and chemotherapy are mainstream forms of therapeutic treatments, in recent years, targeted therapy has gained a large amount of attention due to reducing the toxicity of off-target cells and targeting specific cells (143). Targeted therapy aims to stop the growth and spread of malignant cells by interfering with malignancies gene and proteins, the environment wherein the cells are rapidly dividing (78). Immunotherapy attempts to use the immune system to kill cancerous cells, essentially by supercharging or boosting the immune system. Given the targeted nature of these therapeutic options, healthy cells are not readily impacted. Though, targeted therapies are not without side effects. Commonly reported impacts of targeted therapies are fatigue, muscle aches and dermatological, resulting in damage to hair, nails, and skin (144, 145, 146).

Treatments such as radiotherapy, chemotherapy, surgery, and immunotherapy, are the common curative treatment approaches for those diagnosed with lung cancer. These may be given individually or combined with other treatments (e.g., chemotherapy and radiotherapy, commonly known as '*ChemoRad*'). Albeit these treatments can be lifesaving, they can prolong and intensify symptoms, such as fatigue and breathlessness (147, 148, 149). Coupled with exacerbated symptoms of breathlessness and fatigue, depression can be severe in this population, with reports of feelings of extreme isolation, which can adversely affect one's mental well-being (150, 151). Quality of life is often reduced due to the curative treatment regime (152). Symptoms vary and are often dependent on the type of treatment received, often resulting in a complex array of psychological and physiological symptoms.

Table 1: Illustrating the changes caused by common curative treatment methods of common cancers adapted from Fairman & Galvão (78).

	Surgery	Radiation	Chemotherapy	Hormonal	Targeted
Fatigue	×	×	×	×	×
Pain	×	×	×	×	×
Cardiovascular		×	×	×	×
Pulmonary	×	×	×		
Cognitive	×	×	×	×	×
Immune System		×	×	×	×
Lymphedema	×	×			
Organ Function	×				

Empirical evidence of 19 studies reports pain, coughing, breathlessness, and fatigue as the most common symptoms post-surgery for lung cancer, with reports of breathlessness and fatigue persisting for two years (153).

1.7.3 Accelerated Ageing

Ageing is an inevitable process of nature. The process of ageing often incurs various physiological declines in human health, such as shortening telomeres, exhaustion of stem cells, reduced muscle mass and strength, decrease in bone density, respiratory decline (e.g. lung volume and elastic recoil), and cardiovascular decline (e.g., decrease in cardiac output and heart rate modulation and an increase in arterial stiffness) (154).

However, individuals living with and beyond cancer have an accelerated biological ageing compared to healthy adults (155). Essentially, an individual's biological age is greater than chronological age. The accelerated ageing phenotype due to cancer treatments, is shown in Figure 2**Error! Reference source not found.**. Clinically, accelerated ageing phenotypes for those living with and beyond cancer can be expressed as the onset and development of common age-related health conditions. This accelerated ageing is often exacerbated due to varying curative or controlling treatments (156, 157, 158). This process of accelerated ageing is principally due to the impact of treatments leading to divergent hallmarks of biological ageing, such as stem cell exhaustion, DNA damage, epigenetic alterations (e.g. DNA methylation and Histone modification, and Non-coding DNA), deregulated nutrient sensing, increased cellular senescence, and telomere attrition (159, 160, 161).

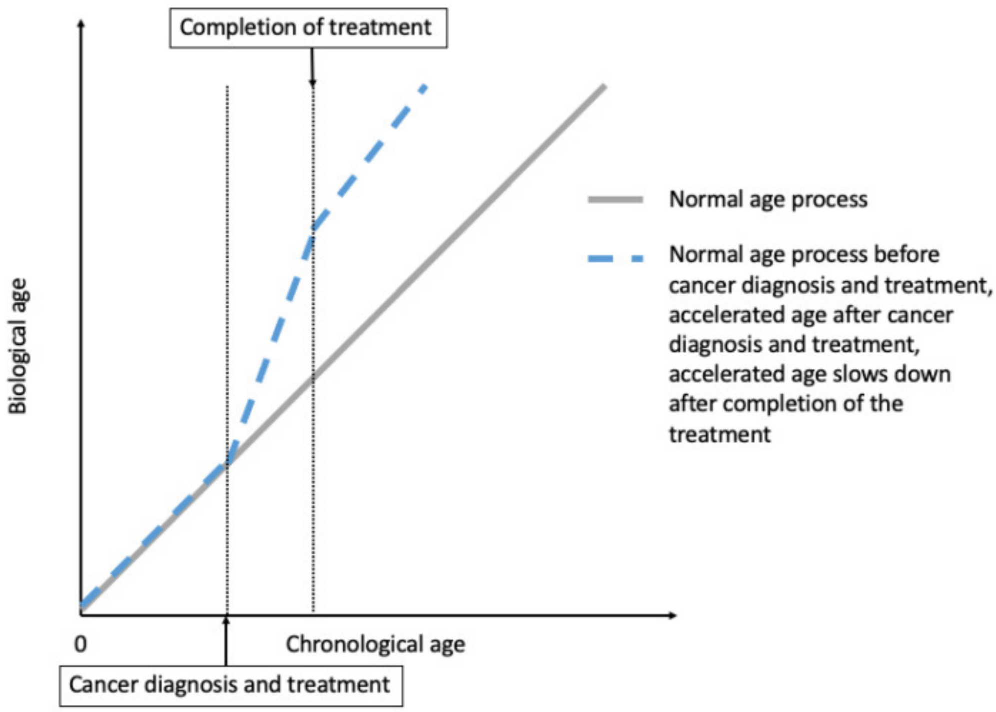


Figure 2: Illustrating hypothesised accelerated ageing due to cancer treatments (155). Figure adapted by Wang et al. (2021) from Guida et al. (2019) (162).

As mentioned, those whose biological age increases at a greater rate than their chronological age are likely to suffer from age-related health conditions, such as frailty, cognitive impairment, organ dysfunction, secondary cancers, and premature death (155). Therefore, it is critical to understand methods to manage the impact of cancer and its associated treatments.

1.7.4 Long Term Symptom Management

Integrating early initiation of survivorship and palliative-based care has been shown to be beneficial for symptom management and the improved survivorship trajectory (163, 164). Across the course of the disease, access to rehabilitation services has been noted to be lacking (165). Services such as physical and pulmonary therapy, informational support, and social work services can help ease the symptoms of fatigue and breathlessness while increasing physical function (165, 166). Comprehensive management of symptoms, including pharmacological and non-pharmacological strategies, may be optimal for this population (167, 168). Additional psychological support is essential for managing emotional well-being (169). Walker et al. (2014) reported that across five cancer types in the UK (sample: n= 21,151) lung cancer presented the highest rate of depression, followed by gynaecological, breast, colorectal, and genitourinary (170). Though depression is substantially more prevalent within cancer populations than in the general public, most of those living with and beyond cancer do not receive sufficient support to manage psychological symptoms (170).

Research into using PA to manage problematic symptoms has increased (171). Physical activity is deemed a primary source of self-management (taking responsibility for one's own behaviour and well-being) among cancer survivors (172), with a wealth of evidence supporting the benefits of managing symptoms. Longitudinal evidence suggests engagement in moderate PA can alleviate and mitigate the severity of symptoms for those LWBLC, particularly fatigue, breathlessness, sleep disturbance, and appetite loss (173). Such findings are consistent with systematics reviews (174, 175), randomised controlled trials (RCTs) (176, 177), and a pilot study (178) demonstrating PA and exercise can be beneficial in the management of symptoms such as reduced muscle strength, anxiety and depression, and fatigue. Though symptom management is a crucial portion of supportive care, it is vital to fully comprehend the term 'supportive care' to understand how PA and digital technology can play a role.

1.8 Physical Activity and Lung Cancer

1.8.1 Benefits of Physical Activity for those Living with and Beyond Lung Cancer

There is mounting evidence that PA and exercise is safe and beneficial for those LWBLC (115, 179), with a wide range of benefits, demonstrated in Figure 3, including improvements in QoL, sleep, fatigue, pulmonary function, cardiorespiratory fitness, strength and muscle mass, psychological state, and biological changes (e.g. soluble programmed cell death protein-1) (115, 171, 180, 181, 182, 183, 184, 185). The evidence is explicit, yet it is reported that many living with and beyond cancer do not meet the PA guidelines. In fact, 67% of those living with and beyond cancer do not meet the guidelines (73). However, historically targeted rehabilitative therapies such as physical and pulmonary therapy, nutritional support, and educational and information support have been either unevenly accessible or lacking across the UK for those LWBLC (165).

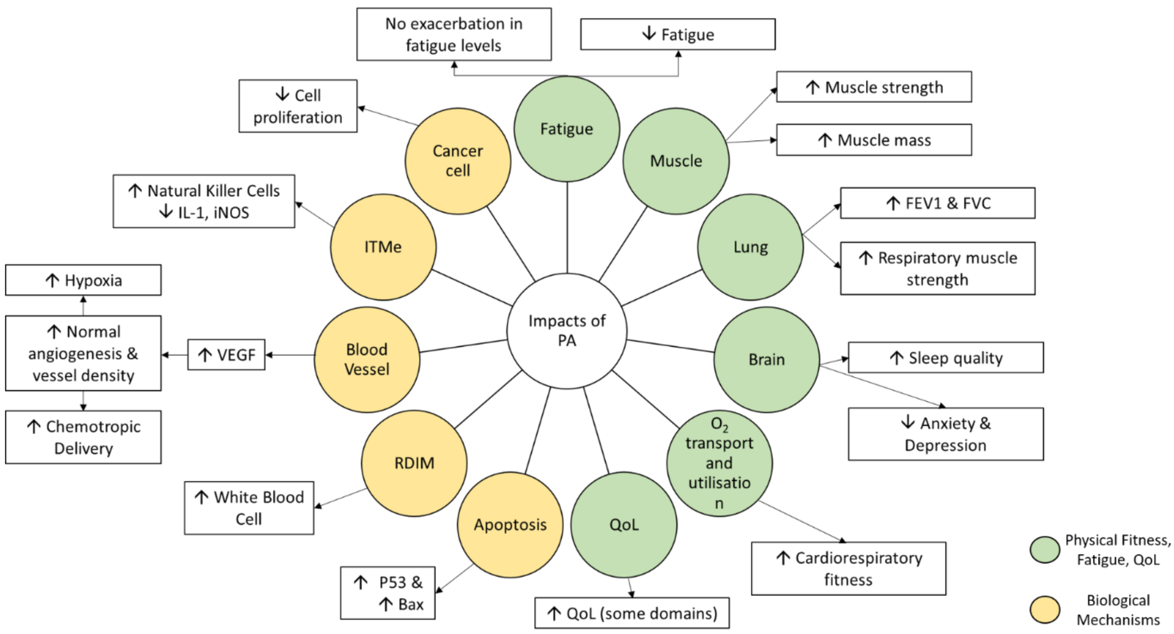


Figure 3: Summary of the effects physical activity and exercise can have for those living with and beyond lung cancer. Abbreviations: QoL, quality of life; NK, natural killer; IGF-1, insulin-like growth factor 1; FEV1, forced expiratory volume in one second; VEGF, vascular endothelial growth factor; iNOS, inducible nitric oxide synthase; PI3KA, phosphoinositide 3-kinase; ITMe,

Immunomodulation tumour microenvironment; RDIM, Reduction drug-induced myelosuppression. Adapted from Avancini et al., (2019 (125)).

Despite the large portion of those LWBLC not meeting the PA guidelines, Lin and colleagues (2013) reported that of 81 lung cancer patients, ~70% demonstrated an interest in PA programmes. Moreover, 69.1% of the 81 patients would participate in a PA programme (186) .

1.8.1.1 Quality of Life

The National Institute for Health and Care Excellence (NICE) states that health related QoL is:

> *"A combination of a person's physical, mental and social well-being; not merely the absence of disease" (187).*

As the NICE definition suggests, QoL encompasses three core principles (physical, mental, and social well-being) which PA has been shown to impact individually and collectively. Increased PA levels have been shown to be associated with an increase in health related QoL domains for those LWBLC (74, 125, 174). Due to lung cancer diagnosis frequently being late stage, often patients do not meet the criteria for surgical interventions (176). Therefore, it is apparent that the need for high quality supportive and palliative care is warranted, including how we can increase QoL and physical capacity while decreasing symptom burden. By understanding the commonly reported burdens of those LWBLC, we can strategies how best to improve QoL.

Below are some of the most commonly reported symptoms, burdens, and considerations for those LWBLC, which will be discussed in turn.

1.8.1.1.1 Fatigue

Cancer-related fatigue (CRF) is a persistent sense of physical, psychological, or cognitive tiredness or exhaustion that stems from cancer or cancer treatment (188). CRF is often present throughout the entire disease trajectory leading to long term impairment of QoL (189, 190). Fatigue has been reported as one of the top symptom burdens for those LWBLC (191). CRF has been observed to affect approximately 70% - 100% of those living with and beyond cancer (192). Physical and pulmonary based rehabilitation programmes have been noted to ease symptoms such as fatigue and breathlessness (also known as dyspnoea) (165, 166).

The mechanisms, causes, and treatments of CRF are not well established (193). Related to cancer and any associated treatments, CRF often occurs due to muscle metabolism/Adenosine Triphosphate dysregulation (194). PA may reduce CRF by improving muscle function and cardiorespiratory fitness (193). In essence, physically fitter individuals may be able to withstand CRF more so than those with lower cardiorespiratory fitness and muscle function. LaVoy and colleagues propose that PA may mitigate CRF by decreasing inflammation (via increasing anti-inflammatory cytokines), improving the autonomic nervous system, physical and psychological health, and neurotrophic factors (195).

With CRF being a significant contributor to QoL, PA should be integral to any rehabilitation programme. Interestingly, Schwartz and colleagues (1999) proposed that PA's observable beneficial effect on QoL may be mediated by the illustrated beneficial impact PA has on CRF. Therefore, indicating a possible inverse correlation between CRF and QoL (196).

1.8.1.1.2 Muscular Strength and Endurance

Those LWBLC may benefit from exercise to increase muscular strength and endurance for those weakened from treatment (197). Due to a myriad of often concurrent symptoms experienced by those LWBLC, low PA levels may lead to disuse atrophy of skeletal muscle, notably in the lower limbs (198). Peripheral skeletal muscle changes in COPD have illustrated a loss of type one muscle fibres (those responsible for aerobic activities) (199) and a reduction in oxidative enzymes (200), resulting in reduced aerobic capacity. Moreover, early onset lactic acidosis resulting in contractile fatigue has been highlighted in COPD patients (87). Given the evidence of molecular similarities between those LWBLC and COPD (86), the changes in peripheral skeletal muscle may translate to those LWBLC. The changes to skeletal muscle or deterioration in physical capacity are not immediate, rather, occur over time, leading to individuals not being aware until substantial deterioration. Similarly, these processes are observable for those experiencing cachexia. Cancer related cachexia is defined via an international consensus as:

"a multifactorial syndrome characterised by an ongoing loss of skeletal muscle mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support and leads to progressive functional impairment. The pathophysiology is characterised by a negative protein and energy balance driven by a variable combination of reduced food intake and abnormal metabolism" (201)

Though, cachexia itself is not specific to cancer. Cachexia may also present as a complication in neurological disease, chronic heart failure, and lung disease. Literature suggests comparable causal processes throughout these conditions for breathlessness and fatigue (202).

Furthermore, it is well established that those LWBLC are typically diagnosed older (≥ 65y) (9). The standard muscle loss due to ageing (sarcopenia) may further contribute to weakened muscle strength and endurance. In addition, increased chest wall stiffness, reduced respiratory muscle strength, and decreased lung elasticity may all further contribute to the ageing and breathlessness state highlighted in those LWBLC.

Henke et al. (2014) reported that conducting a strength-based PA intervention for those LWBLC has a beneficial impact on daily living activities. Supplemental improvements were recorded in perceived dyspnoea during submaximal walking (176). This evidence aligns with additional literature within the exercise oncology domain (174). Due to commonly reported breathing difficulties in this population, activities that may increase lung function may be highly beneficial (197).

1.8.1.1.3 Dyspnoea

Dyspnoea, also known as breathlessness, is a subjective sensation of unpleasant breathing and discomfort that vary in intensity (203, 204). Dyspnoea is a common concern for up to 90% of those LWBLC (205). Dyspnoea can have a substantial impact on ones QoL and vastly minimise an individual's typical activities of daily living. Dyspnoea is not solely localised to lung cancer and is also a commonly reported symptom for those with COPD, pulmonary fibrosis, cystic fibrosis, asthma, and bronchiectasis (206). Pulmonary rehabilitation, created for those with COPD, can be functionally restorative for the conditions above. The driving force behind pulmonary rehabilitation programmes is grounded in PA and exercise to improve endurance, enabling individuals to have a better QoL by leading more active lifestyles (207).

PA and exercise have been proposed to be the most effective means to ameliorate dyspnoea from long term physical exertion (208). Though, given the complex nature of dyspnoea and its underlying mechanisms, such as skeletal muscle, cardiac function, diaphragmatic function, and gaseous exchange (209, 210, 211), it is increasingly clear that psychological factors play a significant role (212). Therefore, it is imperative to address individuals' psychological concerns and processes as part of their rehabilitative programme. The fear of dyspnoea can be a considerable barrier to engagement in PA (213, 214). Without addressing concerns, individuals may not participate and gain the established health-related benefits.

1.8.1.1.4 Psychological Health

Psychological health, emotional well-being, and positive functioning together are categorised as mental health (215, 216). WHO defines mental health as:

> *"a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community." (217)*

PA has been demonstrated to be beneficial for psychological health outcomes, such as anxiety, depression, self-esteem, efficacy, and energy levels for those living with and beyond cancer (35). Specifically, within supportive care, management of both physiological and psychological symptoms and the minimisation of suffering are primary goals of treatment (218). Mood, depression, and anxiety are positively impacted for those living with and beyond cancer as an impact of PA (219). Given the vast variety of symptoms and their severities across the lung cancer continuum, evidence has illustrated home-based PA presents benefits to psychological well-being (171, 220)

1.8.2 Physical Activity Guidelines for Those Living with and Beyond Cancer

National and international guidelines all converge on the American College of Sports Medicine (ACSM) PA guidelines (221), which were recommended by the Physical

Activity Advisory Committee in the United States of America (222). These international guidelines have been deliberated to an international consensus (223). Given the initial ACSM roundtable discussion in 2010 (35) and the updated roundtable discussion in 2018 (221), the accepted recommendations are to engage in 150 – 300 $min \cdot wk^{-1}$ of moderate PA or 75 – 150 $min \cdot wk^{-1}$ of vigorous PA with resistance training two days per week, and daily stretching (223). However, the guidelines proposed by the ACSM are primarily derived from evidence from those living with and beyond breast, prostate, haematological, colon, and gynaecologic cancers (125). Furthermore, no universal guidelines exist for those LWBLC. Given that these guidelines are mirrored for healthy individuals, a specific focus on modifications and tailoring should be made based on disease status, treatment impacts, and health status; crucial for those living with and beyond cancer (222). It has been urged that at a minimum, those living with and beyond cancers avoid being inactive for large bouts of time0 and be physically active where and when possible (35).

1.8.2.1 Bone Metastasis and Metastatic Spinal Cord Compressions

Cancerous cells from a primary site may spread to secondary locations around the body. Cancerous cells do this by intravasate (when cancerous cells enter the basement membrane and enter the bloodstream or lymphatic system) into the lymphatic and circulatory systems and travel to a distant location where they extravasate (the leakage of fluid, such as blood) throughout the capillary network (224). It is well established that the primary sites of cancer metastasis are the lung, liver, and bone (225, 226). There are three primary types of bone metastasis (bone mets). Osteolytic bone mets are those which destroy normal bone and are often present in NSCLC. Osteoblastic bone mets (also known as sclerotic) are when there is an increase bone production (deposition of bone). This can often be observed in SCLC. Lastly, individuals can present with an Osteoblastic and Osteolytic mix, known as Mixed Bone Mets (227). The evidence about bone mets for those LWBLC is limited, though data from those living with and beyond prostate cancer has shown an increase risk in spinal or nerve compression, pathological fractures, and muscular skeletal impact which has a negative impact on QoL (228). Due to the fears of increase risk to injury, those with bone mets have often been excluded from research exploring PA and exercise (229). However, emerging evidence has highlighted PA and exercise is safe for those with bone mets with supervision by a qualified exercise professional (230).

Bone mets have been reported to be present in approx. 20% - 30% of those who are newly diagnosis with lung cancer; furthermore, ~35% - 45% of those LWBLC have been reported to have bone mets throughout their cancer trajectory, with the spine being the most common site (231). In addition to bone mets, 15% - 29% of all patients who develop metastatic spinal cord compressions are those LWBLC (232, 233, 234). Metastatic spinal cord compressions are often the result of a vertebral body that contains a metastatic disease compressing or collapsing or a secondary metastatic tumour extending into the vertebral column (235).

As previously highlighted, exercise prescription is not a one size fits all policy. Bone mets and spinal cord compressions can be seen as a primary contraindication for those LWBLC participating in exercise. Though, with adequate supervision and tailoring, PA and exercise has been reported to be feasible and acceptable for those living with and beyond cancer with bone mets (230). Moreover, importantly to the patient, with supervision from an exercise professional, PA has been highlighted as safe (230).

1.8.3 Duration and Intensity of Physical Activity

In a recent review, Haberlin et al. (2018) reported noteworthy variation in the duration and intensity of eHealth-based PA interventions for those living with and beyond cancer. Duration is an important factor when developing a PA programme to establish behavioural change and adaptation. For example, a 14-day programme (236) or a four-week programme (237) may have been too short to ascertain viable results on behaviour change. Furthermore, short term studies are limited in how eHealth impacted PA behaviour long term. However, Kanera et al. (2017) and Sturgeon et al. (2017) carried out 12 months follow-ups and reported significant improvements in self-reported PA between intervention and control groups (238, 239).

1.8.4 Common Concerns of Physical Activity and Lung Cancer

Drawing on lung cancer-related studies, PA and exercise are safe and well-tolerated pre- and post-treatment (115). Nevertheless, caution should be taken when developing digital programmes supporting self-management of long-term conditions, such as cancer. Incorporating inappropriate advice, mishandling and sharing data, and interactions that may undermine desired behaviours can elicit negative and potentially harmful actions for applying digital technology within healthcare for long-term disease populations (240).

1.9 Next Steps

Although supportive care for those LWBLC is a prominent feature of international health systems, published research into supportive care for this particular population is relatively limited (120). Despite the vast increase in research on supportive care and lung cancer over recent decades, it remains less common in comparison to other prevalent cancers (120). Improving one's QoL is a primary component of the design of supportive care. However, QoL is a complex, multifaceted paradigm, including physiological, psychological, spiritual, and social determinants of health (241).

Evidence indicates those LWBLC have noticeably more unmet needs than other cancers (242, 243), raising the concern about the limited funding allocated to lung cancer survivorship (65). The shifting survival curve for thoracic malignancies has promoted the importance of working with those individuals, aligning with supportive care and patient goals (244). Despite the increased funding, supportive care for those living with and beyond lung cancer does not receive adequate attention. Giuliani et al. (2016) highlighted that 78% of those living with and beyond cancer present at least one unmet supportive care need, with the mean number of unmet needs within the study being eight. The highest unmet needs were reported within the physical and psychological domains (182). Supportive care is paramount for those living with and beyond cancer. Reports indicate that within the first six months post-diagnosis, those LWBLC display significantly higher levels of unmet needs in comparison to other types of cancer (243, 245).

Despite the evidence highlighting the supportive care needs for those LWBLC (246), due to the difficulties in recruitment and high attrition rates, those LWBLC are often neglected within the supportive care literature (247). Moving forward, it is expected there will be an overall increase in cancer cases with the ageing population, even with advancements in preventative measures, as, with these advancements comes greater survival rates (248, 249). However, reports indicate that post-diagnosis yields the highest proportion for unmet needs, indicating the need for supportive care and reviewing current practice (250, 251).

Therefore, this doctoral degree will discuss the development and exploration of an online supportive care exercise platform for those LWBLC.

1.10 Summary of Chapter One

Lung cancer is the leading cause of cancer-related death worldwide and is the third most common form of cancer. Lung cancer is often categorised by two histological types, NSCLC and SCLC, with PM being cancer found within the lung's lining (known as the pleura).

Supportive care is a vital part of the cancer journey and remains a consistent construct of national and international cancer policies. Though, lung cancer is often under-researched and lacks funding when discussing survivorship and supportive care. Online technology presents promising evidence for those living with and beyond cancer who are presented with travel and access barriers, in addition to real-time symptom monitoring and symptom management. The application of digital technology within healthcare offers many advantages for cancer care, reducing the healthcare professional-patient relationship (252), which many individuals value. The intention is to supplement face-to-face contact with digital healthcare to provide continuous symptoms and health status monitoring and support Additionally, digital technology can provide an alternative to standard face-to-face supportive care programmes such as PA and pulmonary rehabilitation. Furthermore, digital technology may offer a suitable alternative for those who live in remote areas or experience health inequalities regarding limited or poor travel.

There is unequivocal evidence that PA is beneficial for those living with and beyond cancer, published by national and international guidelines. Despite the known benefits, those living with and beyond cancer are largely sedentary and do not meet the national guidelines for PA. Commonly, those living with and beyond cancer report a lack of available support. Changing PA behaviour and being more active is challenging. Coupled with the fear of exercise, individuals are apprehensive with a concern of increasing their symptom burden. Furthermore, a large portion of oncological health and support staff do not feel adequality competent to provide PA related advice.

Digital technology can provide accessible and personalised care, with studies showing telehealth is feasible, acceptable, and clinically safe for those living with and beyond cancer. Evidence indicates exercise is the most common form of self-management post-cancer treatment. Individuals use it for several reasons, relaxation, minimise treatment side effects, regaining health and fitness, and a sense of normality (172).

1.11 Overarching Aim of Thesis

This chapter has demonstrated the significant burden of LWBLC. Lung cancer is a complex disease that can be treated with curative intent or palliation. Curative treatment can impact the body in many ways, often leading to physiological and psychological impairments. Limited literature has shown that the benefits of PA are unequivocal for those LWBLC. Physical activity can help alleviate symptom burden and increase the QoL within this population. Though barriers and health inequalities exist, it may make it difficult for those LWBLC to participate in supervised ('face-to-face') PA and exercise sessions.

The overarching aim of this thesis was to investigate the feasibility and acceptability of a supportive care platform (ExerciseGuide UK) that aimed to provide tailored PA programmes and educational resources to those LWBLC. Specific research questions can be found in Research Questions (4.1).

The following chapter discusses the systematic review, examining the current evidence that informs and challenges our understanding of online supportive care interventions for those LWBLC. This exploration is key not only to identify where this doctoral research fits within the existing literature but also to contribute to the selection of methods which will be employed throughout this doctoral degree.

Chapter 2 Online supportive care for those living with and beyond lung cancer: a systematic review.

The first chapter introduced lung cancer regarding physical activity (PA) and online technology and the evidence base for PA being unequivocally beneficial for those living with and beyond lung cancer (LWBLC). Furthermore, the evidence for applying digital technology as a supportive care method highlights a simple yet effective method of delivering tailored PA programmes. However, limited evidence is available for those living with and beyond cancer, creating a gap in the literature.

This chapter introduces the type of review chosen to explore the existing data and the published systematic review exploring the feasibility, acceptability, and efficacy of online supportive care platforms for those LWBLC. The content within this chapter has been modified for the purpose of this doctoral thesis. This systematic review was published in May 2021 in *the Journal of Supportive Care in Cancer* (DOI: 10.1007/s00520-021-06274-x). Acknowledgement is given to the publishers, Springer Nature. Consent from the corresponding author was not required because the corresponding author is the author of this doctoral thesis (3). The published systematic review is licensed under the Creative Commons Attribution 4.0 International License (253). The published version of the systematic review is provided in the appendix (see appendix 13.5.1).

2.1 Introduction to Systematic Reviews

Systematic reviews are a process of research synthesis that is conducted by a researcher or research group who aim to identify national and international literature which is relevant to a pre-specified question or questions and evaluate and synthesise the evidence and relevant results to inform research, policy, or practice (254, 255, 256). The primary purpose of systematic reviews is to methodologically collect, appraise, and summarise evidence pertaining to a pre-specified question to make available evidence readily accessible following a systematic appraisal.

Systematic reviews began appearing in healthcare literature in the 1970s and 1980s (257, 258). In the 1990s, there was the emergence of networks such as the Joanna Briggs Institute and Cochrane (259). In recent years, systematic reviews have rapidly emerged and maintained strong popularity throughout healthcare for the amount conducted (257) and the demand to inform new or existing policies and practices (260). The available evidence must be evaluated for any biases (261) and methodological quality to ascertain an impartial answer to the initial question. Strategies exist to evaluate the methodological quality and given common biases in studies, which can be found in Figure 4.

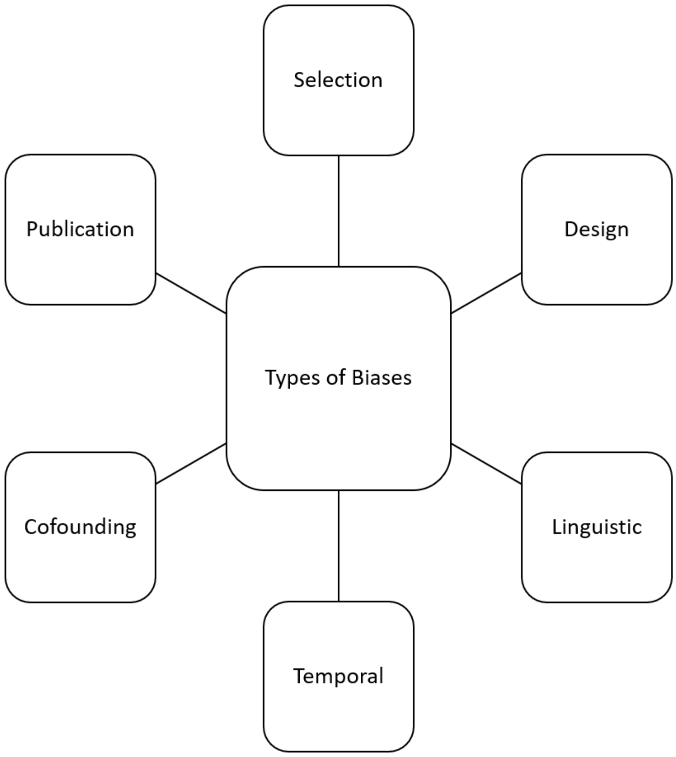


Figure 4: Illustrating common types of bias that exist within published literature.

Various biases can impact studies in several ways, leading to numerous concerns, such as distorted results, inaccurate or wrongful conclusions, and unnecessary costs (261). Some biases are out of the researcher's control, such as publication bias, wherein a journal will favour the publication of a study pending whether it demonstrated positive findings instead of non-desirable or negative findings (261). Though a review appraises the literature for several forms of bias that may impact the quality of studies before inclusion, systematic reviews aim to minimise known biases in search for the 'true' answer.

2.1.1 Advantages of Systematic Reviews

Systematic reviews have the longstanding title of being the gold standard of research evidence appraisal and reporting of evidence or sometimes lack thereof. Figure 5 demonstrates the hierarchy of evidence within healthcare research by Evans (2003), showing systematic reviews consistently ranked excellent for effectiveness, appropriateness, and feasibility (262). Systematic review includes both quantitative, qualitative, or both leading to mixed methods. The suitability of systematic reviews leads to a favourable outcome within healthcare research as various methods beyond RCTs, such as observational and interpretive studies, can be included as long as they are reasonably conducted and produce valid evidence. Though, the hierarchy of evidence must be taken with caution. The hierarchy of evidence serves as a guide as opposed to a fixed set of rules. Population and outcome metrics play a major impact in the usability of evidence.

	Effectiveness	**Appropriateness**	**Feasibility**
Excellent	• Systematic review • Multi-centre studies	• Systematic review • Multi-centre studies	• Systematic review • Multi-centre studies
Good	• RCT • Observational studies	• RCT • Observational studies • Interpretive studies	• RCT • Observational studies • Interpretive studies
Fair	• Uncontrolled trials with dramatic results • Before and after studies • Non-randomized controlled trials	• Descriptive studies • Focus groups	• Descriptive studies • Action research • Before and after studies • Focus groups
Poor	• Descriptive studies • Case studies • Expert opinion • Studies of poor methodological quality	• Expert opinion • Case studies • Studies of poor methodological quality	• Expert opinion • Case studies • Studies of poor methodological quality

Figure 5: Hierarchy of evidence in healthcare research by Evans et al., (2003 (262)

The primary distinguishing feature of a systematic review from traditional literature reviews is achieving transparency, replicability, and rigour through a fixed process. Furthermore, the ability to address biases to mitigate poor-quality research inclusion early in the process is an invaluable feature in seeking the 'true' answer to a research question (263). Moreover, the key process of developing a structured search strategy allows a holistic and comprehensive search compared to a literature review, which is often limited to authors' knowledge or small cursory searches (263).

2.1.2 Disadvantages of Systematic Reviews

Although systematic reviews aim to mitigate biases and appraise studies for methodological quality, they succumb to several biases. The pre-defined search strategy is a cardinal feature of systematic reviews, enabling researchers to search databases for articles about their research question broadly. However, not all literature is openly accessible or accessible via institutional access, creating a payment barrier. Housed behind a paywall, inaccessible literature may reduce the scope of systemic reviews.

With systematic reviews and meta-analysis being expressed as the optimal method of answer a specific research question, inherent concerns exist, such as inadequate reporting of information and outcomes, heterogeneity, study selection, and publication bias (264). As previously stated, publication bias is very prevalent within research, though in an extensive review of systemic reviews (n=300), few reviews reported the impact of publication bias (265). Given the known impact and high prevalence of publication bias, the absence raises concern, highlighting a limitation to systematic reviews.

Beyond systematic reviews, several alternative types of reviews could have been chosen. A summary of alternative reviews will be discussed below.

2.1.3 Alternative Reviews

Reviews of the literature have existed within academia since near its inception, with the fundamental approach of consolidating and reviewing available evidence to guide new investigations being an essential approach within research. Specifically, within healthcare, Mulrow (1987) questioned the once standard process of medical reviews for the varying published quality of these traditions' reviews. In response, a systematic review provided a more transparent, reproducible, and audible method (266).

A recent study exploring the types of reviews published within health-related disciplines reported 48 reviews categorised into seven types of wider review groups known as 'families' (267). The review families Sutton and colleagues (2019) reported include the traditional review, systematic review, review of reviews, rapid review, qualitative systematic review, mixed methods review, and purpose-specific review

(267). A figure detailing the parent of the review families and their extensions can be found in Figure 6.

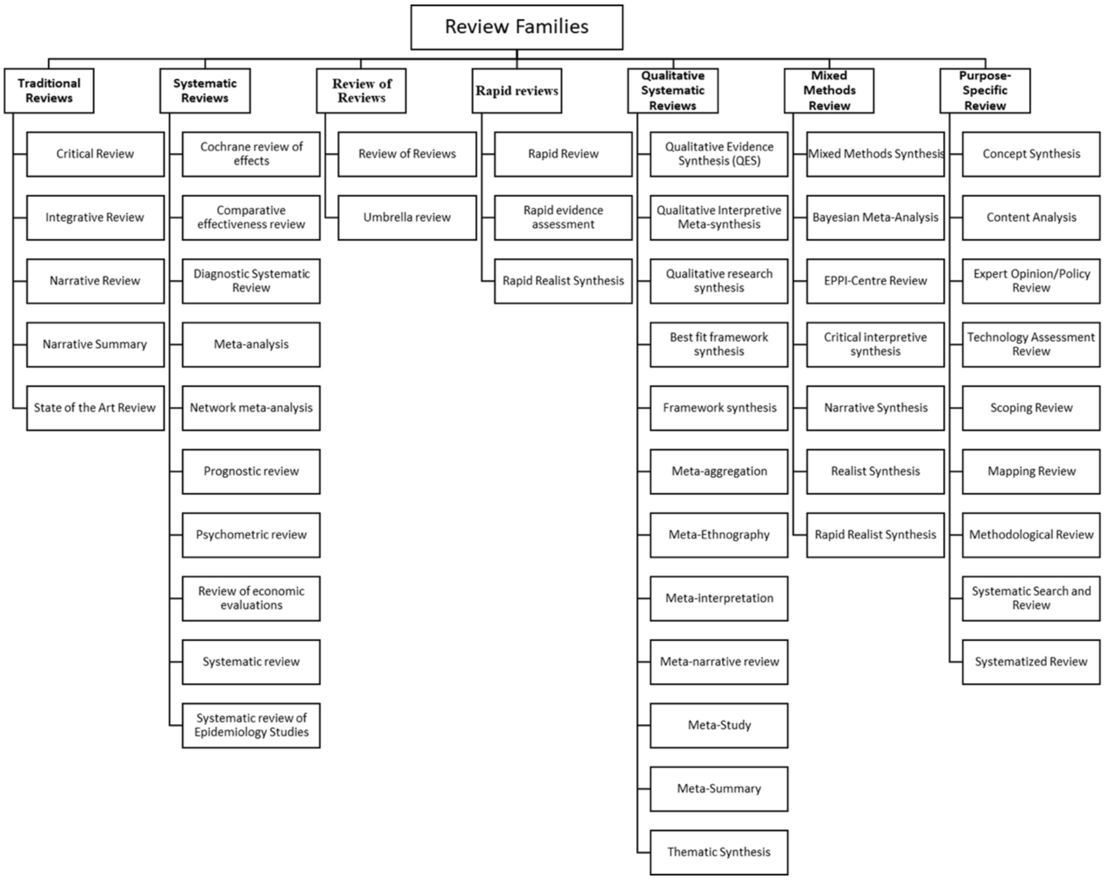


Figure 6: Review family breakdown (adapted from Sutton et al. (2019) (267)).

2.2 Rationale for a Systematic Review Approach

There are several benefits of physical activity for those LWBLC, with a large body of literature supporting PA presenting many benefits. Moreover, digital technology promises many benefits for those living with and beyond cancer, especially with the rapid transition to digital technology within healthcare during the COVID-19 pandemic. Little evidence exists about whether online supportive care for those LWBLC is feasible and acceptable. Given the nature of online supportive care being in its infancy, the type of review was limited from the offset. A systematic review was deemed best suited in systematically addressing whether online supportive care is feasible and acceptable for those LWBLC?

2.3 Research Question

The question this systematic review posed was, are online platforms feasible and acceptable methods of supportive care for those LWBLC?

2.4 Objectives

The primary objective was to determine whether online supportive care is feasible and acceptable for those LWBLC. Additionally, efficacy was explored within studies.

2.5 Inclusions and Exclusion Criteria

2.5.1 Inclusion

The following criteria was used to ensure relevant papers were found to extract data.

2.5.1.1 Study Design

Single arm or Randomised Controlled Trials (RCTs), pre/post designs were included in this review.

2.5.1.2 Participants

Adults (18 years and older) who have been diagnosed with lung cancer or a cancer affecting the lung (i.e., pleural mesothelioma) were included in this study. Studies which reported mixed cancer types had to report lung cancer data independently to be considered.

2.5.1.3 Study Outcomes

Studies included must have examined the feasibility, acceptability, and/or efficacy of an online intervention aiming to provide supportive care for people LWBLC.

2.5.2 Exclusion

Studies were excluded if they did not report mixed samples independently. The review focused solely on those LWBLC. Additionally, studies that could not be obtained via institutional access and contacting study authors were excluded. Lastly, those studies which were not in English were excluded.

2.6 Search Methods

2.6.1 Electronic Searches

A preliminary search of the electronic databases was made through the library electronic resources at the University of Hull and the University of York during February 2020 and updated in April 2020.

Search strategies were developed in the following electronic databases:

1. MEDLINE via OVID (1946 - 2020)
2. EMBASE via OVID (1974 - 2020)
3. CINAHL via EBSCOhost (2000 - 2020)
4. PSYCInfo via OVID (1806 - 2020)

2.6.1.1 Search Terms

The search strategies were developed per database. An Information Specialist (SG) assisted with the development of the search strategies. A pilot strategy was developed by combining Medical Subject Headings (MeSH) and keywords using Boolean operators (e.g., AND and OR). An example of the search strategy can be found in appendix six (see 13.6). The Medline, EMBASE, and PsycINFO search strategies focused on the following MeSH terms and keywords: lung cancer AND (Internet OR social media/online supportive care interventions).

In contrast, the terms in CINAHL focused on lung cancer AND social media platforms AND internet platforms. All searches were conducted by a single author (JC). Forward and backward citation searching was conducted as a supplementary method technique of the literature search.

2.6.1.2 Supplementary Searches

Backwards citation searching of authors' bibliography for relevant literature was examined for further appropriate studies. Furthermore, forward citation searching was conducted via Web of Science (Clarivate Analytics, United States of America).

2.6.2 Article Screening

Upon completing the database and supplementary searches, studies were imported into an EndNote X9 (Clarivate Analytics, London) library for deduplication. Post-deduplication, all remaining studies were exported to a Rayyan library (268). Two authors (JC and MJP) first screened titles and abstracts. Following title and abstract screening, the two authors (JC and MJP) completed full-text screening. One disagreement was settled by a third author (CF). Following the full-text screening, data extraction commenced.

2.6.3 Data Collection

A modified data collection form was used to collect data on the included studies (269). The modified data collection form was pilot tested to ensure it captured all relevant data by two authors (JC and CF). A blank copy of this *pro forma* can be found in appendix seven (see 13.7).

Two authors (JC and MJP) independently screened each included study and extracted study content. Using the *pro forma*, evidence was recorded systematically summarising the following information:

1. Population and Setting
2. Methods
3. Participants
4. Study Groups
5. Outcomes
6. Results
    a. Feasibility
    b. Engagement
7. Acceptability
8. Other Information

One disagreement regarding the data collection of Maguire et al (2015) (270) was resolved by mutual consensus with input from a third author (CF).

2.6.4 Risk of Bias/Methodological Appraisal

Two authors (JC and CF) independently assessed the methodological quality of the studies via the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (271). The Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields provides two distinct subscales for the methodological assessment of qualitative and quantitative data. This tool was selected based on its ability to examine methodological quality for quantitative non-randomised studies, such as feasibility and pilot studies. The methodological appraisal tool was chosen considering study design (272, 273) within this review and prior literature (274, 275). Methodological quality and risk of bias are often misapplied when assessing non-randomised studies (273), leading to inaccurate appraisal of a study. Previous literature has noted that within single-study designs, aspects such as feasibility, reliability, validity, and utility are variable or often unmeasured (276).

Methodological quality was rated in accordance with the established and accepted following ranges: >80% "strong", 71 – 79% "good", 50% - 70% "adequate", and <50% "poor" (274, 275, 277). No studies were excluded based on their methodological appraisal score. See

Table 2 and

Table 3 for the methodological quality of the included studies.

2.6.5 Study Selection

The study selection flow is depicted in the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram below (see Figure 7). A total of 2468 publications were identified via database searching, with one additional publication found through hand searching. Follow deduplication, title and abstract screening was conducted on 2111 articles, with 128 articles being included for full text review.

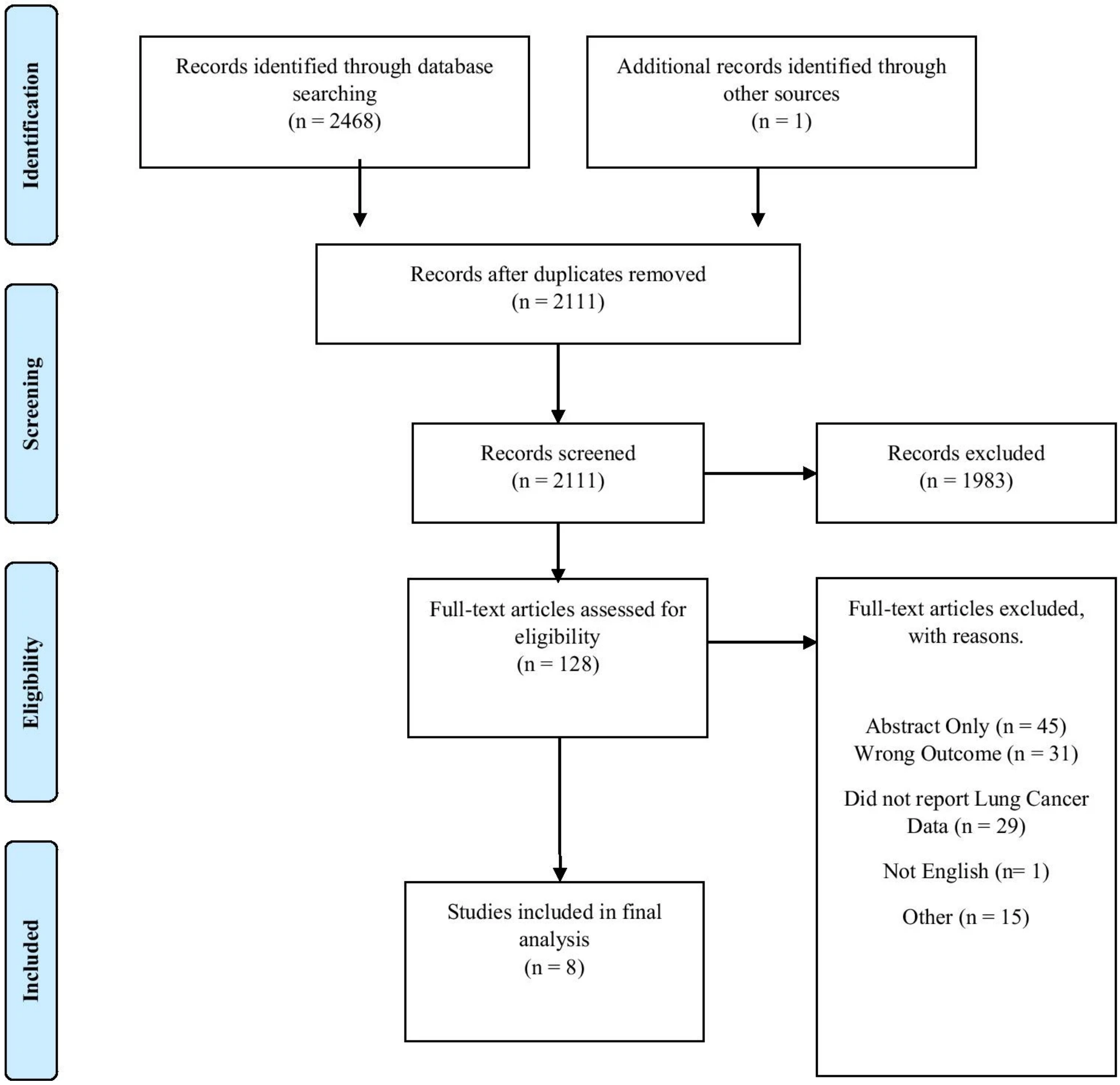


Figure 7: PRISMA flow diagram of the flow of information for systematic reviews. This PRISMA flow diagram is adapted from Moher et al., (278).

2.7 Results

A total of eight studies met the inclusion criteria and were included in the final analysis for this systematic review regarding the feasibility, acceptability, and efficacy of online supportive care for those LWBLC (270, 279, 280, 281, 282, 283, 284, 285).

2.7.1 Risk of Bias/Methodological Quality Appraisal

The methodological quality appraisal is detailed for quantitative measures (see

Table 2) and qualitative measures (see

Table 3). Two authors (JC and CF) conducted methodological quality appraisals independently. Six studies were assessed as solely quantitative methods (280, 281, 282, 283, 284, 285) and two studies were assessed for both quantitative and qualitative methods (270, 279).

Of the eight quantitative studies, 100% were rated as strong (>80%) (270, 279, 280, 281, 282, 283, 284, 285). Of the two qualitative studies, one study was rated strong (>80%) (270) and one rated adequate (50% - 70%) (279).

The inter-rater reliability (also known as the level of agreement) for all eight appraised studies was 100% between the two authors (JC and CF). The inter-rater reliability scores can be found in

Table 2 and

Table 3.

Table 2: Demonstrating the breakdown of quality appraisal scores and inter-rater reliability values for quantitative method studies.

Author	Checklist Item							
	1) Question or objective sufficiently described?	2) Evident and appropriate design	3) Subject selection	4) Subject characteristics	5) Random allocation	6) Blinding of investigators	7) Blinding of subjects	8) Defined and robust outcome measures
Huang *et al.*, (2019)	2	2	2	2	2	N/A	N/A	2
Park *et al.*, (2019)	2	2	2	2	2	N/A	N/A	2
Ji *et al.*, (2019)	2	2	2	2	1	N/A	N/A	2
Lafaro *et al.*, (2019)	2	1	2	2	N/A	N/A	N/A	1
Timmerman *et al.*, (2017)	2	2	2	1	N/A	N/A	N/A	2
Coats *et al.*, (2019)	2	2	1	2	N/A	N/A	N/A	2
Maguire *et al.*, (2015)	2	2	2	2	N/A	N/A	N/A	2
Denis *et al.*, (2014)	1	1	2	2	N/A	N/A	N/A	2

Table 2 Demonstrating the breakdown of quality appraisal scores and inter-rater reliability values for quantitative method studies (Continued)

Author	Checklist Item						Inter-Rater Reliability
	9) Sample size	10) Analysis described and appropriate	11) Estimate of variance	12) Controlled for confounding	13) Sufficient Results	14) Results match Conclusions?	
Huang et al., (2019)	2	2	2	0	2	2	1 (100%)
Park et al., (2019)	2	2	2	N/A	2	2	1 (100%)
Ji et al., (2019)	2	1	2	2	2	2	1 (100%)
Lafaro et al., (2019)	1	2	1	N/A	2	2	1 (100%)
Timmerman et al., (2017)	1	2	2	N/A	2	2	1 (100%)
Coats et al., (2019)	1	2	2	1	2	2	1 (100%)
Maguire et al., (2015)	2	2	2	N/A	2	2	1 (100%)
Denis et al., (2014)	1	2	N/A	N/A	2	2	1 (100%)

Table 3: Demonstrating the breakdown of quality appraisal scores and inter-rater reliability values for qualitative method studies.

Author	Checklist Item										Inter-Rater Reliability
	1) Question or objective sufficiently described?	2) Evident and appropriate design	3) Clear context for the study	4) Linked to a theoretical framework	5) Appropriate and detailed sampling strategy	6) Clear and detailed data collection methods	7) Complete, appropriate and systematic data analysis	8) Verification procedure(s) used in the study	9) Conclusions supported by results?	10) Evident reflexivity	
Maguire *et al.,* (2015)	2	2	2	2	2	2	2	0	2	0	1 (100%)
Timmerman *et al.,* (2017)	2	2	1	1	1	1	1	2	2	0	1 (100%)

2.7.2 Study Characteristics

Of the eight included studies, six studies were feasibility and pilot studies (270, 279, 280, 283, 284, 285) and two were RCTs (281, 282). The included studies were completed across seven countries; two in South Korea (280, 281), one in the United States of America (283), France (285), Netherlands (279), Taiwan (282), Canada (284), and the United Kingdom (270). Seven studies explored explicitly those LWBLC (270, 279, 280, 281, 282, 284, 285), with one study exploring two populations, those LWBLC and those living with and beyond gastrointestinal cancer (283). However, Lafaro et al. (2019) did provide independent data sets for lung and gastrointestinal cancers. The majority of studies detailed focused primarily on non-small cell lung cancer (NSCLC) patients (279, 280, 281, 282), two recruited lung cancer patients undergoing or undergone surgery (283, 285), one cohort receiving radiotherapy (270), and one exploring participants with a diagnosis of unresectable thoracic neoplasia (284).

Cancer disease stage was reported in five studies, ranging from I to IVb (270, 279, 280, 281, 282, 284, 285). One study did not report cancer stage but reported the American Society of Anaesthesiology (ASA) physical status classification, with those LWBLC ranging from classification III – V (283). Five studies reported the treatment being received. Treatments included were chemotherapy (280, 282, 284), thoracic radiotherapy (270), and maintenance therapy (285). Surgical extent was reported in one study (279) Two studies did not report any information pertaining to treatment (281, 283). A summary of study characteristics can be found in Table 4.

Table 4: Study Characteristics for the included studies of the systematic review. Table cited from (3)

Study Details (author and year)	Population Characteristics			Feasibility	
	Sample Size; Age	Location	Disease Stage; Treatment	Recruitment Rates	Retention Rates
Huang et al., (2019)	Intervention n=27; mean: 61 Control n=28; mean 58.68	Taiwan	Exercise Group: IIIA: 0; IIIB: 6; IV: 21 Control Group: IIIA: 1; IIIB: 2; IV: 23 Treatment: Chemotherapy	91.67%	100%
Park et al., (2019)	n=100; mean: 55.1	South Korea	Stage: II: n=5; III: n=0; IV: n=95 Treatment: Chemotherapy	No Information	90% (90/100)
Ji et al., (2019)	Fixed-Interactive Exercise Group n=32; mean 60.50 Fixed Exercise Group n=32; mean 57.97	South Korea	Fixed-Interactive Exercise Group Stage: I: n=13; II: n=3; IIIA: n=6; IIIB: n=1; IV: n=8 Fixed Exercise Group Stage: I: n=7; II: n=5; IIIA: n=7; IIIB: n=0; IV: n=13 No Treatment Information	40.5% (64/158)	Fixed: (23/32): 71.88% Interactive: (20/32): 86.96% Total (43/64): 67.19%
Lafaro et al., (2019)	n=18; median: 74	USA	ASA: III: n=12; IV: n=2; V: n=1 No Treatment Information	86.96% (20/23)	90% (18/20)
Timmerman et al., (2017)	Stage 1 n=10; median 56.6 Stage 2 n=12; median 59.5	Amsterdam	Disease Stage not reported. Stage 1 Treatment: Lobectomy: n=10; Pneumectomy: n= 0; Neoadjuvant: n=1; Adjuvant: n=3 Stage 2 Treatment: Lobectomy: n=8; Pneumectomy: n=2; Neoadjuvant: n=2; Adjuvant n=1	Consent Rate: 67%	67% (8/12)
Coats et al., (2019)	n=5; mean 62	Canada	Stage 3 IIIb = 3; Stage IVb = 2; Treatment: Chemotherapy	No Information	100% (5/5)

Study Details (author and year)	Population Characteristics			Feasibility	
	Sample Size; Age	Location	Disease Stage; Treatment	Recruitment Rates	Retention Rates
Maguire et al., (2015)	n=16; mean: 63.6	United Kingdom	No Disease Stage Information Treatment: thoracic radiotherapy	28.1%	Five died (11/16) 68.75%
Denis et al., (2014)	n=42; median: 62	France	Stage: I/II: n=9; IIIA: n=15; IIIB: n=1; IV: n=17 Current Treatment: None 36; Maintenance therapy 6 Previous treatment: Surgery 11; Radiotherapy 1; Concomitant radio-chemotherapy 13; Chemotherapy 17	No Information	Two died (95.24%)

Note: ASA, American Society of Anaesthesiology

2.7.3 Intervention characteristics

Three primary supportive domains were explored across the eight studies, comprising PA and exercise (279, 283, 284), self-evaluation and symptom monitoring (270, 285), and education (282). Two studies explored exercise and symptom management combined (280, 281).

Of the eight studies, 50% were delivered via mobile phone-based applications (270, 279, 280, 281). The remaining four studies were delivered by a website (282), videoconferencing (283), web-based applications (285), and specialised Tele-Rehab Station (284). The Centre developed a specialised station for Interdisciplinary Research in Rehabilitation and Social Integration in Quebec City. The station was an 'all in one' system with physiological and biomechanical sensors and supplementary video and activity equipment. The video equipment supported videoconferencing with capabilities to deliver audio-visual communication. The computer system ran on a Windows 8 interface.

Coats et al. (2019) explored the feasibility, adherence, satisfaction, and any technical issues of a home-based telerehabilitation (a specialised tele-rehab station) over an eight-week duration (284). Sessions started supervised with progression to unsupervised. Huang and colleagues (2019) focused on investigating the impact of a web-based health education programme on global quality of life (GQoL), QoL-related function, and symptom distress over three months (282). Another three-month intervention examined the outcomes of home-based pulmonary rehabilitation (PR) regarding exercise capacity, dyspnoea symptoms, and QoL in adults receiving chemotherapy treatment for NSCLC (280). Timmerman et al. (2017) interventions explored the use of telehealth in two mediums: ambulant symptom and physical activity monitoring (S&PAM) and a web-accessible home-based exercise programme (WEP) (279).

The use of theories and modules to inform the design and development was specified in three studies (270, 282, 283). Lafaro et al. (2019) specified the use of the Chronic Care Self-Management Model (CCM) (286). Huang et al. (2019) stated the use of the Symptom Management theory (SMT) (287) and the e-learning theory (288). Finally, Maguire et al. (2015) stated the use of the Medical Research Council (MRC) Complex

Interventions Framework (289). No other study detailed the use of theories, models, or frameworks.

2.7.4 Feasibility

Of the eight studies included in the review, six were deemed feasible by study authors (270, 279, 280, 281, 283, 284, 285). The remaining two studies did not state feasibility outcomes (281, 282). Though Huang et al. (2019) and Ji et al. (2019) did not explicitly state feasibility as an outcome, they reported metrics which can be used to assess feasibility (281, 282). Huang et al. (2019) reported a recruitment rate of 91.67% and a retention rate of 100%, and Ji et al. (2019) reported a recruitment rate of 40.5% and a retention rate of 61.17% (281, 282). Five studies reported recruitment rates with a mean recruitment rate of 62.83% ± 27.99% (270, 279, 281, 282, 283). Three studies did not report the recruitment rate (280, 284, 285). One study specified a recruitment goal that was not achieved (270).

All eight studies reported a retention rate. The mean retention rate for the eight studies was 84.77% (67–100%). Two studies reported a loss of follow-up due to participants' death during the study's duration (270, 285).

Several concerns about recruitment were highlighted by four studies (270, 279, 280, 283), such as poor health status, scheduled surgery, knee replacements, emotional burden, lack of familiarity with the internet and digital technology, lack of overall interest, and patients felt adequately supported by their clinical team and required no further supportive care. None of the eight studies reported the cost or financial information of the study. Though multiple studies required researchers, equipment, and healthcare professionals, monetary costs were absent in all studies. However, one study highlighted the absence of a monetary assessment of the intervention as a limitation (279). Further information regarding the feasibility of studies can be found in Table 5.

2.7.5 Acceptability

Due to the varying study designs documented in this review, adherence was assessed in only three studies (283, 284, 285). Across the given studies, 'adherence rates' and 'compliance rates' were assessed to establish overall study adherence. The mean' adherence rate' across the three studies was 84.5% (73.5–100%). Adherence rate was defined as a) the mean sum of pedometer use preoperative and post-discharge (283), b) completion of exercise sessions (284), and c) the completion of forms (285). Though, caution should be noted regarding the sum of preoperative and post-discharge pedometer use as lung and gastrointestinal cancer were combined, with no independent data reported (283).

Of the eight studies, five reported on one or more measures of satisfaction, with the majority of participants reporting there were highly satisfied with the interventions within the study (279, 280, 281, 283, 284). Three studies did not report on measures of satisfaction (270, 282, 285). However, one study reported that the majority of participants were reassured and highlighted that the advice provided during the intervention was easy to understand and user-friendly (270).

Of the five studies that reported satisfaction measures, two studies reported reasons for dissatisfaction (279, 280). Reasons reported in one study were lack of interaction with a health care professional, insufficient tailoring of exercises, inadequate insight into progression, and difficulty accessing via mobile phone (279). The second reported dissatisfaction was due to system errors and difficulty handling the application (280). No study reported any adverse effects throughout the study duration. The acceptability results are shown in Table 5.

Table 5: Intervention Overview, Engagement, and Acceptability Outcomes. Table cited from Curry et al. (2020)

Source (author and year)	Objectives and Description	Engagement	Acceptability (satisfaction)	Conclusion
Huang et al., (2019)	Objective: evaluate the effects of a web-based health education program on global QoL, QoL-related function, and symptom distress in patients diagnosed with advanced NSCLC. The experimental group participated in the web-based education program twice a month for three months.	Those who consented (55/60) completed all assessments.	Satisfaction measures not discussed	The web-based program can improve global QoL, emotional function, and reduce top ten significant symptom distresses within the first three months post-diagnosis and treatment of advanced-stage NSCLC patients. Web-based health education can enhance self-learning to assist with coping with cancer, treatments, and side effects.

Source (author and year)	Objectives and Description	Engagement	Acceptability (satisfaction)	Conclusion
Ji et al., (2019)	Objective: explore the outcome of home-based pulmonary rehabilitation (PR) regarding exercise capacity, dyspnoea symptoms, and QoL in patients being treated for NSCLC. Participants were randomly allocated to a fixed exercise group or a fixed-interactive exercise group. The fixed exercise group used only the fixed exercise program during the 12 weeks. The fixed-interactive exercise group received the app with the fixed exercise regimen for the first six weeks. Switching to an app with an interactive exercise regimen for the remaining six weeks.	64 participants allocated to the two groups. 49 made it to six weeks analysis; 43 made it to the 12 weeks analysis.	Participant Satisfaction (Patient Global Assessment [PGA]): Week 6: n=39, Mean (SD): 13.769 (3.681 Week 12: n=39; Mean (SD): 15.077 (3.989)	Personalized mHealth PR can supplement traditional health care rehabilitation programs for NSCLC patients. Findings support the use of this technology to improve exercise capacity, dyspnoea symptoms, and QoL.

Source (author and year)	Objectives and Description	Engagement	Acceptability (satisfaction)	Conclusion
Denis et al., (2014)	Objective: investigate whether patient self-evaluated symptoms transmitted via the internet could be used between pre-planned visits to indicate early disease relapse in lung cancer. Patients report their weight and ten symptoms, such as appetite loss (anorexia), fatigue (asthenia), pain, cough, and breathlessness (dyspnoea) weekly. The physician would be notified via email when self-evaluated symptoms met a pre-specified criterion.	564/691 of all forms were completed, which is 82% of the maximum. Mean monthly compliance was 94% Mean weekly compliance was 79%.	100% of participants felt reassured they were being followed by their oncologist.	A weekly follow-up system using the internet deemed feasible to detect relapse or tumour progression with a high rate of compliance.
Coats et al., (2019)	Objective: investigate the feasibility, adherence, satisfaction, and technical issues of a home-based telerehabilitation intervention for patients with unresectable thoracic neoplasia receiving chemotherapy.	The mean duration of supervised sessions was 67 ± 12 minutes. Total duration of all 75 supervised exercises sessions was 85 hours. Mean time for cardiovascular exercise was 247 ± 48 minutes	5/5 patients reported being quite satisfied (score of 4) or very satisfied (score of 5) with all aspects of the home-based telerehabilitation platform. Mean satisfaction score: 4.7 ± 0.4.	Findings support the feasibility of a Tele Rehabilitation program (TELERP) and suggest the intervention may help patients overcome barriers to pulmonary rehabilitation services.

Source (author and year)	Objectives and Description	Engagement	Acceptability (satisfaction)	Conclusion
	The intervention was an eight-week home-based telerehabilitation program (three sessions of ~75 minutes per week) using the eChez-Soi telerehabilitation platform. The platform provided a combination of interactive exercises with real-time physiological parameter acquisition. Sessions started off supervised but with study progression reduced to mainly unsupervised.	over the 15 supervised exercise sessions and 223 ± 111 minutes over the 8.6 ± 3.0 unsupervised exercise sessions. Mean duration of each cardiovascular exercise session was 18 ± 6 minutes and 26 ± 9 minutes during supervised and unsupervised exercise sessions.		Participation in TELERP may assist improvements or maintenance in muscle strength and functional capacity for lung cancer patients on chemotherapy treatment.
Timmerman et al., (2017)	Objective: evaluate the feasibility of a Tele-healthcare application for operable lung cancer patients. Stage One: Prior to the start of the study, thoracic surgeons and pulmonologists were given a short presentation about content and possible benefits of the symptom and physical	Ambulant S&PAM system: 100% of patients used the S&PAM system at least once. Mean usage: Five - six days per treatment period. WEP: Eight patients (67%) used the exercise portal at least 1 week following lung resection. Patients started 4 (n = 3),	S&PAM: most patients indicated that the monitoring system had good usability. All felt competent using the module (perceived self-efficacy score >5). WEP: most patients were satisfied with usability of the module, except for two (score <5) stating the	Findings support that remote monitoring and treatment is feasible to lung cancer patients both pre- and post-surgery. Patients actively used the S&PAM and WEP modules prior and following surgery and perceived both as a beneficial contribution to their care.

Source (author and year)	Objectives and Description	Engagement	Acceptability (satisfaction)	Conclusion
	activity monitoring S&PAM module. Physiotherapists were introduced to the web-accessible exercise program (WEP) during a two-hour workshop. Stage Two: The Remote Monitoring and Treatment RMT it consists of two modules: (1) a symptom and physical activity monitoring (S&PAM) system, and (2) a web-accessible exercise program with remote supervision by a physiotherapist.	5 (n = 2), 6 (n = 2), or 7 (n = 1) weeks following resection.	program was difficult to access on mobile phone. All patients felt confident in their ability to use the module.	A low level of adoption by referring physicians may reduce successful implementation.

Source (author and year)	Objectives and Description	Engagement	Acceptability (satisfaction)	Conclusion
Lafaro et al, (2019)	Objectives: (1) determine the feasibility and acceptability of a personalized telehealth intervention, for physical activity perioperatively for GI and lung cancer patients and their caregivers. (2) describe the trends, trajectories, and patterns of both functional recovery and self-reported outcomes pre- and post-surgery. The intervention consisted of five sessions. Session one was after baseline assessment and a minimum of seven - fourteen days prior to surgery via videoconferencing. Session two (in-person) functional re-assessment (6MWT, TUG, SPPB) and self-reported measures. Session two content was delivered post re-assessment. Sessions three, four, and five (telehealth) were completed at days two, seven, and two -	Preoperative pedometer adherence: 79%, post-discharge 68%. Median preoperative daily steps were 6324. The value decreased to 1050 during hospitalization, The value increased to 2927 in the first 2 weeks after discharge.	Self-reported satisfaction: 3.2/4.0 93.3% of patients thought that the timing of the intervention was appropriate.	The personalized telehealth perioperative physical activity intervention was feasible and acceptable for both adults undergoing GI or lung cancer surgery and their caregivers.

Source (author and year)	Objectives and Description	Engagement	Acceptability (satisfaction)	Conclusion
	four weeks post-discharge. All given outcomes were re-assessed at two - four weeks post-discharge. Acceptability was measured via a satisfaction survey. Pedometer data was collected throughout the study duration. Strategies to overcome barriers to staying active after discharge were discussed.			
Park et al., (2019)	Objective: determine the feasibility and efficacy of smartphone app–based PR on QoL, exercise capacity, and symptom management for patients with advanced lung cancer who were undergoing chemotherapy. Patients were provided with the Smart Aftercare app, an Internet of Things (IoT) wearable device, a portable pulse oximeter, thermometer, scale, and resistance bands.	90 finished the rehab program. 85/90 completed all 6MWT tests.	Satisfaction: 77% (69/90) reported they were satisfied. 88% (79/90) reported they would recommend it to others. 96% (86/90) stated they were paying more attention to their health and disease status since using the app.	12 weeks of comprehensive smartphone app-based individualized PR seems to be an effective and feasible approach for improving exercise capacity, symptom management, and distress in patients with advanced NSCLC undergoing systemic chemotherapy.

Source (author and year)	Objectives and Description	Engagement	Acceptability (satisfaction)	Conclusion
	The to-do list provided an alarm notification for daily tasks related to taking medication, performing rehabilitation exercises, and visiting the clinic on schedule. This study consisted of a 12-week rehabilitation program. The Smart Aftercare app provided animation videos on stretching exercises, aerobic exercises, muscle strengthening exercises, and finishing (stretching) exercises. The Smart Aftercare app provided an animation video on pain control, nutritional support, and symptom management.			

Source (author and year)	Objectives and Description	Engagement	Acceptability (satisfaction)	Conclusion
Maguire et al., (2015)	Objective: (a) explore the feasibility and acceptability of the Advanced Symptom Management System with patients with lung cancer receiving radiotherapy (ASyMS-R) and clinicians involved in their care; (b) assess changes in patient outcomes during implementation of the ASyMS-R in clinical practice. Patients used the ASyMS-R at home during working hours (9 AM - 5 PM), seven days a week, for the duration of their radiotherapy treatment in addition to one month after treatment. They were instructed to follow local procedures regarding out-of-hours care. After completing the daily questionnaire on their mobile phone, patients' daily symptom data were sent to a central study server, where	89% of participants reported the self-care system was easy to understand and user friendly	Nine patients indicated that they had received enough training to use the ASyMS-R handset. 100% of patients reported that they never or very rarely encountered problems in using the handset (n = 10; 100%), answering and submitting questionnaires (n = 9; 90%), reading the self-care information after submitting a questionnaire or again later (n = 10; 100%), or finding cancer information pages (n = 8; 89%).	This study demonstrated the potential to provide an accurate and acceptable assessment of radiotherapy-related toxicity and management in clinical practice. Therefore, effectively responding to the needs of patients in this study and facilitating the delivery of timely interventions. Participants reported the ASyMS-R to positively impact their care and promote the timely reporting and management of their symptoms.

Source (author and year)	Objectives and Description	Engagement	Acceptability (satisfaction)	Conclusion
	an integrated risk model analyzed the symptom reports.			

Note: QoL, Quality of Life; NSCLC, Non-Small Cell Lung Cancer; PR, Pulmonary Rehabilitation; mHealth, Mobile Health; SD, Standard Deviation; TELERP, Tele Rehabilitation program; WEP, web-accessible exercise program; RMT, Remote Monitoring and Treatment; S&PAM, symptom and physical activity monitoring; GI, Gastrointestinal; 6MWT, 6-minute walk test; TUG, Time Up and Go, SPPB, Short Physical Performance Battery; IoT, Internet of Things; ASyMS-R, Advanced Symptom Management System with patients with lung cancer receiving radiotherapy; PGA, Patient Global Assessment

2.7.6 Efficacy

Efficacy outcomes are only reported for RCTs. Of the eight studies, there were two RCTs (281, 282). Outcomes assessed included QoL (281, 282) , physical functioning (281), and symptom distress (282).

2.7.6.1 Quality of Life

Participants who participated in an online-based health education programme had a significant increase in global QoL ($p = < 0.05$) in comparison to a control group ($p = 0.288$) over the four measure time points (baseline (T0), and then one (T1), two (T2), and three (T3)) months using the EORTC QLQ-C30 (282). All participants who participated in a mobile-based pulmonary rehabilitation platform exhibited an overall significant increase in QoL (visit one, 76.05 ± 12.37; visit three, 82.09 ± 13.67 ($P = 0.002$)), assessed using a visual scale (EuroQol-visual analog scale). However, a small, non-significant change in QoL was observed (visit one, 7.54 ± 1.82; visit three, 6.93 ± 2.85 ($P = 0.17$)) via the EQ-5D questionnaire (EuroQol 5 dimensions questionnaire) (281). There was not a significant difference between pre-intervention and post-intervention for QoL between the Fixed-interactive exercise group and Fixed exercise group for both visual scale ($P = 0.99$) or EQ-5D ($P = 0.50$) (281).

2.7.6.2 Emotional Functioning

Participants who engaged in the online health education programme reported significant improvements in emotional function compared to those who did not engage ($F\ b = 11.270$, $p < 0.01$) (282). Those who did not engage in the online health education programme displayed a non-significant decrease in emotional function (282). Significance was determined from baseline (T0) to three months after the programme (T3) for both experimental and control groups via the EORTC QLQ-C30.

2.7.6.3 Physical Functioning

Participants who performed PA displayed an improvement in their physical function, assessed via their six-minute walk distance (6MWD) over 12 weeks (visit one, 433.42 ± 65.60; visit three 471.25 ± 75.69 ($P = 0.001$)) (281). However, no statistically significant difference ($P = 0.30$) was reported between the fixed exercise group (58.10 ± 73.66) and the fixed-interactive exercise group (25.37 ± 66.64) (281). Furthermore, those who participated in an online-based health education programme illustrated no significant difference between the four stages for both the exercise group (T0, 90.59; T1, 87.65; T2, 84.23; T3, 84.78 p = 0.429) and the control group (T0, 80.46; T1, 81.44; T2, 69.94; T3, 71.13; p =0.121) when assessed via the EORTC QLQ-C30 (282).

2.7.6.4 Symptom Distress

Participants who participated in an online education programme had a significant reduction ($P < 0.05$) in the top ten significant symptom distresses from baseline (T0; 1.45 ± 0.08) to three months post-programme (T3; 1.26 ± 0.06), whereas the control group demonstrated a non-significant increase ($P = 0.53$) from baseline (T0; 1.41 ± 0.09) to post three months (T3; 1.73 ± 0.27) (282). Data on symptom distress was collected via the symptom distress scale (290).

2.8 Discussion

This review aimed to examine the evidence regarding the feasibility, acceptability, and potential efficacy of online supportive care interventions for those LWBLC. The results show that online delivery of supportive care has shown preliminary feasibility and acceptability for those LWBLC. However, the field of delivering online supportive care to this population is in its infancy. To our knowledge, this systematic review is the first to explore the feasibility, acceptability, and efficacy of online supportive care for people LWBLC.

Eight studies met the inclusion criteria, two of which were RCTs. The average recruitment rate was 62.58%, though this was not universally reported, and the average retention rate was 84.77%. Problems with recruitment and attrition are common in studies involving people living with and beyond cancer, especially people LWBLC (120). The challenge of recruiting people LWBLC stems from the high symptom burden and lower health performance status (120, 247). Low rates of participation and consent are common among people living with and beyond cancer, people with advanced diseases, and those approaching palliative end-of-life care (291, 292). Older adults (≥ 65y) are reported to be underrepresented in research, with a small increase of older adults in oncological clinical trials over recent years (293). Though people LWBLC typically tend to be older individuals, with 44% of new lung cancer diagnoses in the UK among those 75 years or older (9), the mean age for the included studies was 61 years. This affirms the argument above by Hurria et al. (2014) that older individuals are underrepresented in oncological research, suggesting that consideration should be given when interpreting the results for this population (293). The capabilities of older adults to use digital technology are often questioned within the literature (280). However, elderly adults are becoming increasingly literate using digital technology and are eager to adopt new technologies (294).

Adding to the growing body of literature exploring online supportive care for people living with and beyond cancer, this review shows emerging evidence that online supportive care platforms show promise of being feasible and acceptable for people LWBLC. This aligns with the larger body of literature on breast (295, 296), prostate (297, 298), colorectal cancer (299, 300), and chronic obstructive pulmonary disease (COPD) (301, 302), a progressive chronic lung disease which has similar symptoms and QoL impact to lung cancer (86). This evidence suggests that online supportive care is feasible and acceptable in these populations.

Supportive cancer care is important for the management of symptoms and improvements in QoL for people LWBLC (120). In the current COVID-19 pandemic, people living with and beyond cancer are at greater risk of experiencing serious illness if tested positive for COVID-19 (303), particularly those receiving chemotherapy and/or radiotherapy for lung cancer (110). Throughout the pandemic, the frequency of in-person assessments and programmes has been severely reduced, leading to various concerns such as missed diagnoses, unnoticed development of new symptoms, unobserved disease progression, reduction in PA sessions, and access to educational resources. Literature has reported weekly symptom monitoring via a web-based patient-reported outcomes platform associated with increased survival for those living with and beyond metastatic cancer compared to standard care (18) and those LWBLC in comparison to standard imaging surveillance (304). Therefore, the importance of delivering supportive care via online modalities is paramount. However, even before the COVID-19 pandemic, barriers existed supporting the implementation of any supportive care for people LWBLC. Economically, a considerable financial burden is associated with societal and personal lung cancer (305). The cost of travel is an out-of-pocket expense which could be a barrier for people living with and beyond cancer to access appointments and treatments (305). In addition, various studies have associated lower socioeconomic status (SES) with a higher incidence of lung cancer (306, 307). The use of digital technology and telehealth has become more prevalent since the COVID-19 pandemic (308), with exponential growth in platforms such as videoconferencing (110). However, the evidence about online supportive care for people LWBLC is still limited. The evidence that other forms of cancer overshadow lung cancer in the literature is clear within supportive care in both standard and online modalities (26, 309). With the complexity of the current global climate, many individuals are unable to seek the supportive care usually provided. This systematic review provided a timely contribution to the sparse knowledge of online supportive care for people LWBLC.

More rigorous research must be conducted to advance this area, building upon the available pilot-based studies, such as ensuring adequately powered samples and the generalisability of results (310). The studies have shown a lower mean age than the average for a lung cancer diagnosis. Furthermore, RCTs using a clear randomisation process should be performed to explore the effects of online supportive care compared to well-balanced groups (311). Conducting trials over multiple sites may prove useful regarding greater samples for recruitment. Furthermore, the literature suggests that methodological appraisal is often misapplied when assessing non-randomised studies (273). Studies must appraise their literature's methodological quality to provide high-quality evidence. Although this systematic review has illustrated several strengths, it is not without its limitations.

2.9 Review Limitations

Although four databases exceed the minimum number of databases required by both Cochrane and the Assessment of Multiple Systematic Reviews (AMSTAR) tool, there are some existing limitations. Firstly, the Cochrane Handbook for Systematic Reviews of Interventions (version 6.2), chapter four (312, 313), stipulates a minimum of three databases should be searched, Embase, Medline, and Cochrane's CENTRAL database. The electronic search for this review may be considered limited for a systematic review due to the database sources. This review did not explore clinical trial registries within the electronic search. This limitation is echoed by scoring partial agreement with the AMSTAR checklist, point four, about whether the search was deemed comprehensive. The review scores a partial yes by exceeding the minimum of two databases but does not obtain a full yes due to the lack of a clinical trials registry in the database search. However, the review's inclusion criteria were not limited to RCTs of interventions. Therefore, it seemed more appropriate to perform supplementary searches for qualitative studies in additional databases (e.g., CINAHL) instead of registries for unpublished RCTs.

2.10 Conclusion of Review

Online supportive care for people living with and beyond cancer has shown promise within this review. Given the complexity of delivering cancer services online, the current COVID-19 pandemic has highlighted the need for online supportive care for people living with and beyond cancer, specifically lung cancer (110). The studies discussed in this review cover two primary domains of supportive care, symptom management and increasing QoL, which have been highlighted as crucial components of supportive care (120). This illustrates that key components of supportive care can be administered online, showing feasibility and acceptability. Though, the concept of adherence rates requires further exploration within this population. A recent shift has been observed from inpatient to ambulatory care for people living with and beyond cancer. An increased number of outpatients receiving treatment has rapidly increased (270), leading to more individuals being responsible for the self-management of treatment-related toxicities within their own home. Using digital technology such as mobile or web-based platforms to enable real-time communications could be vital in supportive care.

This review provides evidence that online supportive care programs for people with LWBLC are feasible and acceptable. The conclusions are limited to a small number of studies, though the strong methodological quality of the studies strengthens the results. With limited evidence presented from RCTs, it is difficult to determine efficacy. Though online supportive care for lung cancer is in its infancy, further larger RCTs and rigorous studies are warranted.

2.11 Summary of Knowledge

The advancements in digital cancer care, particularly through online exercise support, has demonstrated an advancement towards addressing the accessibility and personalisation of supportive care for individuals LWBLC. This development is supported by a growing body of research that explores the feasibility, acceptability, and efficacy of such interventions. Studies have shown promising outcomes, indicating that online and telehealth-delivered exercise programmes are not only feasible but also beneficial in enhancing quality of life, physical functioning, and psychological well-being among cancer patients (110, 314)

Moreover, the feasibility of exercise interventions delivered via telehealth highlights a vital opportunity to extend supportive care to those affected by cancer, overcoming traditional barriers such as geographical and physical limitations (315). Home-based aerobic and resistance exercise programmes further promote the potential of remotely delivered interventions in fostering physical recovery and rehabilitation, in addition to emotional resilience in cancer survivors (37).

The concept of exercise as a key component in oncology care is further supported by the American College of Sports Medicine's Exercise is Medicine initiative, underscoring the need for integrating exercise recommendations into standard cancer care practices (316). This initiative serves as a foundation for the growing acknowledgement of exercise as a fundamental component of the cancer pathway. Despite these advancements, the field is at a key stage, requiring focused research to optimise online supportive care interventions. The diversity in intervention designs, patient engagement strategies, and the outcomes measured reflect how adaptable in nature online exercise support can be. However, this variability also underscores the need for a wider understanding of which intervention components are most effective, when, and for who.

The state of evidence from this systematic review sets the landscape of online exercise support interventions for individuals LWBLC. The review synthesised data from eight studies, including a mix of randomised controlled trials (RCTs) and pilot studies, to evaluate the feasibility, acceptability, and preliminary efficacy of such digital interventions.

Key Findings from the Review:

1. Feasibility and Acceptability: The review demonstrated a moderate level of feasibility and acceptability for online exercise interventions among those LWBLC. These findings are indicative of the potential for these digital platforms

to extend the reach of supportive care services to a broader audience, overcoming traditional barriers such as geographic and physical limitations.

2. Preliminary Efficacy: Initial evidence from the included studies suggests positive impacts on quality of life, emotional well-being, and physical functioning. These outcomes illustrate the potential of online exercise interventions to alleviate some of the treatment-related side effects and improve the overall health status of individuals LWBLC.
3. Gaps and Research Directions: Although there is early evidence of effectiveness, this review identified a crucial need for more rigorous, large-scale trials and RCTs to provide conclusive insights into the effectiveness of online exercise support interventions. Furthermore, the review identified the need for research to explore the long-term impacts of these interventions and to understand how different components of online exercise programmes contribute to reported outcomes.

2.12 Summary of Chapter

PA and exercise have been demonstrated to be beneficial for those LWBLC across the entire spectrum, from prevention to survivorship. Additionally, literature has illustrated that digital technology is a feasible and acceptable method of delivering tailored intervention to those living with and beyond cancer, mitigating several established barriers to delivering personalised care, such as geographical location and cost. A research gap was identified when exploring the feasibility and acceptability of online supportive care for those LWBLC. Thus, a systematic review was chosen to answer whether online platforms are feasible and acceptable supportive care methods for those LWBLC.

Systematic reviews allow a methodical and structured approach to answering a research question. This review adhered to the 2009 PRISMA and appraised the methodological quality of the included studies (n=8) with the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (271), ensuring a fair and appropriate appraisal. All eight studies reported on quantitative measures, and all eight achieved a 'strong' rank (>80%). Two studies included qualitative methods. One qualitative study was rated strong (>80%), and one rated adequate (50% - 70%). There was 100% inter-rater reliability (also known as the level of agreement) for all eight appraised studies between the doctoral student (JC) and first supervisor (CF).

The review concluded that online supportive care shows initial promise for feasibility among those LWBLC. However, due to the small number of studies in this emerging field, more research is required to definitively establish the feasibility and acceptability of online supportive care for this population.

Therefore, this review justified the further exploration of a novel approach to providing online and tailored supportive care to those LWBLC. A small portion of participants reported barriers across the eight studies, but overall satisfaction was high. Furthermore, the mean retention rate for the eight studies was relativity high (84.77%), illustrating that those LWBLC completed the interventions once enrolled. The evidence from this review highlights that online supportive care for LWBLC may be feasible and acceptable. Based on the findings, the adaptation commenced on the online supportive care platform for this doctoral research, ExerciseGuide UK.

Chapter 3 Methodology

This chapter will present and discuss the overall methodological approach and considerations of this doctoral research, examine the philosophical approach, and explore the ontological and epistemological positions taken. The methodologies used to answer the research questions include mixed methods, user-centred design, and Think-Aloud approaches. However, firstly, building upon the insights gained from the systematic review, the following research questions have been developed to guide the doctoral degree and inform the methodological approach within the three-year period of this doctoral degree:

1. Is an online supportive care platform that aims to provide tailored physical activity programmes feasible for those LWBLC?
2. Is an online supportive care platform that aims to provide tailored physical activity programmes acceptable for those LWBLC?
3. What barriers exist for those LWBLC to engage in an online tailored physical activity platform?

The terms feasibility and acceptability are used widely throughout research. However, operational definitions may vary across different fields. Therefore, the definitions which were operationalised will be set out. The Implementation Outcomes Framework (317) was used to inform the operationalised definitions adopted in this study. See Table 6 for the definitions used for the outcomes of interest within this thesis.

Table 6: The operational definition of feasibility and acceptability based on the Implementation Outcomes Framework (317)

Term	Implementation Outcomes Framework definition	Operational definition applied to this doctoral degree
Feasibility	The extent to which a new treatment, or an innovation, can be successfully used or carried out within a given agency or setting	The recruitment and retention rates for the intervention.
Acceptability	The perception among implementation stakeholders that a given treatment, service, practice, or innovation is agreeable, palatable, or satisfactory.	The degree to which the participants (those living with and beyond lung cancer) or healthcare professionals find the online intervention satisfactory.

The doctoral systematic review (see Chapter 2) informed the methodological decisions in this study. The systematic review provided insights not only into various aspects of the study design and data collection for the feasibility acceptability study but also into the process of developing the site.

The review highlighted the importance of integrating telehealth interventions within existing care processes and formalising the tasks required for their implementation. For instance, Timmerman et al. (2017) emphasised the need to align Remote Monitoring and Treatment (RMT) applications with current healthcare protocols. From Timmermans's work, ExerciseGuide UK was integrated into a normal clinical routine and discussed in the clinical setting. In addition, Lafaro et al., (2019) focused on a telehealth perioperative physical activity intervention based on the chronic care self-management model. The intervention aimed to empower the participants, build self-efficacy, and improve patient-reported outcomes (PROs) through engaging participants in health planning and skills building. Lafaro and colleagues (2019) methods included personalised coaching and the integration of behavioural change techniques to tailor the intervention to individual needs. Foundationally, Maguire et al., (2015) developed the Advanced Symptom Management System (ASyMS) using a participatory process involving key stakeholders. Involving stakeholders and end-users seemed to align with my philosophical views, which are discussed below in 3.1.

Moreover, the systematic review identified common metrics used to evaluate feasibility and acceptability, such as recruitment rates, retention rates, and PROs. Studies like Maguire et al. (2015) and Ji et al. (2019) provided frameworks for these evaluations, which we incorporated into our study. Additionally, the review influenced our sample size estimations, ensuring it was adequately powered to detect significant feasibility and acceptability outcomes.

Having outlined the key research questions that will guide this doctoral research, the next section explores the philosophical underpinnings that shape the research methodology, providing a foundation for the chosen methods and approaches.

3.1 Philosophical Approach

A reflection on the research paradigm was conducted when approaching this doctoral research. Research paradigms can be explained as the ‘set of common beliefs and agreements shared between scientists about understanding and addressing problems (318). We can characterise the research paradigm by responding to ontological, epistemological, and methodological questions (319). Though designing a study to address a gap within the research, a cluster of issues for further exploration, or even commissioned to explore a topic by an institutional or organisational body may be straightforward, the challenge of developing a meaningful, purposeful, and intellectually worthwhile project is still relevant (320). To ensure that this research is both meaningful and purposeful, it is important to first establish a clear understanding of the underlying philosophical assumptions, specifically the epistemological and ontological perspectives that guide this study.

3.1.1 Ontology

Ontological questions are those that explore what is and the structure of reality (321), the nature of the 'knowable' (319), or what is possible to know about the surrounding world (322). In essence, ontology encourages us to ask, ‘what is the very nature of what we are seeing?’. Researchers may experience difficulty understanding their ontological position as the core principles of social elements seems fundamental. Therefore, questioning their longstanding position of social things' very nature and essence and entertaining possible alternative views may be challenging. Nevertheless, one’s ontological view and stance should be established early on rather than merely accepting the established universal truth that can be misapplied or taken for granted.

The human world as we know it exists with several realities. I agree that our thoughts, feelings, and emotions are real. I agree that objective realities exist that impact us. Effectively, I agree with the existence of objective reality (physical and material things), subjective reality (personal and experiential), and intersubjective reality (nonmaterial cultures and social structures) (323). However, it is important for a researcher to detail their understanding and views on the meaning of the varying realities.

Objective reality refers to the notion anything exists in its natural state, independent of our conscious awareness. For example, a double-decker bus driving down the road. Naturally, upon hearing this statement, we can look around us and verify the presence of the double-decker bus, providing a fact or fiction decision. By doing so, we are using a cognitive ability to discern objective reality, or in other words, physical things we can bump into. Objective reality can be vital in situations where physical or material things are present, such as a double-decker bus. If we were to cross a street and see a double-decker bus coming towards us, by accepting the truth the bus is real and tangible within reality and knowing the consequences, we could decide not to cross at the current time. Ultimately, accepting or even denying the existence of the bus, the objective truth remains, if we stepped in front of it, we may get hurt. In contrast, reality exists in the presence of your conscious mind, for example, someone saying, “I am thinking of a red rose”. There is no way to prove this fact or the level of the truthfulness of the statement. This concept would be known as a subjective reality. We cannot physically touch or bump into the thought of a red rose, it is intangible. Intersubjective realities are once again only present within the mind and considered intangible. However, intersubjective reality exists when an intangible concept exists in more than one mind and is given force by collective belief. For example, religion. Religion is intangible, it cannot be touched or bumped into, though it exists globally, permeating the minds of millions, if not billions of people.

I agree that these three realities do not merely exist, but they exist in harmony within human life. I would echo the views of Johnson and Gray (2010), who express this stance as multiple realism or ontological pluralism (324).

Throughout this doctoral degree, my ontological position has guided the research methods chosen to answer the overarching question, is an online supportive care platform for those LWBLC feasible and acceptable? Examining objective realities such as through comparative assessment of quantified data (e.g., recruitment rate, retention rate, and usability outcomes) with subjective realities and thoughts via Think Aloud interviews and post-intervention interviews to further explore thoughts, feelings, and beliefs regarding the online tool.

Bringing together objective, subjective, and intersubjective realities have allowed me, as a researcher designing this doctoral researcher, to accept both tangible and intangible concepts are real and influence daily decisions, actions, and thoughts.

3.1.2 Epistemology

The origin of the word 'Epistemology' is drawn from the Greek words "episteme' and "logos' (325, 326). In Greek, 'episteme' refers to 'knowledge' or 'understanding'. Whereas the term "logos" refers to 'reason' or 'argument' (325). Epistemological questions can be expressed as assumptions about the kind of knowledge (327) and what can be known (328). Essentially, what do we regard as evidence or knowledge? Though the field of epistemology is thought to be only a couple of centuries old, the practice is deeply rooted in philosophy and is thought to be equally old to original philosophical concepts (325).

There are longstanding arguments regarding the variance in the research paradigms between quantitative and qualitative methods that the two are irreconcilable (329). The quantitative paradigm is based on positivism (330), whereas the qualitative paradigm is based on constructivism (331) and interpretivism (330, 332, 333). Ontologically, quantitative research advocates an objective reality, wherein the reality exists independently from the perceptions of humans (330). Samples sizes in quantitative research are often larger than in qualitative research to ensure they are representative and able to draw statistically meaningful conclusions (334).

Opposingly, when examining the qualitative paradigm, we need to further explore Interpretivism and Constructivism. Interpretivism theory can be expressed as the knowledge pertaining to the world through understanding and interpreting the meaning individuals attach to their actions (335). In contrast, constructivism proposes that individuals (or learners) acquire knowledge by actively developing knowledge, allowing reality to be based on the experiences the learner has built (336). Contrasting the often larger sample sizes in quantitative research, qualitative research focuses on smaller samples that can provide important and purposeful information regarding a phenomenon (337). In essence, ontologically, there are multiple 'truths' or 'realities' based on an individual's construction of reality. Reality is a social construct and therefore socially constructed around us, thus perpetually and constantly changing

(338). Epistemologically, reality is inaccessible independent of our minds due to the absence of an external referent to compare any claims of truth (339). Therefore, the studies objectives and the researchers are linked through the findings being reported within the specific setting, which shapes the inquiry (340). Fundamentally, prior to the activity, in this instance, research, reality has no existence. Furthermore, post-research, reality ceases to exist. Reality is truly only present in existence during the conduct of research wherein a topic is under focus (339). Within the qualitative paradigm, sample size does not follow the same principles as quantitative. In fact, where quantitative often relies on larger and representative samples to population-based inferences, qualitative focuses on smaller, meaningful, and personal acquisition of information.

The underlying and long-standing assumption that the qualitative and quantitative paradigms are incompatible goes far beyond philosophical and methodological arguments (330, 340). Both research paradigms are built upon specific values, methodologies, and assumptions which explore the world we live in (341, 342). Given the complexity of a phenomenon, such as in areas of health research (343) (e.g. nursing (344), health education and health promotion (345) may require a mixed-methods approach combining qualitative and quantitative methods (330).

I present this doctoral research by addressing the questions using a mixed methodological approach, bringing together the paradigms by accepting both realities in qualitative and quantitative paradigms.

3.1.2.1 Epistemology of Mixed Methodology

A mixed-methods approach has been chosen for this doctoral research to address the various research questions and answer the overarching research question of whether an online tailored physical activity platform for those LWBLC is feasible and acceptable. Additionally, the impact on quality of life (QoL), anxiety, and depression will be explored as part of this thesis. Given the varying nature of outcomes of interest, combining both quantitative and qualitative paradigms would suit the overall aim of this thesis.

Mixed methods can be defined as:

"The combined use of both quantitative and qualitative methodologies within the same study in order to address a single research question" (346).

The quantitative and qualitative paradigms have a long-standing perception of being incompatible and dichotomous, particularly when the paradigms are expressed from a conceptual standpoint to the origin of the understanding and generation of knowledge. Whereas in literature, the emphasis often lies on the differences in the strengths of each approach, rarely the differences in weaknesses are discussed. When considering the differences between the previously outlined paradigms, they can be viewed as both compatible and complementary. Essentially, combining each approach enhances the other by providing unique strengths. Therefore, in the context of this thesis, the combination of methods is justified to gain a better understanding of the participants than either method alone.

3.1.2.1.1 Pragmatic Approach

Pragmatism advocates that research should use the philosophical or methodological approach which fits best with the research question (347). Pragmatism originated in the United States of America in the 19th century by Charles Sanders Peirce, William James, Chauncey Wright, Oliver Wendell Holmes Jr, and Nicholas St. Johns Green (348). The term pragmatism stems from the Greek word "pragma", meaning action, a key component of this approach (349). The pragmatic paradigm focuses on the production of 'useful knowledge' grounded in reality, which is key when adapting a website to provide tailored physical activity programmes and educational resources to those LWBLC (348, 350). Fundamentally pragmatism suggests using an approach of 'whatever works best' for a particular context of research, thus leading the way for mixed methods (346). By not only broadening the scope of the thesis and building on the independent strengths of quantitative and qualitative methods, applying a mixed-methods approach allows for the possibility for triangulation of the outcomes. Triangulation refers to approaching a research question from various angles (two or more), with the aim of converging and cross-validating from multiple sources (e.g. collecting data pertaining to QoL from a survey and interview) (346).

3.1.2.1.2 Mixed Method Limitations

Although mixed methods present an approach that builds on both the strengths and weaknesses of independent research paradigms, it is not without criticisms and limitations. Firstly, the lengthy and often heavy data collection and analysis is said to have an unnecessary strain on the researcher with large time and financial commitments. Within the context of a doctoral degree within a three-year period, this is a highly relevant concern that must be considered during the planning of the degree. Secondly, the given demand for a researcher to be an expert in one methodological approach is challenging. However, the demand is even higher for those incorporating mixed methods, and they're expected to be an expert in both qualitative and quantitative simultaneously. Thirdly, the validity of mixed methods is still being scrutinised by researchers. Though they may be complementary in their strengths, there is an ongoing debate as to whether they are compatible or incompatible (346). Though the theoretical debates for independent or mixed methods are continuing, researchers across various disciplines are further advancing and refining mixed methods.

Building upon the ontological and epistemological foundations laid out in this chapter so far, an exploration of my positionally will now be discussed, which critically shapes how these knowledge frameworks are applied and interpreted within the context of my research.

Research methods often are conducted using qualitative or qualitative methods. Quantitative research is often used to describe and explore a topic statistically, test a theory, generalise, or make causal inferences (351). Qualitative research is used when exploring a phenomenon, understanding thoughts and feelings, or developing a theory of consensus (351, 352). Often, quantitative data has been widely used due to its ability to be measured or counted, yielding greater scientific credibility and reliability as opposed to its qualitative counterpart (353). On the other hand, though, human behaviours are often multidimensional and require a holistic exploration of the "how" and "why" (353). Therefore, the complexities of human behaviour cannot be addressed merely by the quantification of data but by a qualitative inquiry.

3.1.3 Mixed-Methods Approach

As previously stated within above in Epistemology section (3.1.2), mixed methods were employed within this thesis. A pragmatic approach will be utilised by the research of this thesis, building on the once thought to be opposing paradigms in a synchronous approach.

In the initial phases of developing an online platform to provide tailored PA programmes and educational material to those LWBLC, it was practical to begin understanding the current literature regarding online supportive care for those LWBLC. Thus, a systematic review (see Chapter 2) was planned and undertaken as the preliminary step.

3.1.3.1 Systematic Review

The purpose of the systematic review was to explore the feasibility, acceptability, and potential efficacy of existing online supportive care interventions for those LWBLC. Understanding the current literature and evidence is a vital component of intervention development to minimise research waste and ensure worthwhile research. The doctoral systematic review was important for informing and shaping the mixed-methods approach adopted for this doctoral body of research. Although the systematic review was not a mixed-methods review, it incorporated elements that align well with qualitative and quantitative research paradigms. Specifically, the review focused on the feasibility, acceptability, and efficacy of online interventions, areas that are naturally multifaceted and benefit from a comprehensive methodological approach.

3.1.3.1.1 Feasibility and Acceptability in Online Interventions

The systematic review examined existing literature on online interventions, particularly assessing their feasibility, acceptability, and potential efficacy. These dimensions are highly important and relevant for understanding such interventions' practical application and user experience.

3.1.3.1.2 Qualitative Insights

While the systematic review primarily aggregated quantitative data on feasibility and acceptability metrics, it also included studies that used qualitative methods. These qualitative insights are valuable as they provide a deeper understanding of user experiences, highlighting issues such as emotional responses, perceived barriers, and facilitators to using online interventions. The inclusion of qualitative data in the review aligns with the qualitative component of the mixed-methods approach, emphasising the importance of capturing and including rich, descriptive data that quantitative measures alone are not able to provide.

3.1.3.1.3 Quantitative Outcomes

The review also compiled quantitative data on various outcomes related to online interventions, such as recruitment rates, attrition rates, and measurable improvements in targeted behaviours and health outcomes. Capturing these quantitative metrics is key for assessing the overall effectiveness and efficiency of the interventions, providing a solid evidence base that supports the generalisability of the findings. This review's quantitative aspect directly informs the mixed-methods approach's quantitative component, ensuring that the study is grounded in robust statistical analysis.

3.1.3.1.4 Integration into Mixed-Methods Approach

The systematic review served as a key component of the mixed methods approach by providing a solid foundation of current evidence. It identified key themes and outcomes related to feasibility, acceptability, and potential efficacy, which ensured the research was appropriate and relevant. The review established an evidence-based foundation that justifies the use of a mixed-methods approach by demonstrating the multifaceted nature of feasibility and acceptability, underscoring the need for this body of doctoral research. Additionally, the insights gained from the review inform specific methodological choices, such as the design of data collection instruments and analysis strategies, ensuring that the feasibility and acceptability study within this doctoral research was grounded in robust and relevant evidence.

3.1.3.2 Theoretical Framework

When developing the aims and research questions for this thesis, careful consideration was taken during the planning phase on how to best approach and structure the redesign or new iterations of the online platform and explore the feasibility and acceptability for those LWBLC. The Person-Based Approach (PBA) by Yardley and colleagues (354, 355) aimed to ground the development of an intervention in rich qualitative research through an iterative approach. The approach explores the perspective and psychological context of the target population to develop an appropriate intervention for the population. The general agreement of the digital health and telehealth research community is that eliciting the views and perspectives of those at which an intervention is aimed is critical and should be a cardinal feature of eHealth intervention development (356, 357, 358). The redesign and development of new content for the existing platform was guided by the Person-Based Approach (PBA), which emphasises understanding and addressing the perspectives, needs, and experiences of end-users. Central to PBA is User-Centred Design (UCD), which involves end users or stakeholders throughout the design and development process to ensure that the final product is functional, intuitive, and appealing (359). The rationale for using UCD in this research is multifaceted, aligning with the core principles of PBA. For example:

User Engagement and Satisfaction

- Principle of PBA: Tailoring interventions to end-user needs and preferences (355).
- Rationale for UCD: Involving users in the design process ensures that the application is user-friendly and meets their needs, which enhances user engagement and satisfaction (360).

Contextual Relevance

- Principle of PBA: Understanding the context in which users interact with the intervention.
- Rationale for UCD: UCD involves iterative feedback, ensuring that the application is relevant and practical for the aims of a given device and the end-users needs.

Iterative Improvement:

- Principle of PBA: Flexibility and adaptability to user feedback.
- Rationale for UCD: UCD's iterative nature allows for continuous refinement based on user input, ensuring that the application evolves to meet user needs better.

Empathy and User Experience:

- Principle of PBA: Building empathy for users to understand their experiences and challenges.
- Rationale for UCD: UCD focuses on empathising with users to create approaches that address their problems and needs, enhancing the platform's overall user experience and relevance.

3.1.3.2.1 Theoretical Underpinning

The theoretical underpinning for using PBA and UCD lies in several key theories and models from psychology, human-computer interaction, and design thinking:

- Self-Determination Theory (SDT): SDT states that individuals are motivated to engage in behaviours fulfilling their autonomy, competence, and relatedness needs. By designing interventions that align with users' needs and preferences, the PBA helps ensure these psychological needs, enhancing motivation and engagement (354).
- Technology Acceptance Model (TAM): TAM expresses that both perceived ease of use and a technologies usefulness are important determinants of users' acceptance of technology. UCD addresses these factors by ensuring a user-friendly platform meets end-users' needs (361).
- Design Thinking: Design thinking is a user-centred approach to problem-solving that involves empathy, ideation, prototyping, and testing. PBA aligns with design thinking principles by focusing on empathy, ensuring the design process remains grounded in users' real-world experiences, challenges, and the voices of lived experience (362).

3.1.3.2.2 Integration with Paradigms and Mixed-Methods Approach

The adoption of PBA, including its UCD component, is consistent with the philosophical paradigms and mixed-methods approach underpinning this research. Ontologically, the approach taken acknowledges users' subjective realities and lived experiences, aligning with a constructivist perspective. Epistemologically, it emphasises the co-construction of knowledge through active user involvement, consistent with interpretivist principles.

Methodologically, the mixed-methods approach provides a robust foundation for implementing PBA and UCD. The qualitative components, such as iterative PPI and

Think Aloud interviews, allowed an in-depth exploration of user needs, preferences, and experiences. These qualitative insights were important for informing the design and development of the platform. Concurrently, the quantitative components, such as Think Aloud interviews and surveys (e.g., systems usability scale), provide measurable data on user engagement and satisfaction, ensuring that the design and internal processes met the needs of the end-users.

In summary, the use of the Person-Based Approach, with User-Centred Design as a core component, in redesigning the application and creating new content is theoretically grounded and methodologically sound. It ensures that the intervention is user-centred, enhancing its relevance, acceptability, and effectiveness. By integrating qualitative and quantitative methods, this approach aligns with the mixed-methods framework, providing a comprehensive and user-informed basis for the design and development process. Figure 8 provides a visual pf this process.

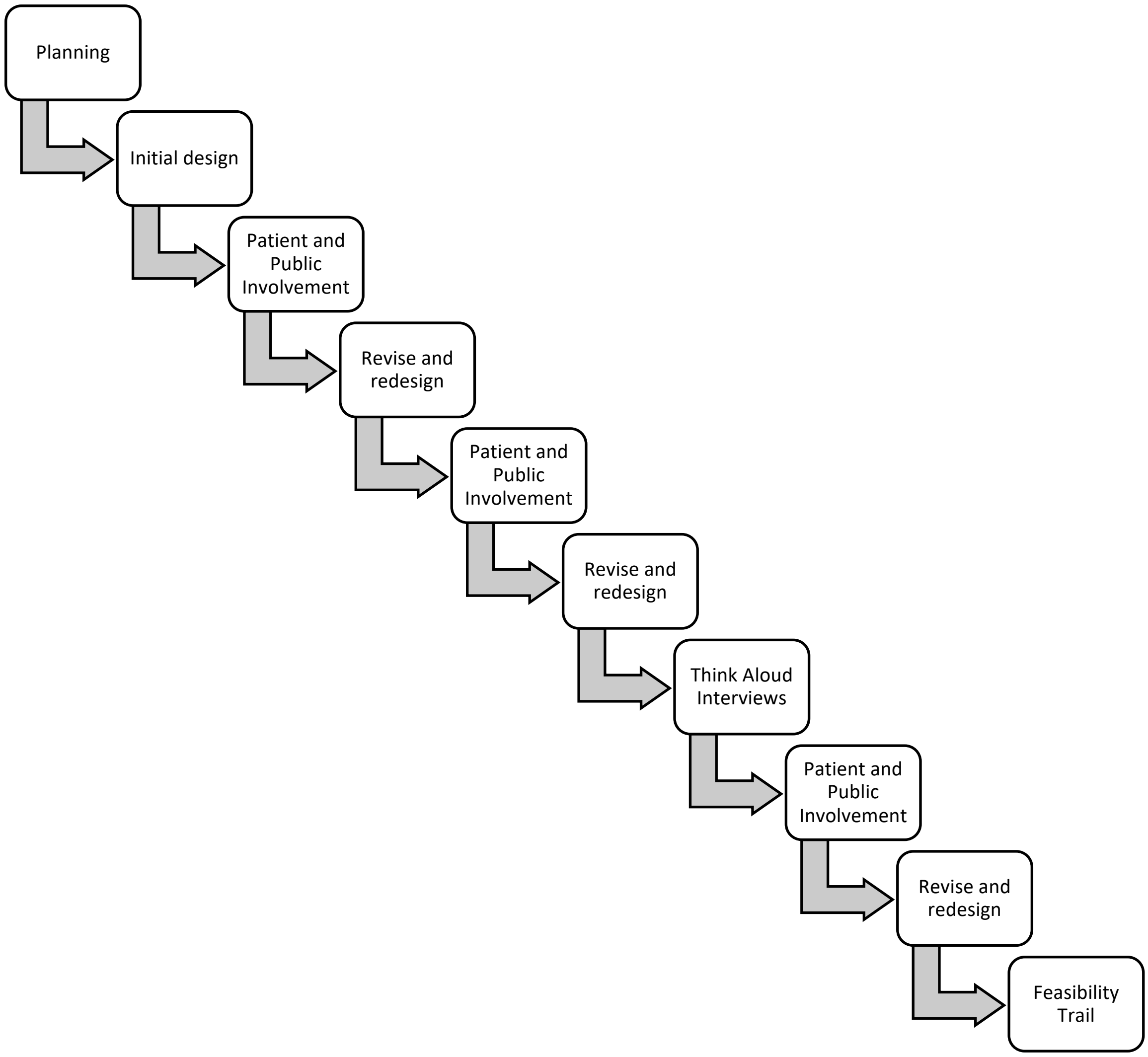

Planning
Initial design
Patient and Public Involvement
Revise and redesign
Patient and Public Involvement
Revise and redesign
Think Aloud Interviews
Patient and Public Involvement
Revise and redesign
Feasibility Trail

Figure 8: Platform pathway based on the principles of the Person-Based Approach.

3.1.3.3 Feasibility and Acceptability

The overarching aim of this thesis was to explore the feasibility and acceptability of an online tailored PA programme for those LWBLC. The underpinning theory was selected due to its position of aiding the development of digital health intervention development. Collecting quantitative and qualitative data to explore feasibility and acceptability allowed a deeper understanding of whether practical consequences are accepted, and impractical ones are rejected. In essence, was the platform accepted, and did it work satisfactorily by being feasible and acceptable?

3.1.4 User-Centred Design Approach

Employing user-centred design (UCD) was essential in the adapting, updating, and redeveloping of the existing website, playing a vital role in the iterative process. Pragmatism holds strong views on the qualitative paradigm, illustrating that an individual's views, feelings, and beliefs have value, in addition to the quantitative research paradigm. The pedagogy and ideas of one of the founding fathers of pragmatism, John Dewey, is relevant and can be applied to technology, UCD, and iterative adaption with end-users. Dewey viewed philosophy as a method in which tools can be developed to enable individuals to cope with real-world problems (363). Dewey's pragmatism proposed two key themes, 1) Practices, Experiences, and Knowledge, and 2) Communication, Cooperation, and Change. Fundamentally, the aim was to promote cooperation among people and reflect on and discuss their practices and experiences (363).

User-centred design with end-users is pragmatic and practical to create meaningful and worthwhile research valuable to the end-users. Following Dewey's philosophy, the group adaption of an online supportive care intervention aiming to enable those LWBLC to cope with their real-world problems is fundamentally an example of pragmatism.

Given the pragmatic stance, I have illustrated I am taking with this doctoral research, and aligning with the PBA, a UCD was used, bringing together the qualitative and quantitative paradigms to seek thoughts, feelings, and experiences of those LWBLC and numerical data to help adapt and revise the platform through an iterative process with the iterative patient and public involvement (PPI) and Think Aloud interviews.

3.1.4.1 Patient and Public Involvement and Think Aloud Interviews

As previously demonstrated, I have firmly situated this doctoral research within the epistemological and ontological view that mixed methods can provide a wealth of rich and worthwhile qualitative and quantitative data. Thus, utilising a pragmatic approach, this thesis sought contributions from the target population the platform is intended to be used by (those LWBLC), also known as end-users. This seemed the most appropriate approach considering when reflecting on my positionality as an outsider. As a younger (28y), educated individual, completing a doctoral degree, not having had a diagnosis of lung cancer, or any cancer, I am positioned as an outsider of my end-users. However, this may be seen as a strength for maintaining objectivity and appearing to be the 'expert' and focusing on seeking information from participants. Though, being an outsider incurs substantial limitations, such as lacking the first-hand impacts of LWBLC.

Furthermore, the engagement with end-users must remain unbiased of my benefits, judgements, and practices. It was important for me to continually pay close attention to my own beliefs about the benefits of PA and digital technology, so that those LWBLC put forward honest and authentic commentary. Considering my positionality, the PBA allows the end-users to have a prevailing voice in the decisions being made and final outputs. Ignoring the end-users may contribute to the vast global research waste through designing an intervention which does not meet the needs of the end-users. Through involving the end-users in the intervention and/or content development, appropriate content can be designed which in turn will reduce the likelihood of inappropriate content. Globally, an estimated 85% of health research data resulted in being wasted, causing an astronomical blow to the tens of billions of investments (364). Engaging with patients and public members may reduce the immense funds being wasted. For research aiming to develop interventions for specific special populations, it seems rational to include their thoughts, beliefs, and views within no less than the development, ideally any further iterations.

3.1.5 Think Aloud Interviews

From the early stages of my doctoral degree, I believed involving the target end-users in the website's redevelopment was the most practical and logical method. Among the iterative development from PPI, a study wherein those LWBLC engaged with the website and performed common tasks would typically be expected to seem logical and obvious. Pragmatically, recruiting individuals who had no prior engagement with the platform to use the website while thinking aloud their actions and thoughts would be a satisfactory and reasonable method of ascertaining information about the website's user experience (e.g., usability) and their underlying thoughts and beliefs.

3.1.6 Qualitative Analysis Approach

3.1.6.1 Thematic Analysis

Thematic analysis is a method of reporting, presenting, and interpreting of qualitative data using themes and constructs. Within thematic analysis, a theme is referred to as the pattern across a given set of data. Thematic analysis has long been credited for its ability to be applied throughout a wide array of epistemological and theoretical frameworks, in addition to varying sample sizes, study questions, and designs (365) Various academics have questioned what realm thematic analysis belongs within qualitative research. Previously, thematic analysis has been poised to be within the scope of ethnography (366), whereas others have claimed it fits within phenomenology (367). However, Braun and Clarke (2006) suggest thematic analysis is able to be an independent analytical method and a foundational method for further qualitative research methods (365). Though it must be noted, thematic analysis does share similarities in its principles with other qualitative methods, such as discourse analysis (368) and Grounded Theory (369). Thus, due to this and its given flexibility, Braun and Clark (2006) suggest opposed to a methodology, thematic analysis is a method (370). Due to the flexibility of thematic analysis is thought not to be bound to a single paradigmatic orientation (370). For example, it can be used within a pragmatic, critical realist, constructivist, or post-positivist approach (370). It has been argued that thematic analysis is particularly suited to a constructivist approach as it can illustrate how particular social constructs emerge through its ability to analyse a vast array of data (367). Through interactions between participants and researchers, thematic analysis can enable the development of how social, cultural, or structural contexts may influence or impact an individual's beliefs or experiences, underpinning the meanings that are socially constructed (370). Whereas thematic analysis could be applied to explore the power relations which may inform the reality and provide those oppressed with a voice, which would align with a critical realist framework (367, 370). Finally, thematic analysis could be applied to a post-positivist orientation, gaining insight into external reality through individual experiences and meanings. Through this process, we are able to support the development of conjectural knowledge about reality.

Within this thesis, the Think Aloud interviews and post-feasibility and acceptability study interviews will be analysed and reported using the principles of thematic analysis. Although thematic analysis is positioned to be a good ‘go to’ analytic method for those starting within qualitative research (370, 371, 372, 373) it is important to ensure the appropriate method is applied, based on the research aims and goal, irrespective of a method which provides simplistic steps. The thematic process was carefully chosen based on its ability to understand thoughts, experiences, and/or behaviours within a given population across a spread of data. Moreover, as previously mentioned, thematic analysis shares common principles with already established qualitative research methodologies which employ date-set coding and data-generated themes, such as Grounded Theory and Ethnography (365). However, it remains important to situate the chosen method in relation to alternative methods. To do this, we must first understand the scope and purpose of thematic analysis. Sandelowski and Barroso (2003) propose a useful concept to compare and contrast qualitative methods. Sandelowski and Barroso (2003) suggest qualitative analyses are spread across a spectrum (374). This spectrum is defined by the degree that the data under analysis is translated during the analysis. At one end of the spectrum, you have solely descriptive, wherein data is not truly applied or translated, merely reporting the lists, classify or organising data, often within forms such as frequencies or percentages. This descriptive method lacks a true interpretation of the findings. Whereas at the opposing end of the spectrum, there is a highly interpretive analysis. An example of this would be phenomenology, where analysis examines how the meanings which we attach to individual experiences can inform the questions we, as researchers, are exploring (375).

Kiger and Lara Varpio (2020) suggest that based on the qualitative spectrum concept proposed by Sandelowski and Barroso (2003), thematic analysis falls around the middle of these two opposing polls (365, 374). Although themes are generated to organise and label data, an interpretation of data is conducted. Nevertheless, the engagement of data is not to the extent of theory development, a key aim of grounded theory (376). Thus, thematic analysis seemed appropriate to understand the meanings behind their experiences of using ExerciseGuide UK to explore concepts such as satisfaction through categorisation and thematic similarities, but not moving further across the spectrum towards theory development.

3.1.7 Quantitative Analysis Approach

3.1.7.1 EORTC-QLQ-30 and HADS Analysis

As previously mentioned in the discussion regarding my epistemology and ontology, I stand firmly in the belief that quantitative and qualitative research can complement each other well to provide a holistic mixed-methods understanding of a phenomenon. The EORTC-QLQ-30 and HADS provide quantitative measures which can be statistically analysed. Both questionnaires are used widely used throughout the literature and within oncological populations. However, basing the decision to include a questionnaire in one work should and does not rely on popularity. In essence, just because others use it does not mean it is appropriate. Both the EORTC-QLQ-30 and HADS are highly validated and reliable within oncological populations. Together they provide good coverage of an individual's QoL (including physical and psychological well-being).

Questionnaires, such as the EORTC-QLQ-30 and HADS, are commonly understood to be research methods that aim at capturing, measuring, and analysing information from a given time point to explore relationships between given variables which exist in our social reality (377). From an epistemological standpoint, questionnaires, such as the EORTC-QLQ-30 and HADS are often underpinned by positivist/post-positivist positions (377). These questionnaires provide a window into individual biographical information, their views, and their behaviours. A comparison of varying epistemological positions and their understandings of questionnaire usage is presented in Table 7*Error! Reference source not found.* by Romm et al., (2013) (377).

Table 7: Comparing Understandings of Questionnaire Use by Romm et al., (2013) (377)

	Rationale for Using Questionnaires	Relationship to Respondents/Participants	Relationship to Wider Society
Positivist/Postpositivist	Questionnaires are designed as a method of advancing knowledge of relationships (correlation and causality) between measurable variables in social reality.	Respondents' responses ideally offer a window into their biographical information, their social positioning, their behavior (as they recall it), and their opinions/attitudes/views. These responses, when analyzed statistically, allow researchers to test for relationships between the variables so that certain statements can be made (with some degree of confidence).	Readers of the results, including policy makers, become more informed about relationships between variables than they were before the studies were undertaken (using scientific protocols).
Interpretivist	Questionnaires are designed as a possible method of advancing knowledge of causal sequences that can be explained on the level of meaning (when combined with additional methods directed at understanding meaning-making).	Respondents' responses ideally offer some window into their biographical information, their social positioning, their behavior (as they recall it), and their opinions/attitudes/views. These responses, when analyzed by researchers (with a view to locating causal sequences operative in specific social contexts), can provide some information, which is complemented by the exploration of meaning via alternative methods.	Readers, including policy makers, of the researchers' interpretations become more informed about the patterning of social life than they were before the studies were undertaken (using the protocols of social science).
Constructivist	Questionnaires can be considered as one method, amongst others, of creating constructed knowledge, which is recognized to be a social construction (created here through the interaction between researchers and participants).	Responses given in questionnaires are admitted to bear the mark of the context of interaction between “the instrument” (as interpreted by participants) and the participants. This context must be made visible at the point at which results are interpreted by researchers. Multiple interpretations can be offered in terms of what researchers believe participants are expressing in response to the various questions asked.	Audiences of (draft) results are invited to offer interpretations of any “connections” between variables. Draft reports need not express a univocal account of what the “results” indicate. Processes (e.g., workshops) should be initiated to reconsider the report

	Rationale for Using Questionnaires	Relationship to Respondents/Participants	Relationship to Wider Society
			so that a variety of interpretations can be discussed.
Trusting constructivist emphasis	Questionnaires are constructed with researchers bearing in mind that the social consequences of the instrument itself will not be neutral; researchers appreciate that the questionnaire can be a tool for *forming* people's ways of envisaging/framing "problematic" issues.	Researchers make provision for listening to key participants' conceptions of how issues should be framed (before the final questionnaire items are set). Researchers make it clear to participants (e.g., at the top of the questionnaire and/or via research assistants) that they do not regard the instrument as a neutral tool for "data extraction." Questionnaires can also be aimed at generating a pedagogical context enabling participants as well as researchers to develop enriched perspectives.	Researchers acknowledge that any results presented (tentatively) are a product of the way the questions were framed and the categories created. Any "reporting" is therefore subject to revision by inviting feedback from original participants and wider audiences. Trust can be earned by researchers showing that they are willing to take this feedback seriously as part of the discussion on presented reports. These discussions include considering extended action options in view of various interpretations of the research import.

Based on the suggestions proposed in the Positivist/Postpositivist lens in table 7 above, the purpose of these questionnaires is to explore the relationship between variables of individuals and aim at advancing the knowledge of these relationships within social reality.

3.1.7.2 Website Engagement Data

Akin to the questionnaire data, analytical engagement data will be obtained from inbuilt website engagement tracking. This approach lends itself to a positivist epistemology, observing and exploring the social facts, which will, in turn, allow the laws or mechanics which govern human behaviour to be revealed.

3.1.8 Integration of Findings

Over recent years, mixed methods research has rapidly expanded and continues to gain popularity, spanning numerous fields of research (378, 379). Although there is an emphasis placed on the integration of quantitative and qualitative research in mixed-method studies, there are a relatively limited number of techniques available to do so for researchers.

The final study will present the quantitative and qualitative data collect separate (Chapter 7 and Chapter 8). As a researcher, I believe the existence of multiple, diverse realities and ontologies. Therefore, it is important to choose a technique which acknowledges and privilege one type of data over the other.

The Pillar Integration Process (PIP) is a four-stage approach which has been developed to assist in the integration and presentation of qualitative and quantitative data. The PIP aligns with both multiple realism and ontological pluralism by acknowledging the range of realities and ontologies that can be captured through both qualitative and quantitative paradigms. Moreover, the PIP seeks to integrated both of these data paradigms together, but in a rigorous and transparent manner. Additionally, the PIP is thought to be very suitable for those using a triangulation technique (380). As noted in section 3.1.2.1.1 Pragmatic Approach, triangulation was used for the collecting of data, for example data pertaining to QoL from a survey and interviews. The PIP is presented in Chapter 9, with individual tables, per research questions being presented following each question. Therefore, the PIP will be used to bring together the data in study three.

3.1.9 Positionally

My positionality is a unique blend of my personal experiences, education, and professional journey, all coming together to shape my worldview and research path. From my childhood years, physical activity was a cornerstone of my identity, not merely as a means of enhancing physical fitness or being social, but also as a vital tool for nurturing mental well-being. Growing up in an environment where exercise was not just encouraged but celebrated, I developed an appreciation for its wide-ranging benefits, instilling in me a lifelong commitment and passion to understanding and harnessing its potential in promoting holistic health.

However, I also experienced the real-life impact and reality of cancer within my family and social circles. Witnessing loved ones navigate the complexity and challenges of diagnosis, treatment, and survivorship drove me to research interventions that could help alleviate this burden. These experiences, coupled with my keen belief in physical activity as a cornerstone of health, formed the core of my research interests.

My cultural and social identity further shapes my approach to research, instilling it with a nuanced perspective rooted in empathy and inclusivity. As a white British male from a lower socioeconomic background, I am keenly aware of the dynamics of privilege and marginalisation within society. Although my racial identity does not inherently bias my research, I am aware of the systemic healthcare disparities and work to address access barriers.

Moreover, my status as a member of the "Zillennial" micro-generation provides my research with a distinctive lens, characterised by an interdependent relationship with digital technology. Growing up during the rapid expansion of the internet and digital connectivity, I strongly believe in the potential of technology to break down barriers in healthcare. Despite being raised in an environment where technological resources were not readily accessible, my education provided me with access to the digital world, allowing me to explore its applications in health promotion and disease management.

Guided by an educational philosophy centred on hands-on learning and real-world relevance, I have developed a comprehensive understanding of how physical activity, health outcomes, and technological advancements intersect. This interdisciplinary perspective not only enhances my research but also underscores my commitment to exploring my scientific curiosity and developing interventions that positively impact the lives of those living with and beyond cancer.

In my research, I am dedicated to community engagement and prioritising the needs of patients. Embracing the ethos of participatory research, I actively seek input from a diverse range of stakeholders, including patients, caregivers, and support groups, recognising the invaluable insights from lived experiences. This collaborative approach not only informs the development of research questions but also shapes the methodologies employed, fostering a good blend of quantitative and qualitative approaches.

Confronting potential power imbalances and ethical considerations, I follow the principles of transparency, empathy, and respect for autonomy. By fostering an environment of trust and mutual respect, I strived to cultivate genuine partnerships with research participants. Through open dialogue and shared decision-making, I aimed to empower individuals to actively shape the trajectory of the research process, ensuring that their voices were heard, and their contributions meaningfully integrated into my work.

In essence, my positionality is driven by a commitment to advancing healthcare equity and empowerment through the integration of physical activity and technology. Grounded in prior experience and dedication to equality, I remain committed in my passion to leverage research as a catalyst for positive change, acknowledging the incremental steps that I can take toward a more inclusive and equitable future in both research and healthcare.

3.1.10 Summary of Methodology

Entering the doctoral degree as an exercise physiologist with a background mainly in quantitative methodology, I went through a positive learning process where I combined my practical background with a growing understanding and use of the fundamental philosophical concepts in my decision-making process. Throughout the doctoral degree, I, as a researcher, have developed a strong understanding of the fundamental principles of ontology and epistemology and how they guide my view of reality and the assumptions of knowledge and the truly knowable.

This thesis employed a mixed-method, pragmatic approach. The longstanding argument that qualitative and quantitative paradigms are incompatible due to their ontology and epistemology being incommensurate does not mean they cannot be used in a complementary process (330), particularly surrounding the generation of knowledge. However, the website's adaption to a specific cancer population and country of residence, involving end-users in the process, makes pragmatic sense. Qualitatively, the views, beliefs, and experiences of those LWBLC lead to content that is appropriate and desired. Furthermore, the acceptability and satisfaction of the platform will be explored using qualitative methods. Whereas feasibility and engagement metrics will be explored using quantitative methods. The pragmatic approach taken throughout this doctoral degree as I value the strengths of using qualitative and quantitative approaches synergistically as the methods required to address the research questions of this thesis differ. Therefore, allowing me to develop a holistic analysis of the data acquired, incorporating multiple relevant factors and variables into the study.

Chapter 4 Methods

This chapter describes the methods undertaken to explore the feasibility, usability, and acceptability of the ExerciseGuide UK platform, an online supportive care platform for individuals living with and beyond lung cancer (LWBLC). Throughout this chapter, a detailed description of the methods used to conduct the research studies will be presented. Prior to this, the systematic review and its methods have been detailed in Chapter 2, providing a foundation and context for these studies. By outlining the methods used to address each research question, this chapter lays the groundwork for understanding how the research was structured and conducted and sets the stage for the subsequent discussion of the findings.

4.1 Research Questions

This research sought to explore the feasibility and acceptability of an online supportive care platform (called ExerciseGuide UK) designed to provide tailored physical activity programmes and educational resources specifically for individuals LWBLC. The overarching aim is to determine whether such a platform is not only feasible and acceptable for this demographic but also to identify the barriers these individuals face when engaging with this type of digital health intervention.

4.1.1 Feasibility and Acceptability Study

The feasibility study was important in determining whether digital platforms, such as ExerciseGuide UK, were practical for the target population. It assessed various aspects, such as user engagement, the suitability of the platform's structure and content, and patient perspectives regarding its need within the current healthcare framework. This study aimed to address the first research question: "Is an online supportive care platform that aims to provide tailored physical activity programmes feasible for those LWBLC?" The evaluation of feasibility was guided by specific, pre-established criteria: achieving a recruitment target between 15 and 35 participants by May 30th, 2022, maintaining a recruitment rate of at least 60%, and ensuring a retention rate of 85% or higher. By meeting this pre-defined criterion and assessing these components, the study provided insights into necessary adjustments and evaluated the potential for scaling ExerciseGuide UK for wider use.

Alongside the assessment of feasibility, the acceptability was examined by focusing on the user's attitudes toward the platform, specifically, how the targeted users perceive and react to the system. This included evaluating satisfaction with ExerciseGuide UK, content relevance, and the perceived value of the platform in supporting their physical activity goals. The second research question, "Is an online supportive care platform that aims to provide tailored physical activity programmes acceptable for those LWBLC?" directs this part of the study. Understanding acceptability is key to refining the platform to better meet the needs and preferences of those LWBLC.

4.2 Barriers to Engagement

In addition to feasibility and acceptability, this research also sought to identify and understand the barriers that those LWBLC may have faced when engaging with digital platforms, such as ExerciseGuide UK. The third question, "What barriers exist for those LWBLC to engage in an online tailored physical activity platform?" guides the investigation into factors that might hinder user participation and engagement. This question is key for developing strategies to overcome these barriers, enhancing the usability and effectiveness of the platform.

This research aimed to contribute to the design and implementation of effective digital health interventions tailored for individuals living with and beyond cancer by addressing these specific research questions through detailed usability, feasibility, and acceptability studies. Each study was informed by a person-based approach, ensuring that ExerciseGuide UK was user-centred and met the complex needs of its users.

4.2.1 Theoretical Framework

This thesis aimed to adapt an existing platform (ExerciseGuide) to provide tailored PA programmes to those LWBLC. Building on a previous platform (381, 382), new educational resources and algorithms were developed to enable personalisation and tailor activity programmes and educational resources. The literature surrounding intervention development highlights the importance and value of following an established process. O'Cathain and colleagues (383) illustrated the importance of following an intervention development process that maximises the intervention's effectiveness and prevents the intervention from not being feasible or acceptable, leading to research waste (384).

The Person Based Approach (PBA), developed by Yardley and colleagues (2015) (354), was used as a guiding framework for this doctoral research, drawing on the key stages and activities outlined for the development of digital health interventions (354). The two key elements of the PBA are developmental processing and guiding principles (354). The PBA has been reported to take approximately 12 – 18 months from planning to trial. Given the nature of a doctoral degree, the PBA acted as a guide, building on intervention development principles instead of a strict methodology.

In addition to the overarching theoretical underpinning of this thesis, the application of established theoretical processes was integrated into the online platform about PA. Given the complexity of a cancer diagnosis, specifically lung cancer, many experience barriers to PA. Behavioural techniques (e.g., goal setting and tracking) were integrated to maximise PA engagement and maintenance.

4.3 Role of Usability Study

The usability study was key within this doctoral degree for ensuring that the ExerciseGuide UK platform was user-friendly and appropriately met the needs of those LWBLC. This study directly contributed to understanding how the system's design and functionality impacted user interaction and satisfaction. It focused on evaluating the usability of ExerciseGuide UK, which included ease of use, the user interface, and the ability to engage with the integrated features. By analysing these aspects, this study helped determine necessary revisions that needed to be made in order to enhance the platform's usability, ensuring it was both practical, appropriate, and relevant for users.

4.4 Role of Feasibility and Acceptability Study

Alongside the feasibility analysis, the acceptability of ExerciseGuide UK was explored. This included the participant's perceptions and values of the ExerciseGuide UK platform. This portion of the study focused on determining the acceptability of the platform in terms of its content, design, and overall utility. Key elements which were explored included user satisfaction and perceived relevance and helpfulness of the platform through both post-study questionnaires and interviews. Understanding these factors is key to refining the platform to better meet the specific needs and preferences of LWBLC, thereby enhancing their engagement and the overall effectiveness of the platform.

4.5 Study Methods

This section will now describe and outline the methods employed in the usability (think aloud) study and the feasibility and acceptability study of the ExerciseGuide UK platform. Both studies were designed to examine and test different aspects of the platform, ensuring it met the needs of those LWBLC. The following sub-sections detail the specific study methods.

The methods chosen are grounded in the person-based approach, which emphasises the importance of understanding the target users' perspectives and experiences. This approach has informed the study design, from the selection of tools and instruments to the methods of data collection and analysis. By employing this framework, the studies aimed to provide clear insight into the usability, feasibility, and acceptability of the ExerciseGuide UK platform, thereby guiding its future development and potential future implementation.

4.5.1 Think Aloud Study Methods

4.5.1.1 Study Design

A single group Think Aloud study was conducted via Zoom between June 2021 and July 2021. Before recruitment commenced, ethical approval was obtained (HYMS reference: 2049 (see appendix 13.3), informed consent was gained digitally via Qualtrics (see appendix 13.9). Guidelines for the Think Aloud interviews were followed (385, 386). The Think Aloud procedure is described below in section 0.

4.5.1.2 Participants Sample and Setting

Seven participants were recruited via the dissemination of a recruitment flyer via lung cancer support groups. The inclusion criteria were as followed 1) participants must have been 18 years or older; 2) living with or beyond lung cancer (living with and beyond cancer is defined as anyone who has had a diagnosis of lung cancer; (387)); 3) had access to a computer, laptop, or tablet; 4) had internet accessibility, and 5) able to read and communicate in English.

4.5.1.3 Think Aloud Procedure

Prior to conducting the Think Aloud interviews, a demonstration was provided. The participants were invited to perform a practice Think Aloud activity. Primarily a Concurrent Think Aloud (CTA) approach was used throughout. A CTA approach involves participants verbalising their thoughts and reasoning processes in real time while performing a given task. However, opportunities were provided for reflection at the end of tasks, drawing on strengths from the Reflective Think Aloud (RTA) approach. A RTA approach involves participants verbalising their thoughts and reasoning processes retrospectively after completing a task. Participants were encouraged 'there is no right or wrong answer' and 'not to worry about being critical'. The researcher would not be offended by any comments and the goal was to improve the platform prior to larger-scale testing. Upon completion of the introductory activity, the interview and video recording commenced. Participants were made aware the recording started by the researcher and an automated message announcement via Zoom.

Participants were given access to the ExerciseGuide UK prototype without requiring sign-up through a usability bypass. No data was collected from the website during this study. Participants were advised to express their thoughts, reactions, emotions, and actions aloud while performing each task in real-time. At the end of a given task, participants were provided with a moment to reflect on the task to provide any further comments. The tasks were given to the participants as questions, not direct instructions. For example:

> *"If you were looking to learn more about goal setting and wanted to set your own goal and action plan, how would you do this?"*

If the participants were struggling, a list of prompts had been pre-determined per task to ensure standardisation. Prompts ascended from neutral (e.g., "what are you thinking now?") to specific prompts (e.g., "Have you tried looking in the top corner?") based on the extent of time and struggle presented in a given task. There was no pre-determined time for this progression in prompts. The decision was made at the discretion of the researcher (JC). The flow of tasks with a brief summary is provided below in Figure 9**Error! Reference source not found.**. To promote transparency and broader context, further information can be located in the topic guide (appendix 13.4)

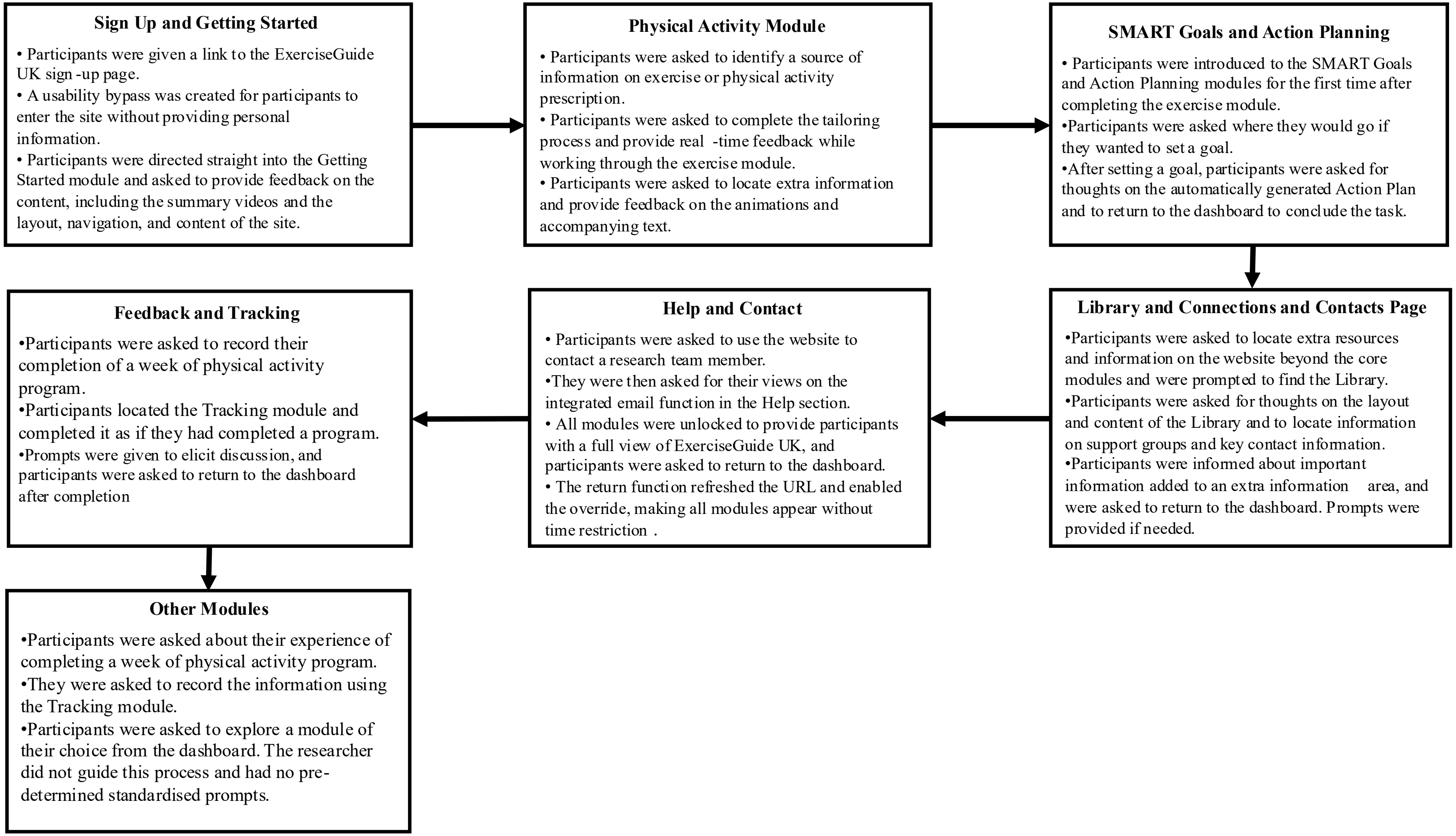


Figure 9: Flow of tasks provided during the Think Aloud interviews.

4.5.1.4 Data Analysis

4.5.1.4.1 Qualitative Data Analysis

The data from Think Aloud interviews were analysed using an inductive thematic analysis (TA), as this method helps researchers construct themes from a meaningful engagement with the data. The analysis was guided by the six phases of TA by Braun and Clarke (371, 372) and was not strictly adhered to. This was to enable a more appropriate output to be generated to examine potential usability concerns.

The initial phase comprised the *familiarisation* of the data. During this phase, the data was transcribed and saved in Microsoft Word (Microsoft Office, Version: 16.96.1, 2023). Initially, the coding of the Think Aloud interviews was to be conducted in NVIVO (QSR International, Version 12.0, 2023), though the complexity outweighed the benefits with the small sample size. Therefore, it was more realistic and straightforward to conduct the analysis in Microsoft Word. An initial read-through was then carried out, taking notes of any potential points of interest using the 'insert comment' function before moving on to the *generation of initial codes*. This phase required a systematic approach to coding positive and negative comments throughout the entire dataset before grouping the relevant data under each code. The next two phases involved *reviewing, examining, and refining the themes* and, finally, *defining and naming* them. A Table of Change was created to record the themes and their associated quotes within each of the given tasks, allowing for an easy overview. The final step involved *proposing initial revisions*, prioritised using a "Must, Should, Could, Would" method, to address any negative comments that may impact usability.

A breakdown of the phases, guided by TA, can be found in **Error! Reference source not found.** below in Table 8. The Table of Change can be found in the appendix three (see appendix 13.2). The definitions of the themes and the number of occurrences is presented in

Table 12 in section 5.2.6.4.

Table 8: Modified phases of thematic analysis for the identification of usability concerns within the Think Aloud Interviews (371, 372).

Phase	Description of the process and Application to Think Aloud Interview Analysis
1. Familiarisation of data	Transcribing data, reading and re-reading the data, and noting initial ideas.
2. Generating initial codes	Coding positive and negative comments within the data systematically across the entire data set, collating data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work concerning the coded extracts (Level 1) and the entire data set (Level 2), generating a Table of Change to store and display themes and associated quotes.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, generating clear definitions and names for each theme.
6. Propose Initial Revisions	Upon completion of refining each theme, the doctoral researcher proposed initial revisions for negative comments that might affect usability. The revisions were initially prioritised using a "Must, Should, Could, Would" prioritisation method.

4.5.1.4.2 Quantitative Analysis

Following the Think Aloud interview, participants were emailed the Systems Usability Scale (SUS) (388) via Qualtrics. Data was analysed using descriptive- and frequency-based methods using Statistical Package for the Social Sciences, commonly known as SPSS (IBM, Version: 29, 2023).

The study information can be found in 5.2.6.

4.5.2 Feasibility and Acceptability Study Methods

4.5.2.1 Study Aim

The aim of this study was to explore the feasibility and acceptability of ExerciseGuide UK (an online supportive care platform) for people LWBLC.

4.5.2.2 Study Objectives

In order to address the research questions listed in section 4.1, five objectives were set:

1. Report the feasibility of the study by summarising the following:
    a. Eligible:consent ratio of recruitment.
    b. retention rate
    c. recruitment rate
2. To understand the how those LWBLC engage with ExerciseGuide UK.
3. To understand the thoughts, beliefs, and feelings those LWBLC have about using ExerciseGuide UK.
4. To understand the impact of an eight-week tailored physical activity programme for those LWBLC.
5. To explore perceived usability of ExerciseGuide UK among people LWBLC.

4.5.2.3 Methods

4.5.2.4 Study Design

The study was a single-arm, eight-week feasibility trial. Ethical approval was gained from the Hull York Medical School (approval: 2116) and Health Research Authority and Health and Care Research Wales (HCRW) (approval: 21/SC/0174) (see appendix 13.3). The protocol was registered *a priori* at ClinicalTrials.gov (389) (ID:

NCT05121259). All participants provided written informed consent prior to entering the study. The Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) guidelines are provided below in Table 9.

Table 9: Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) guidelines for the enrolment, baseline, intervention, and close out.

	Study Period				
	Enrollment	Baseline	Exercise Intervention		Close out
TIMEPOINT		Week 0	Week 1	Week 8	Week 9
ENROLMENT:					
Eligibility screen	X				
Informed consent	X				
Healthcare Team Approval	X				
INTERVENTIONS:					
Exercise Intervention					
ASSESSMENTS:					
Baseline Variables		X			
Post Variables					X
Qualitative Outcomes					X
Post Qualitative Interviews					X

4.5.2.4.1 Participant Identification and Recruitment

Participants were recruited via the Queen's Centre for Oncology and Haematology at the Hull University Teaching Hospital (HUTH). Patients were identified by their medical oncologist and referred to speak with the doctoral research student (JC) if they agreed. The doctoral research student visited clinic once to twice per week to approach eligible patients (see eligibility criteria in Figure 10**Error! Reference source not found.**), following the medical oncologist referral. For those eligible patients, JC provided a summary of the study and for those interested, a recruitment flyer (see appendix 13.13) and a participant information sheet (PIS) (appendix 13.4) was provided. Eligible patients who declined participation were asked if they would provide a reason which would be formally recorded. If they declined to provide a reason, "no reason given" was noted. Potential participants were informed to take time to read the PIS and if they had any questions, to please ask before progressing.

Participants were also provided with a digital PIS. If potential participants were interested in progressing, a digital consent form (appendix 13.4) via Qualtrics (institutional access via the University of York) was provided. The online PIS provided an automated, self-reported, screening process based on the eligibility criteria. Once the virtual documents were completed, a Zoom call (or phone call if preferred) was arranged to confirm eligibility and provide participants the opportunity to ask any questions. Following the verification of eligibility, consent was obtained. Participants were then given access to the website (ExerciseGuide UK; https://www.exerciseguide.org.uk), and baseline measures were collected via ExerciseGuide UK upon registration.

4.5.2.4.2 Exclusion based on Bone Metastasis

Given the high prevalence of bone metastases in those LWBLC, exclusion was carefully deliberated and based on two key elements: 1) ExerciseGuide UK capability and 2) safety. ExerciseGuide UK has the capability to tailor based on bone metastases, which a previous version for those living with and beyond metastatic prostate cancer has shown (390). Though, the depth of code required to do so was deemed not feasible by the research team and software developer given the doctoral timeframe. Secondly, though evidence exists supporting the safety of PA and exercise for those with bone metastases, a minimum level of supervision was noted for safe delivery (230, 391). This iteration of ExerciseGuide had two scheduled consultations over eight weeks with no supervised delivery of exercise. Thus, it was mutually agreed by the researcher, software developer, and clinical team that those with weight-bearing bone metastases would be excluded. However, those with bone metastases in non-weight-bearing locations would be eligible at the clinician's discretion.

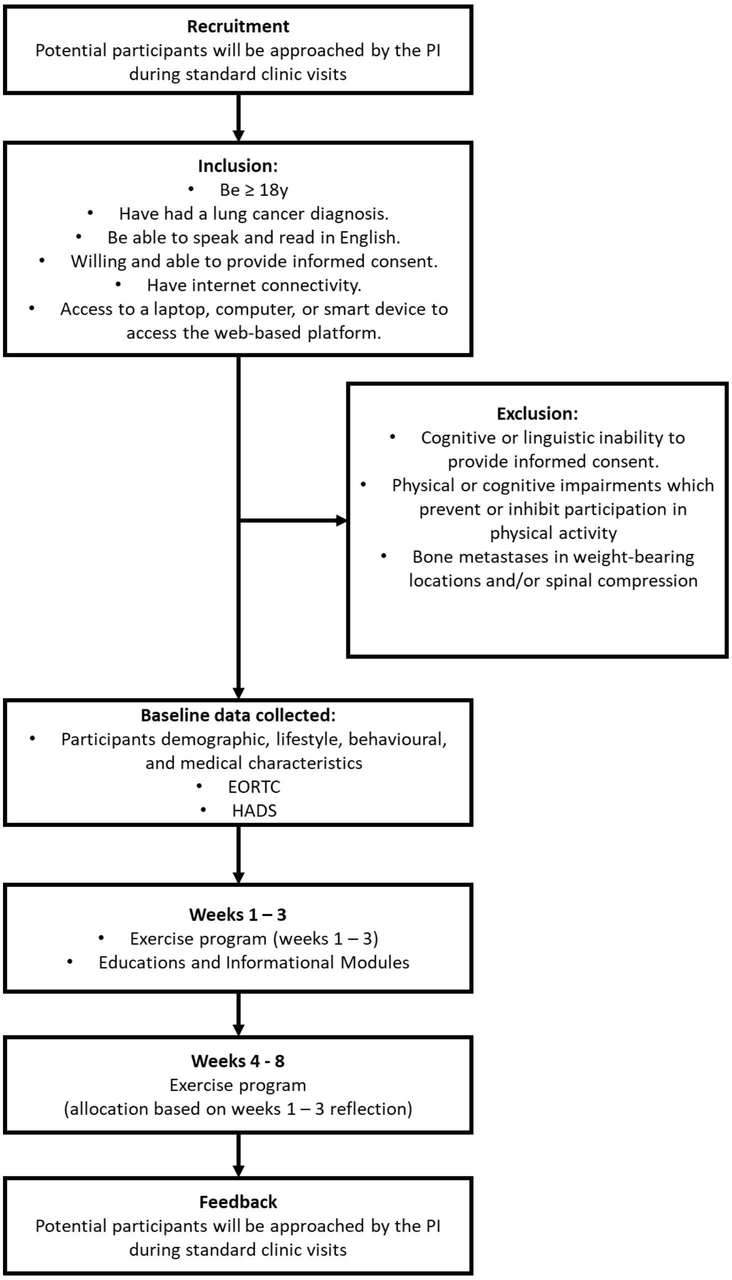


Figure 10: Flow of participants through the ExerciseGuide UK feasibility and acceptability study

4.5.2.5 Intervention

The protocol of ExerciseGuide UK has been published in the *BMC Pilot and Feasibility Studies* (2) (appendix 13.5.2). A brief history and description of the platform, ExerciseGuide, can be found in section **Error! Reference source not found.**.

Participants were enrolled on ExerciseGuide UK for eight weeks. ExerciseGuide UK provided tailored PA prescriptions and personalised educational modules to those

LWBLC. Modules followed a tunnelled approach website architecture to promote usability and guided navigation. A tunnelled approach is a method of providing small batches of information in a pre-defined order over time to minimise overwhelming users and provide them with a guide to the process. This is in contrast to a free-choice architecture which provides users with access to all information at once (392). To ensure baseline modules were completed, participants are directed through these modules before having access to the dashboard. Similarly, participants are directed through the *Safety* module prior to having access to the *Exercise Prescription* to encourage participants to have read the information to maximise safe exercise practice. Modules are released in groups over the first four weeks (see Figure 11**Error! Reference source not found.**). Modules were adapted from previous versions of ExerciseGuide (381, 382, 390) with updated coding and specific content for those LWBLC and new modules were created specifically for those LWBLC within the UK, based on research team or PPI input, such as a *Breathlessness* module or dietary information. A full list of modules and description can be found in appendix one (see 13.1). A tracking module became active after the first seven days and reset every seven days. Information added to each tracking module was carried over to provide visual graphics of tracking and progress.

A mixed-methods approach using recruitment outputs, questionnaires, engagement outputs, and interviews was used to examine the primary outcomes, feasibility and acceptability. The pre-established criteria for primary outcomes are detailed below:

4.5.2.6 Primary Outcome Measures

4.5.2.6.1 Feasibility

The feasibility and delivery of the intervention were explored using the following pre-established criteria:

1. The recruitment target of a maximum of 35 and a minimum of 15 participants had been reached before May 30th, 2022.
2. Recruitment rate: ≥ 60%.
3. Retention rate: ≥ 85%.

The feasibility criteria were established based on a systematic review examining the feasibility, acceptability, and efficacy of online supportive care for those LWLBC (3) and clinician expertise.

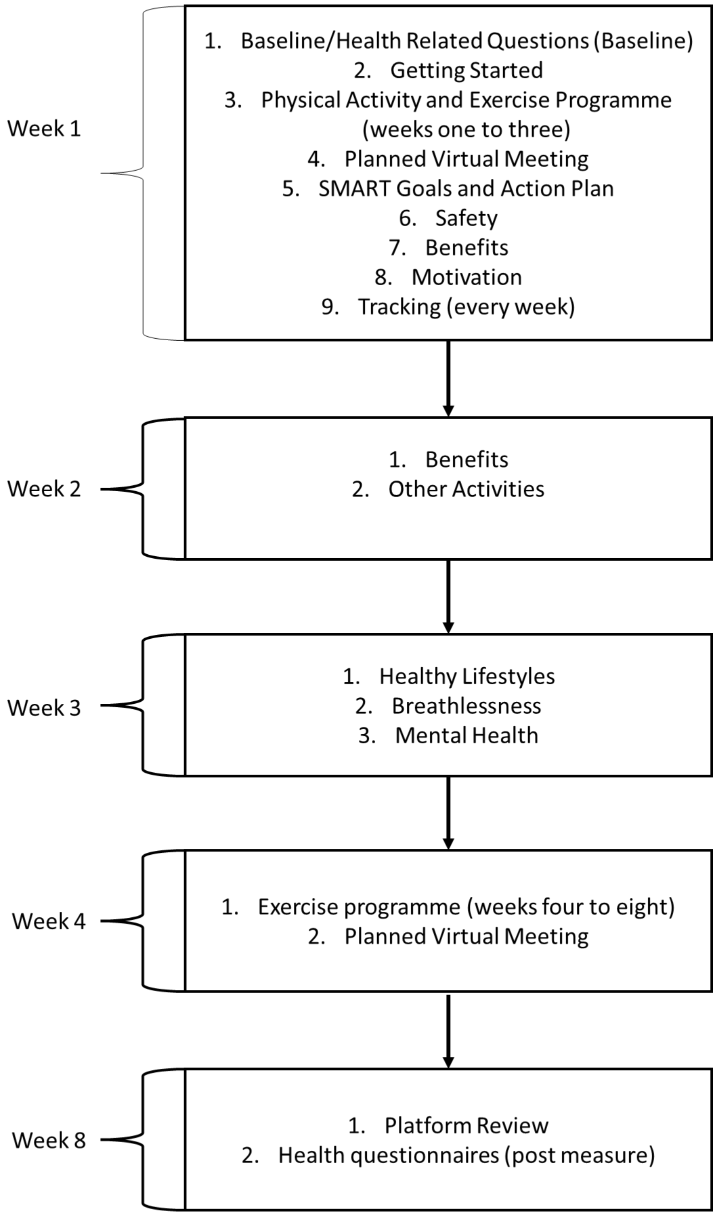


Figure 11: Release time of all modules within ExerciseGuide UK.

4.5.2.6.2 Acceptability

The acceptability of the intervention was assessed using a mixed-methods approach. The following methods were used to examine acceptability:

1. System Usability Score ≥ 68% (388, 393)
2. Positive participant satisfaction illustrated in the end of study survey or post-module surveys.
3. Positive themes identified in follow-up interviews.

The intervention was considered usable if the mean SUS score ≥ 68%, based on the pre-defined thresholds for acceptable usability (388, 393). Following the completion of a module for the first time, participants were able to provide a rating on a 5-point Likert scale using stars, ranging from one (poor) to five (excellent) (see Figure 12**Error! Reference source not found.**). In addition, participants were able to provide text in an open-ended text box. Once the participants reached eight weeks from the beginning of the *Exercise Plan (Weeks 1 – 4)* module, a review module was released. The review module contained a satisfaction questionnaire and the SUS. The review contained a mix of closed and open-ended questions. All participants were asked to take part in a Zoom interview following their eight-week use of ExerciseGuide UK.

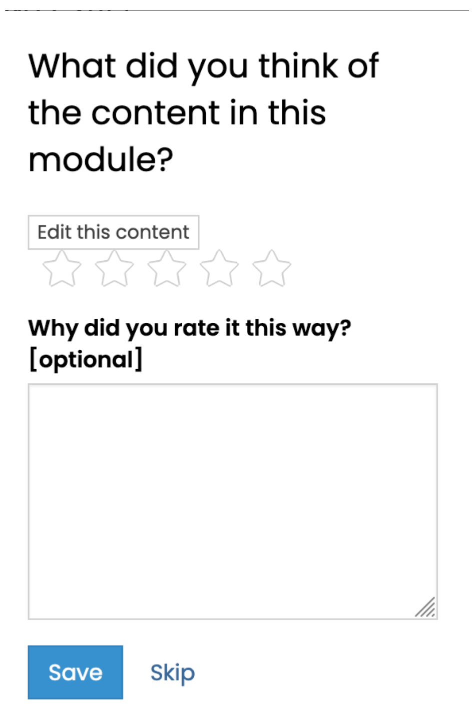


Figure 12: Screenshot of the five-star rating scale with an open-ended text box which appears on ExerciseGuide UK once a participant has completed a new module for the first time.

In addition to the core modules displayed on the dashboard, a wide variety of extra information were available for participants to read if they wish. This library of information provides additional or supplementary information which may be beneficial for those LWBLC but were kept out of the modules to ensure the modules were concise and were not overwhelming. All content in the *Extra Information* page was written in lay language with explanations for more technical content. Hyperlinks to external sources are provided to accompany the content. Furthermore, an *About page* provides information about ExerciseGuide UK and the research team and a *Contact* button for participants to use an integrated emailing system to contact a research team member (JC).

4.5.2.7 Secondary/Proof of Concept Outcomes Measures

4.5.2.7.1 Patient Reported Outcomes

The European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC-QLQ-30) measured health-related QoL, functioning scales, and symptom scales (394). The Hospital Anxiety Depression Scale (HADS) examined anxiety and depression (395).

4.5.2.7.2 Website Usage

Website usage was evaluated using logged database information and Google Analytics (396).

4.5.2.7.3 Safety

Safety was a key component during intervention development. Data pertaining to programme safety was collected through three primary mediums: email, the tracking module, and/or regular check-ins. Participants were advised during the initial, midway, and post-meetings to report any signs of concern or adverse events throughout the duration of the intervention. ExerciseGuide UK recommended consultation with the research team if they wished to change the prescription which was provided. Emergency contact details were provided, along with safety reminders, including warming up and cooling down, clothing, ensuring a safe space, hydration, to inform someone they are exercising, and keep a phone nearby.

4.5.2.8 Sample Size

This study aimed to recruit a minimum of 15 to a maximum of 35 individuals LWBLC. Recruitment began January 2022 and 22nd ceased on May 30th, 2022, or when the target has been reached. This study used previous research collected as part of this doctoral degree (see Chapter 2) (3) and clinical and academic expertise to determine the target sample of 35 individuals. Moreover, a smaller sample size was selected to promote greater engagement with participants opposed to larger samples size which may provide statistical powered outcomes. Though 15 – 35 participants may be considered low for quantitative research for these reasons, it is well-aligned with recommendations for qualitative methodology where the priority is on gathering rich, detailed accounts as opposed to a purely large sample size. This approach allowed for nuanced analysis of individual experiences to explore subtleties related to the feasibility and acceptability of ExerciseGuide UK.

4.5.3 Data Analysis

4.5.3.1 Website Data

Data analysis was conducted using SPSS (version 28; IBM, Chicago, IL, USA). Descriptive statistics were presented for questionnaire-based outcomes using the mean and standard deviation or percentages. Categorical data (e.g., sex or type of treatment) was presented as a frequency (value and percentage). Analysis was conducted on complete data cases.

4.5.3.1.1 Patient-Reported Outcomes

Although the data from the EORTC-QLQ-30 and HADS violated normal variance (i.e., the data was skewed), a Parametric Paired Samples T-Test was performed with Bootstrapping. The decision to conduct a parametric test with Bootstrapping as opposed to a nonparametric test, such as the Wilcoxon signed-rank test, was for two key reasons.

Firstly, a T-Test was chosen to explore if there were a difference in the means of the two samples. Whereas Wilcoxon signed-rank test would have assessed whether there is a difference in the rank totals, comparing medians to a reference/target value. Reporting data in ranks and medians would not provide any signal of change. Reporting a signal of change is more useful than examining if a difference is present as, with a small sample size, the presence of a statistically significant difference is of less importance than a signal of effect. Moreover, if data over two points (e.g., baseline and post) have the same value (known as data ties), this data is excluded from the analysis in a Wilcoxon signed-rank test. This raises concern when reporting whether the outputs which are ranked include a full representation of the sample, no change between scores is still important, albeit underpowered and therefore cannot be used to make any inferences. Secondly, non-parametric tests, such as the Wilcoxon test, are less powerful and underpowered due to fewer assumptions and the exclusions of data ties. With patient-reported outcomes rated on scales ranging from one to four (including the EORTC-QLQ-30 and the HADS), data ties may be common. If this data would be excluded, it would limit the existing small sample to a smaller sample. Thus, a Bootstrapping method was chosen to explore mean change in this sample.

Bootstrapping is a method of data-based resampling. The method developed by Efron and Tibshirani (397, 398) allowed for the resampling of the ExerciseGuide UK sample. Using SPSS, sample characteristics were created. Using a sample of completed sets of data from participants, simulated samples were created. The number of complete data cases was n=12. Thus, Bootstrapping allowed an iterative process of resampling samples of 12 individuals LWBLC within the cohort and take mean scores within the simulated sample. In essence, during a resample, the mean score was taken repeatedly, with replacement. Sampling with replacement ensures the same sample will not be resampled each time. If the same sample were resampled each time, the mean scores would not differ. Therefore, this technique includes some of the original samples means once or twice (possibly more), and other mean scores will not be included. One resample will be completed once a selection of 12 randomly selected observations are compiled. The mean of that resample is stored, and this process is repeated 10,000 times. Means from all simulated samples were put into a distribution known as a Bootstrapped Distribution.

To provide an explanation of the Bootstrapping technique, I will illustrate using an example external to this thesis. In this example, we will be using a random sample of 109 weights of students at nine years old living in inner London in 2021. If I were exploring the weight of students at nine years old and wanted to present a mean weight with confidence interval, since weight is often not normally disturbed and the sample being relatively small, we can use the random sample to perform resampling. It is important that the sample is random as this ensures the sample is representative. If we can assume the current random sample is a small representative sample of the population being explored (weight of students at nine years old living in inner London in 2021), we can resample with replacement from this original sample. The original sample is n=109, therefore Bootstrapping will be able to take the mean of 109 in thousands of resamples. In this example, the resampling will be completed 1,000 times with replacement. This will ensure we do resample all 109 nine-year-olds once again, as this would result in the same mean value being produced. Using the all the weights within the original sample, a random selection of nine-year-olds will be included in the sample again, possibly multiple times, whereas some nine-year-olds will be excluded from specific resamples. Once 109 observations have been selected from the original sample, this will create a new resample. This will happen 1,000 times. The means of each 1,000 samples are stored and tracked. A Bootstrapped distribution is then created by placing all stored means into a distribution. Following this, it would be possible to analyse the mean distribution of the samples and allow confidence intervals (CIs) to be more accurately calculated due to the larger (simulated) sample.

It is important to note, the larger the number of resamples, for example 1,000 vs 100,000. The amount of data is determined from the original sample size, and therefore will remain consistent. However, the benefit of increasing the number of resamples will provide a better sampling distribution estimate.

An advantage of performing a Bootstrap analysis is the process is a relatively straightforward technique to decrease the variation of the CIs, and it does not have any prior assumptions (e.g., normality). Furthermore, it offers a convenient and low-cost approach for cohorts with smaller sample sizes without repeating the experiment to increase cohort size. However, two key caveats which must be highlighted is that Bootstrapping does not perform bias corrections and the sample is still limited in its level of representation. The resamples are generated from the original sample. Thus, even though a powerful tool, it does would not allow or permit for population-based inferences to be made from any given sample.

4.5.3.2 Post-Study Interview Data

Interviews were offered to all participants during their study debrief. Fourteen participants agreed to participate in the end of study interview. Following verbatim transcription in Microsoft Word (Microsoft, Version: 16.96.1, 2023), transcripts were imported into NVIVO (QSR International, Version 12.0, 2023) for thematic analysis

(TA). The Standards for Reporting Qualitative Research (SRQR) (399) was used to ensure all relevant data has been appropriately captured and discussed within this body of doctoral research. A table detailing the SRQR can be found in appendix 13.15.

The process of TA will now be described.

4.5.3.2.1 Qualitative Analysis: Thematic Analysis Process

Post-study interviews were analysed using the TA approach (372). Similar to the Think Aloud interviews discussed in 4.5.1, the analysis was guided by the six phases (1: familiarisation of data, 2: generating initial codes, 3: searching for themes: 4, reviewing themes, 5: defining and naming themes, and 6: produce the report). However, the Theoretical Framework of Acceptability (TFA) was employed to assist with the analysis and interpretation of data (400). The first four interviews were coded independently by two coders (JC and MP) and discussed initial codes and their mapping against the TFA. A further three interviews were selected by a second coder (MP) and coded independently for cross-checking.

The TFA proposes that acceptability is a multifaced construct which is comprised by seven sub-constructs (see Figure 13). The TFA is a theoretical framework which helps with understanding important constructs of acceptability of healthcare interventions.

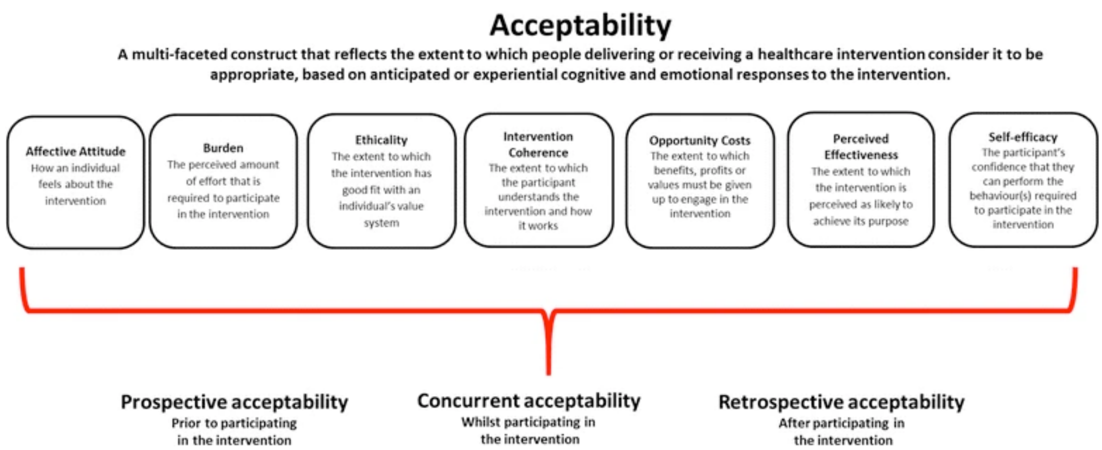


Figure 13: The theoretical framework of acceptability (v2) comprising seven component construct (400).

Sekhon et al., (2017) suggest acceptability should be examined at three following timepoints, 1) Prospectively (prior to intervention delivery), 2) Concurrently (during the active intervention), and 3) Retrospective (after the intervention) (400). However, the interviews were all conducted post-intervention, Therefore, because all data was collected post-study (retrospective), it was necessary for participants to reflect on their experiences, in order to describe their reasoning (prospective) before starting the intervention.

Initially, the TFA was proposed as a method to guide the TA to promote transparency and the communication of findings. For example, using the TFA has allowed explanation of how the data aligns with theoretical concepts and the wider evidence-base. Moreover, the TFA is an established framework with commonly used language. Therefore, situating the findings within this common language would aid in the dissemination and communication of findings within the field.

It is important to note the intersection of the theoretical framework and the phase of TA. Though the TFA was used to guide the coding and thus generation of themes (deductive analysis), new themes were constructed through the researcher understanding, engagement, and interpretation of the data (inductive analysis). The framework was used as an analysis tool through using pre-existing constructs, however, additional constructs were generated, and themes were inductively developed through examining interview data in relation to sub-constructs.**Error! Reference source not found.** below describes the six phases of TA and how TA has guided the analysis (see Table 10*Error! Reference source not found.*).

Table 10: The six phases of thematic analysis adapted from Braun and Clarke (2017) mapped against examples within the data analysis conducted (372)).

Phase	Phase Description	Actions Taken
1) Familiarisation of data	• Immerse self in data. Read and read to gain understanding. • Make notes on initial thoughts of data. • Searching for patterns.	• Interviews were transcribed onto Microsoft Word from MP4 file. • An initial read through was conducted and notes made using the 'Inset a Comment' function. • Transcripts were exported into NVIVO.
2) Generating initial codes	• Organise data and start identifying meaningful or interesting elements of the data. • Generate initial codes, using participant data.	• Label data with initial Microsoft Word comments from phase one. Organised data under TFA constructs. • Map codes back against TFA definitions. If did not match, highlight *'of interest'* and return to later.
3) Searching for themes	• Group codes into potential themes. • Check theme consistency. • Refine themes iteratively to reflect data.	• Codes were refined and grouped into potential cluster based on similarities. • Defining properties of themes were noted.
4) Reviewing themes	• Examine themes and crosscheck with data. • Explore relationships between themes and redefine if needed. • Review and write description of themes as they evolve.	• Expanding and collapsing themes. • Organising data to ensure themes are supported. • General summarises were produced for the themes. • Refining and refining codes and their overarching themes.
5) Defining and naming themes	• Clearly define themes using concise definitions. • Reflect on definitions and finalise theme name. • Write description or summary of the themes.	• Write up definition for all themes and for the newly developed construct from the Theoretical Framework of Acceptability (flexibility). • Summarise the themes.
6) Propose Initial Revisions	• Write up concise and clear findings. • Use quotes and examples from the data to contextualise theme.	• Organise results within thesis chapter. • Explain findings using quotes from interviews

4.6 Summary

This chapter addresses the overarching methods for this thesis. This research aimed to explore the feasibility and acceptability of an online supportive care platform (called ExerciseGuide UK) designed to provide tailored physical activity programmes and educational resources for individuals LWBLC. The overarching aim was to determine whether such a platform is not only feasible and acceptable for this demographic but also to identify the barriers these individuals face when engaging with this type of digital health intervention. Using the Person-based approach as the theoretical framework, the study emphasises understanding the target population's perspectives to tailor and adapt the intervention effectively.

The usability study employed think-aloud interviews, where participants verbalised their thoughts while interacting with the digital intervention. Online interviews using both concurrent and reflective think-aloud techniques were conducted, with pre-defined prompts and tasks developed in collaboration with the patient and public involvement group. Qualitative data were analysed using thematic analysis with NVIVO, and quantitative data, including the System Usability Score (SUS), were analysed using SPSS.

The feasibility and acceptability of the digital intervention were evaluated through pre-defined criteria and post-study interviews. The study was reported to assess these factors following SPIRIT guidelines, identifying and recruiting patients through clinicians during regular appointments. Patients with bone metastases were excluded. Primary outcome measures for feasibility included achieving a recruitment target of 15 to 35 participants by May 30th, 2022, meeting a recruitment rate of ≥ 60%, and maintaining a retention rate of ≥ 85%. Acceptability was assessed with a SUS of ≥ 68%, positive participant satisfaction in end-of-study and post-module surveys, and positive themes identified in follow-up interviews. Website engagement was a secondary outcome measure.

At the study's conclusion, baseline patient-reported outcomes (PROs) were re-evaluated, and post-study interviews were conducted. These interviews were analysed using thematic analysis to gain further insights into participants' experiences and the intervention's impact. This chapter provides an overview of the methods used to assess the feasibility and acceptability of the digital intervention.

The next chapter will describe the development of ExerciseGuide UK, explaining the design and iterative process based on the findings from this think aloud interviews.

Chapter 5 Development of ExerciseGuide UK

This chapter will cover the development of ExerciseGuide UK. It will outline some of the history of the platform which was examined for this thesis.

5.1 What is ExerciseGuide and where did it come from?

The platform known as 'ExerciseGuide' has been used in a wide array of populations across different countries. TaylorActive (396) was a large National Health and Medical Research Council in Australia which provided a large update to the original platform. In Australia, the domain has also been used in prenatal exercise (401), Diabetes Online Risk Assessment (DORA) (402), ExerciseGuide for those with metastatic prostate cancer (381, 390), and ExerciseGuide for breast cancer in Canada (unpublished). However, the original application was adapted from Spittaels and colleagues in Belgium (2007) (403). In 2010 - 2011, the application was transcribed from Belgium to English. Following the transcription, the application was moved to the CakePHP framework, giving rise to the above-mentioned platforms. However, this doctoral degree will be the first time this platform is being used within the UK and for those living with and beyond lung cancer (LWBLC).

Evans' doctoral work (381, 390) on ExerciseGuide provided the foundation for its further development as part of my doctoral research, which aimed to provide personalised exercise programmes and educational resources to those living with and beyond metastatic prostate cancer (381, 390). The current version of ExerciseGuide UK runs on the modern CakePHP framework using PHP language. ExerciseGuide has an adaptable website architecture, allowing software developers and programmers to set up a tunnelled or free choice (also known as free-form matrix) approach. A tunnelled approach allows users to access small batches of information over a pre-specified time (392). In contrast, free choice allows users full access to all given content upfront (404).

Finlay and colleagues (2020) examined the usability of a computer-tailored website (similar to ExerciseGuide UK) for men with localised prostate cancer within Australia. Modules were delivered either in a tunnelled (weekly release) or a free choice scenario (immediately full availability). Higher mean usability scores were reported for the tunnelled approach (67.4 ± 14.6) compared to the free choice approach (56.4 ± 12.2) (405).

ExerciseGuide uses ‘modules’ to share information with users. All modules are tailored based on responses to questions using *IF-THEN* statements. *IF-THEN* statements allow pre-determined outcomes to a question (*THEN*), stored in a database, to be shown when the corresponding answers are selected (*IF*). ExerciseGuide UK can provide participants with the option to select the type of gendered images and animations they wish to see. Furthermore, the name a participant uses during the sign-up phase can be placed throughout the website using the insert [Insert_Name]. These features further enhanced the notion of personalisation.

A baseline security level is inherited using a modern framework such as CakePHP. ExerciseGuide UK runs on a trusted hosting platform only over Hypertext Transfer Protocol Secure (HTTPS), using current Transport Layer Security (TLS) versions. HTTPS is a secure method of sending data between a web server and a web browser. Passwords were never stored as plaintext; they are stored as a salted encrypted hash.

5.2 Process Adaption of ExerciseGuide UK

The process of adapting and developing new content for ExerciseGuide UK was guided by the Person-Based Approach (PBA) (354, 355). The PBA was used to guide the process of adapting ExerciseGuide UK throughout this doctoral degree, which is detailed in the Methodology chapter (see section 3.1.3.2). The PBA focuses on developing a behaviour change intervention by understanding the psychological and perspective-based views of those the intervention is aimed toward (also known as 'end users') through an iterative design (354). Therefore, iterative PPI and Think Aloud interviews were chosen for the development of ExerciseGuide UK.

The next following sections will discuss the process of adapting an engaging in PPI-guided UCD.

5.2.1 Patient and Public Involvement: Workshops One

Workshop one was conducted in March 2021 with four volunteers who had experienced LWBLC themselves or as a carer. Recruitment for the PPI was ongoing until workshop three, which took place from August 2020 to September 2021.

Initially, the PPI workshops were planned to be delivered in person at a local hospital (Castle Hill Hospital, Hull). However, with the declaration of the COVID-19 pandemic, all workshops were moved to online delivery via Zoom. All workshops were recorded with members' consent for post-workshop review.

The aim of the first PPI workshop was to explore the views and understanding of PA and digital technology for those LWBLC and discuss the potential design, important features, and content for ExerciseGuide UK. Thus, the workshop was divided into three primary sections: 1) PA and exercise knowledge; 2) barriers and facilitators to PA, exercise, and digital technology; and 3) website design, features, and content. These sections are broken down further below.

5.2.1.1 Physical activity and exercise knowledge

Despite the well-established benefits of PA for those living with and beyond cancer, adherence to the recommended physical activity guidelines is poor (406). Morton and colleagues explored knowledge of physical activity guidelines with a UK general practice surgery. Of the 94 patients who completed a questionnaire, the majority could not report the national PA guidelines (407). Therefore, before resources were created detailing PA and exercise guidelines and support, understanding the views on the existing PA and exercise guidelines of those LWBLC was critical. The PPI group expressed a lack of guidance across the entire cancer continuum, from diagnosis throughout treatment to living beyond cancer. The majority of the PPI group was unaware that any exercise guidelines for those living with and beyond cancer existed. Once the guidelines were shown to the PPI members, all members voiced confusion surrounding what was expected of them to achieve moderate or vigorous exercise. Moreover, the group perceived these guidelines to be a 'one size fits all' set of principles, which was highly discouraging. The lack of information regarding tailoring and personalisation of guidance was noted to be a major concern for the group.

Finally, there was uncertainty regarding the term 'exercise'. When discussing exercise, the majority of members made references to going to a 'gym' and 'lifting weights'. When explaining the definition of PA and exercise, they were unaware such difference existed and that PA and exercise could be done in various forms (e.g. walking to the shops, housework, and yoga) at differing intensities (e.g. lightly or moderately).

5.2.1.2 Barriers and facilitators to physical activity, exercise, and digital technology

To promote PA, it was important to examine the barriers and facilitators for LWBLC engaging in PA and exercise and understand the barriers and facilitators for LWBLC using digital technology.

There was a reoccurring fear of breathlessness during day-to-day activities, which was emphasised when discussing being physically active and engaging in exercise. Several other barriers were listed by the PPI members related to PA, including unclear access to PA guidance and support, feelings of fatigue pre- and post-exercise, difficulty understanding information at the point of diagnosis, and the stigma of lung cancer from healthcare professionals (HCPs).

The group queried the portability and accessibility of the website. Initially, ExerciseGuide UK was described to the PPI group as an online platform which can be accessed via a laptop or computer. Members of the group asked if the programme could be accessed via tablet (e.g., iPad or Android tablet) or mobile phone. Furthermore, could the exercise programme be taken to a gym or local park?

5.2.1.3 Website design and features

The third item discussed was the design and features of ExerciseGuide UK. The core layout from ExerciseGuide UK was inherited from prior versions. Before showing the PPI members the current layout, members expressed the desire for large boxes and clearly labelled modules. The inherited dashboard (also referred to as the homepage) was presented to the PPI group, which received positive comments. Following the layout, the features and content were discussed.

The platform's ability to tailor the exercise was mutually expressed to be vital, with importance being further acknowledged for the educational content tailoring. However, the focus was continually drawn back to the importance of the tailored exercise programme. The PPI members encouraged a varied selection of activities with the individual's ability and health status as primary tailoring points. The ability to progress and regress over an exercise programme was considered important, as those who are unable to achieve what was prescribed may disengage.

Resources and the integration of information surrounding breathlessness and safety were raised as two primary concerns. Members thought it would be valuable to openly detail safety information and the relationship between being active and breathlessness upfront.

5.2.1.4 Summary of Concerns

In summary, the first PPI workshop provided a vast amount of information to aid in the initial adaption of ExerciseGuide UK. The PPI group expressed several concerns that they felt must be addressed on the website and features they would like to see. This included 1) providing the PA and exercise guidelines for those living with and beyond cancer with clear examples and appropriate detail; 2) ensuring PA and exercise content is tailored; 3) integrating breathlessness and safety information to the platform; 4) ensuring the programme can be portable; and 5) ability for progress/regress the exercise programme. A summary of the first PPI workshop feedback can be found in Appendix Nine (13.8.1).

5.2.2 ExerciseGuide UK Revisions: Round One

Based on the recommendations from the initial PPI workshops, revisions and new content were produced for the website. A large number of revisions took place in the initial adaptation phase. Some of the key updates are detailed below.

5.2.2.1 Physical Activity Guidelines and Explanation of Exercise

One primary outcome of the first PPI workshop was a disconnect between the published information regarding PA and exercise guidelines for those living with and beyond cancer. Initially members of the group were unaware guidelines existed. Once they viewed the guidelines, confusion emerged about what terms such as 'moderate' and 'vigorous' referred to. Therefore, a module dedicated to the benefits of exercise was created, which covered information regarding what PA and exercise are and the guidelines with examples (see Figure 14 and Figure 15). Examples such as "lifting a kettle full of water" or "lifting children" were included to illustrate nonstandard methods of exercise.

Exercise Benefits

Physical Activity and Exercise

Physical activity is any bodily movement caused by expending energy, resulting in the contraction and relaxation of skeletal muscle.

Exercise is a portion of physical activity wherein you plan structured and repetitive activities with the goal in mind to improve or maintain your level of physical fitness.

Physical fitness is your bodies ability to work together in harmony, using two groups of attributes called health-related components of fitness or skill-related components of fitness.

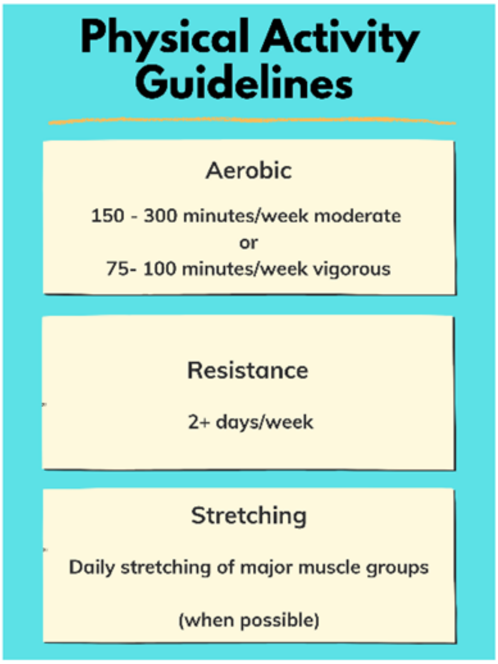
Physical activity in daily life can be categorized into occupational, sports, conditioning, household, or other activities. Exercise is a subset of physical activity that is planned, structured, and repetitive and has as a final or an intermediate objective the improvement or maintenance of physical fitness. Physical fitness is a set of attributes that are either health- or skill-related. The degree to which people have these attributes can be measured with specific tests.

Image above shows components of health-related fitness

Image above shows components of skill-related fitness

Figure 14: Screenshot of the initial page from the 'Benefits of Exercise' module on ExerciseGuide UK, which covers introductory information about physical activity and exercise.

Exercise Guidelines



The image above shows the physical activity guidelines for those living with and beyond cancer.

Examples of Aerobic Activities

Moderate:

- Brisk walking
- Water aerobics
- Riding a bike

Vigorous:

- Jogging or running
- Swimming fast
- Riding a bike fast or on hills
- Walking up the stairs

Examples of Resistance Training Activities

- Lifting weights and/or children
- Working with resistance bands
- Exercises that use your own body weight, such as push-ups and sit-ups
- Yoga
- Lifting a kettle full of water

Figure 15: Screenshot of the second page from the 'Benefits of Exercise' module on ExerciseGuide UK detailing the guidelines for physical activity and exercise for those living with and beyond cancer with examples.

5.2.2.2 *Internal Personalisation*

The ability of the platform to provide tailored PA and exercise programmes was one of the most iterated points of the PPI session. The ability of ExerciseGuide to tailor content has been a longstanding feature and has evolved over time. As discussed in section 5.1, ExerciseGuide UK runs on a set of rules on the CakePHP framework. These rules are written in a scripted language called PHP, using *IF-THEN* statements, which is the process whereby the website can tailor the information provided to participants. For example, when participants completed the initial three weeks of exercise prescription, participants were asked to rate how they found their first three weeks from '*too hard*', '*just right*', or '*too easy*'. If too hard, the exercise programme became lighter. If just right, the exercise programme increased at a moderate pace, and if too easy, the exercise programme increased slightly faster than the 'just right' option. Internal rules executed this tailoring based on participant provided feedback. Initially, the exercise programme was created in Microsoft Excel (Microsoft Office, Version: 16.96.1, 2023). Figure 16 below shows the programme table for weeks four to eight for a participant who selected the lighter option.

	Easier Option (2-2-2-2-2)										
		Week 4		Week 5		Week 6		Week 7		Week 8	
	EXERCISE	session1	session2	session3	session4	session5	session6	session7	session8	session9	session10
Standing Bicep Curl	TBICEPF	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
Standing Row	TROWDB	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
Standing Shoulder Press	TSHOULDER	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
Standing Chest Press	TCHESTPRESSBAND	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
All fours with Single Leg Extensio	TALLFOURS	2 x 10	2 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 12	3 x 12
All Fours Progression	TALLFOURSP	2 x 10	2 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 12	3 x 12
Seated Knee Extension	TLEGExtSeated	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
Sit to stand	TSITSTAND	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
Squat	TSQUATF	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
Standing Calf Raise	TCALVES	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
Superman(unilateral)	TALTSUPER	2 x 10	2 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 12	3 x 12
Superman (both)	TFULLSUPER	2 x 10	2 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 12	3 x 12
Side Leg Raise	TLEGSIDELIFT	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
Bridge	TBRIDGES	2 x 10	2 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 12	3 x 12
Crunches	TCRUNCH	2 x 10	2 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 12	3 x 12
Standing Tricep Kickback	TTRICEP	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
Lunges	TLUNGE	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
Press up (full)	TPUSHUP	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
Press up (knees)	TKPUSHUP	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
Counter Push Up	TCPUSHUP	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
Alternating Leg Lowers	TLEGLOWERS	2 x 12	2 x 12	3 x 12	3 x 12	3 x 12	3 x 12	3 x 10	3 x 10	3 x 10	3 x 10
Heel Touches	THEEL	2 x 10	2 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 10	3 x 12	3 x 12

Figure 16: Demonstrating the easier sets and reps table per exercise for weeks four to eight in Microsoft Excel.

The information was then converted into a web-friendly language using an online tool called Mr Data Converter (408) (see Figure 17).

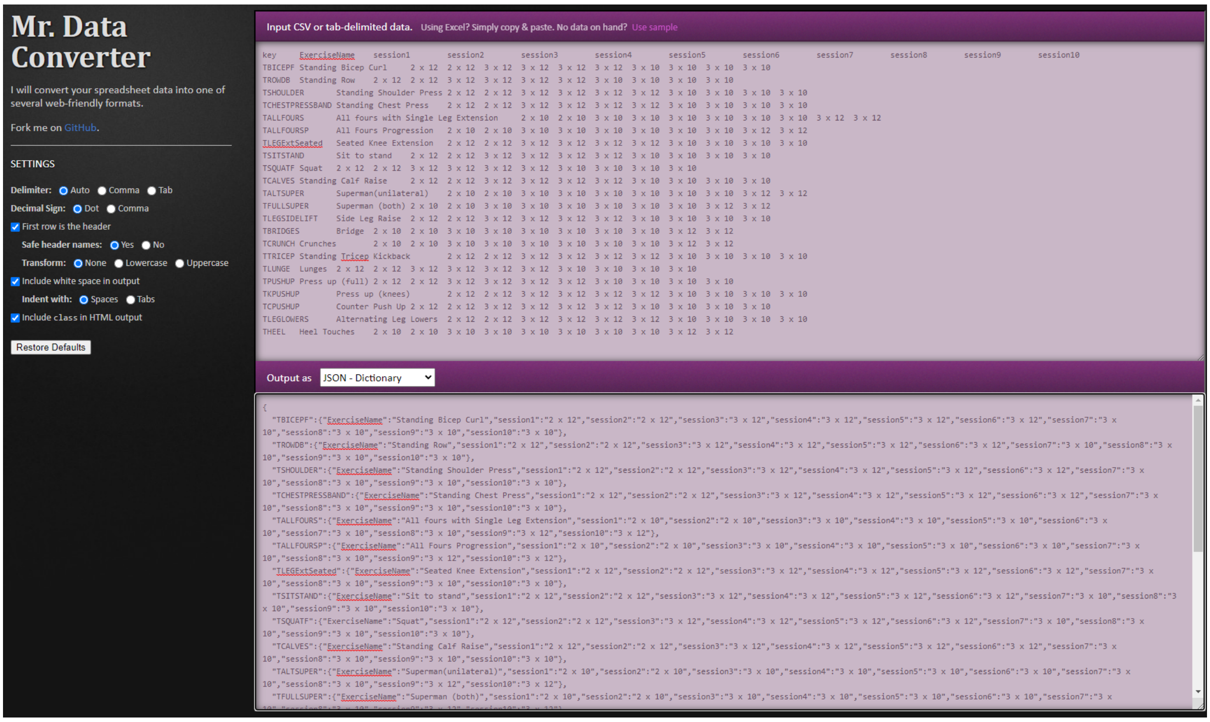


Figure 17: Illustrating Mr Data Converter (408), which was used to convert sets and reps per exercise over a specified duration of time from Microsoft Excel or a scripted language in JSON. This figure shows the easier option for weeks four to eight of the exercise prescription.

After the exercise prescription was converted into a web-friendly language, the output code was transferred to ExerciseGuide UK, which was then deployed (see Figure 18). Further lookups and manipulations were conducted to ensure accuracy and sensitivity.

```
    } {

        $decisionTable = /** @lang JSON */
            <<<EOT
{
  "TBICEP":{"PBACK":1,"PSHOULDER":1,"PELBOW":2,"PHIP":1,"PKNEE":1,"PFOOT_ANKLE":1,"PA_EXP":"<4","PHYSLIMIT":"<5"},
  "TROWDB":{"PBACK":2,"PSHOULDER":2,"PELBOW":2,"PHIP":1,"PKNEE":1,"PFOOT_ANKLE":1,"PA_EXP":"<4","PHYSLIMIT":"<5"},
  "TSHOULDER":{"PBACK":1,"PSHOULDER":2,"PELBOW":2,"PHIP":1,"PKNEE":1,"PFOOT_ANKLE":1,"PA_EXP":"<4","PHYSLIMIT":"<5"},
  "TCHESTPRESSBAND":{"PBACK":1,"PSHOULDER":2,"PELBOW":2,"PHIP":1,"PKNEE":1,"PFOOT_ANKLE":1,"PA_EXP":"<4","PHYSLIMIT":"<5"},
  "TALLFOURS":{"PBACK":1,"PSHOULDER":1,"PELBOW":1,"PHIP":2,"PKNEE":2,"PFOOT_ANKLE":1,"PA_EXP":"<4","PHYSLIMIT":"<5"},
  "TALLFOURSP":{"PBACK":1,"PSHOULDER":2,"PELBOW":2,"PHIP":2,"PKNEE":2,"PFOOT_ANKLE":1,"PA_EXP":">1","PHYSLIMIT":"<5"},
  "TLEGExtSeated":{"PBACK":1,"PSHOULDER":1,"PELBOW":1,"PHIP":1,"PKNEE":2,"PFOOT_ANKLE":1,"PA_EXP":"<4","PHYSLIMIT":"<5"},
  "TSITSTAND":{"PBACK":1,"PSHOULDER":1,"PELBOW":1,"PHIP":1,"PKNEE":2,"PFOOT_ANKLE":2,"PA_EXP":"<3","PHYSLIMIT":"<5"},
  "TSQUATF":{"PBACK":1,"PSHOULDER":1,"PELBOW":1,"PHIP":2,"PKNEE":2,"PFOOT_ANKLE":2,"PA_EXP":">1","PHYSLIMIT":"<4"},
  "TCALVES":{"PBACK":1,"PSHOULDER":1,"PELBOW":1,"PHIP":1,"PKNEE":1,"PFOOT_ANKLE":2,"PA_EXP":"<4","PHYSLIMIT":"<5"},
  "TALTSUPER":{"PBACK":2,"PSHOULDER":2,"PELBOW":1,"PHIP":2,"PKNEE":1,"PFOOT_ANKLE":1,"PA_EXP":"<4","PHYSLIMIT":"<5"},
  "TFULLSUPER":{"PBACK":2,"PSHOULDER":2,"PELBOW":1,"PHIP":2,"PKNEE":1,"PFOOT_ANKLE":1,"PA_EXP":">1","PHYSLIMIT":"<5"},
  "TLEGSIDELIFT":{"PBACK":2,"PSHOULDER":1,"PELBOW":1,"PHIP":2,"PKNEE":1,"PFOOT_ANKLE":1,"PA_EXP":"<4","PHYSLIMIT":"<5"},
  "TBRIDGES":{"PBACK":2,"PSHOULDER":1,"PELBOW":1,"PHIP":2,"PKNEE":1,"PFOOT_ANKLE":1,"PA_EXP":">1","PHYSLIMIT":"<5"},
  "TCRUNCH":{"PBACK":2,"PSHOULDER":1,"PELBOW":1,"PHIP":1,"PKNEE":1,"PFOOT_ANKLE":1,"PA_EXP":"<4","PHYSLIMIT":"<5"},
  "TTRICEP":{"PBACK":1,"PSHOULDER":2,"PELBOW":2,"PHIP":1,"PKNEE":1,"PFOOT_ANKLE":1,"PA_EXP":"<4","PHYSLIMIT":"<5"},
  "TLUNGE":{"PBACK":2,"PSHOULDER":1,"PELBOW":1,"PHIP":2,"PKNEE":2,"PFOOT_ANKLE":2,"PA_EXP":">1","PHYSLIMIT":"<5"},
  "TPUSHUP":{"PBACK":2,"PSHOULDER":2,"PELBOW":2,"PHIP":1,"PKNEE":1,"PFOOT_ANKLE":1,"PA_EXP":">1","PHYSLIMIT":"<4"},
  "TKPUSHUP":{"PBACK":2,"PSHOULDER":2,"PELBOW":2,"PHIP":1,"PKNEE":2,"PFOOT_ANKLE":1,"PA_EXP":"<4","PHYSLIMIT":"<4"},
  "TCPUSHUP":{"PBACK":1,"PSHOULDER":2,"PELBOW":2,"PHIP":1,"PKNEE":1,"PFOOT_ANKLE":1,"PA_EXP":"<4","PHYSLIMIT":"<5"},
  "TLEGLOWERS":{"PBACK":1,"PSHOULDER":1,"PELBOW":1,"PHIP":2,"PKNEE":2,"PFOOT_ANKLE":1,"PA_EXP":"<4","PHYSLIMIT":"<5"},
  "THEEL":{"PBACK":2,"PSHOULDER":1,"PELBOW":1,"PHIP":1,"PKNEE":1,"PFOOT_ANKLE":1,"PA_EXP":"<4","PHYSLIMIT":"<5"}
}
EOT;
        $decisionTable = json_decode($decisionTable,  associative: true);

        //this is all just criteria..
        //2 = exclude them
        //1 or 0 = treated same, is OK
        //data table uses ONLY values 1 and 2
        $excludeWithPain = ['PBACK', 'PSHOULDER', 'PELBOW', 'PHIP', 'PKNEE', 'PFOOT_ANKLE'];

        //intersect then check for any 2's
        $checkArray = []; //will be ['PBACK'=> 2, 'PSHOULDER' => 1 etc]
        foreach ($excludeWithPain as $var) {
            $checkArray[$var] = (int)$qVars[$var];
        }

        $finalExerciseList = [];
        $finalExerciseListVariant = [];

        foreach ($decisionTable as $exId => $exerciseCriteria) {
```

Figure 18: Transferred code from Mr Data Converter to ExerciseGuide UK as a JSON block which is subsequently decoded, followed by lookups and manipulation.

This process demonstrates an example of the tailoring mechanisms put in place to ensure participants receive personalised programmes. Exercises were tailored based on three primary factors: 1) overall physical health status, 2) current PA and exercise ability, and 3) physical limits to everyday activities.

Overall health status, current PA, and exercise ability were used to determine the level of exercise prescribed (lighter to harder) exercises. Physical limits to everyday activities were asked as a five-question matrix (see Figure 19), reporting if specific locations of the body (e.g., upper arm and shoulder, the ankle or feet) present chronic pain or injury. Reports were answered on a three-point radio scale ('*Yes, limits my activities*', '*Yes, but not does not limit my activities*', and '*No, I do not have this condition*'). If a participant answers *'Yes, limits my activities'*, all exercises which include that location as a prime mover or weight-bearing location were excluded from the exercise prescription. Any locations excluded via this matrix were discussed during the initial virtual meeting.

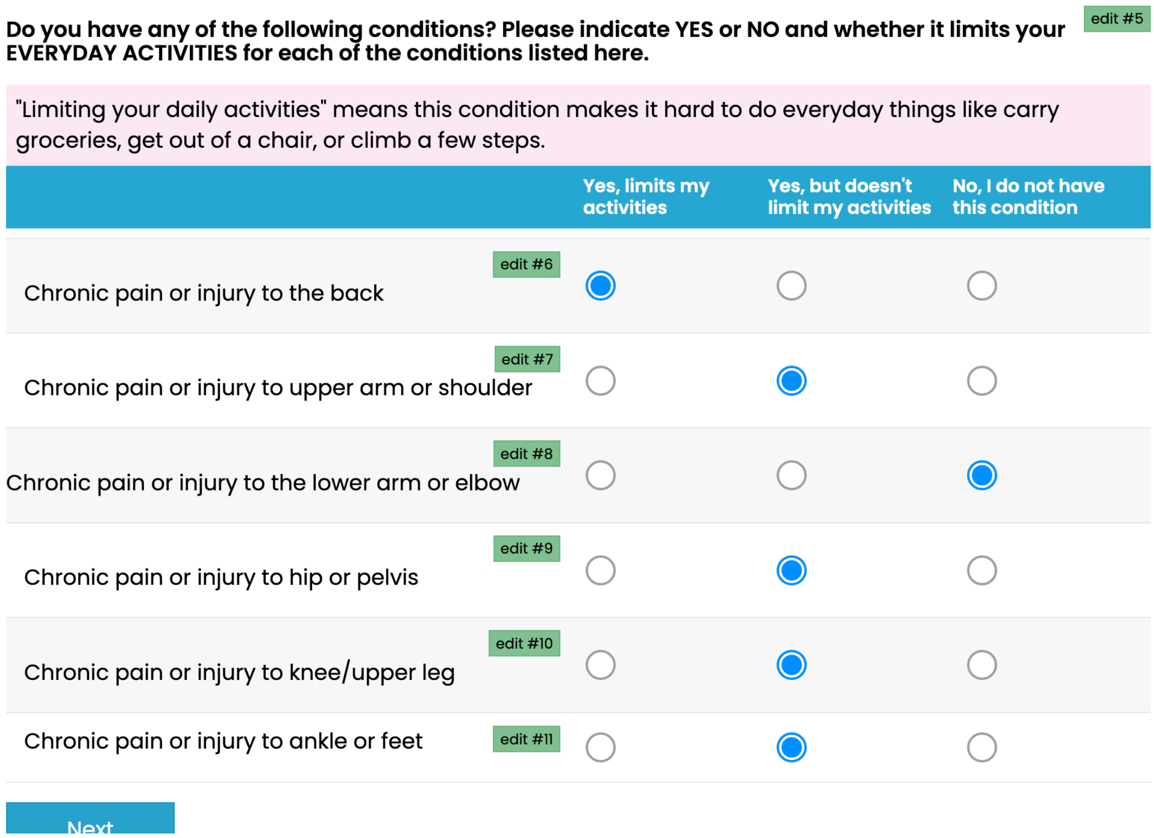


Figure 19: Screenshot of the question matrix, which examines any limits to everyday activities from the initial exercise tailoring on ExerciseGuide UK.

The decision on the number of questions to ask participants was carefully thought out in relation to the clarity of the question (e.g., ensuring it was understandable to the participant) and managing the number of possible output combinations. For example, there were eight questions, with two possible answers (i.e., yes or no), to which the website tailored the exercise plan. Therefore, 256 possible combinations were created. This number is generated from the number of questions (eight) and the number of answers to those eight questions (two). Therefore, 2^8 (or 2*2*2*2*2*2*2*2) equals

256 lines of possible combinations. However, if one extra question was added (2^9), the number of possible combinations would increase to 512, which is double the number of possible combinations than 2^8. This is an example of a combinatorial explosion. The combinatorial explosion occurs when a slight increase in the number of units (within ExerciseGuide UK, this would be the number of questions) results in a rapid growth of possible combinations (409). Figure 20 below demonstrates the rapid Combinatorial growth by increasing the number of questions on ExerciseGuide UK up to a maximum of 10 questions (1,024 possible combinations).

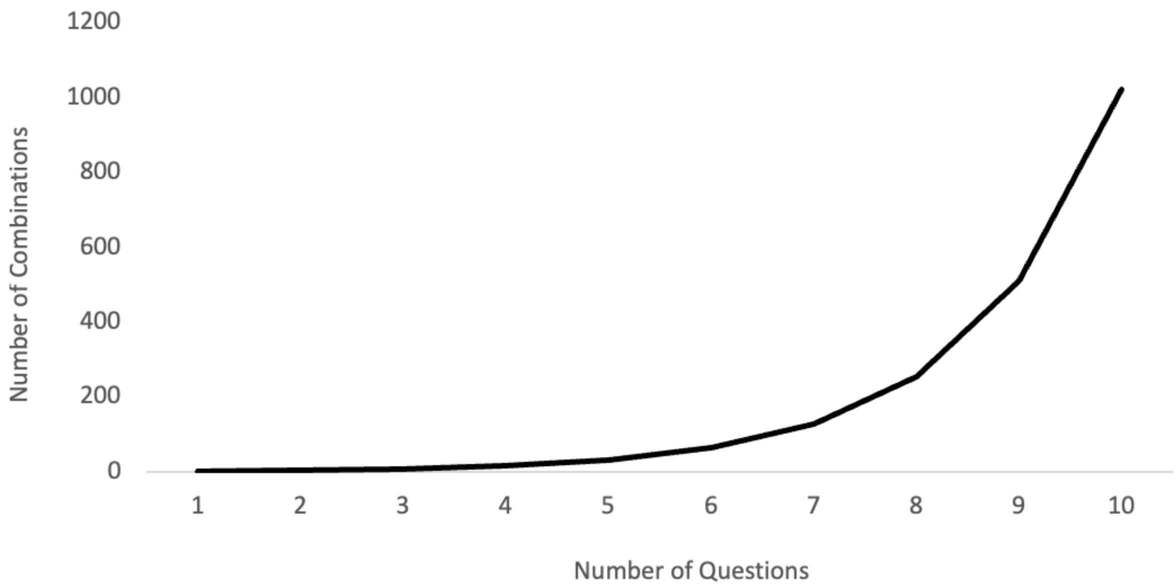


Figure 20: Example of combinatorial explosion regarding the number of questions vs the number of variable outcomes required.

Practically, this is time- and resource-intensive for the purpose of this programme. Therefore, it is important to manage the level of complexity by selecting a specific set of questions.

5.2.2.2.1 Exercise Prescription

To develop the ExerciseGuide UK exercise prescription process for those living with and beyond lung cancer, I aligned the prescription approach with both national (NHS) and international (American College of Sports Medicine Exercise (ACSM)) guidelines. These guidelines advocate for a comprehensive exercise programme comprising 150 minutes of moderate to 75 minutes of vigorous aerobic activity per week, alongside resistance training on two or more days per week. Additionally, the guidelines emphasise the importance of daily stretching of major muscle groups when feasible, with specific modifications tailored to the individual's health status and the side effects related to cancer and its treatment.

Given that lung cancer predominantly affects older adults, with the mean age of diagnosis being 75 years, it was important to also integrate the Older Adult Exercise Guidelines into the prescription process. These guidelines recommend engaging in 30 minutes of physical activity per day, five days a week, totalling 150 minutes. For individuals unable to meet this recommendation initially, the goal is to gradually work towards it while actively reducing sedentary behaviours.

In accordance with multiple guidelines, which suggest prioritising resistance, balance, and flexibility exercises as adjuvant modalities, this approach emphasised the primary role of aerobic exercise in the patient's programme. Patients received education via modules on ExerciseGuide UK on the importance of minimising sedentary behaviour by incorporating regular movement into their daily routines.

The exercise prescriptions were developed to ensure that aerobic activities are performed primarily, followed by resistance, flexibility, and balance exercises. To accommodate the varied abilities and needs of the patients, exercises are categorised into standing, midpoint/sitting, and floor-based activities. This classification aimed to minimise excessive changes in position and was customised based on the patient's health status, preferences, and any existing injuries.

Adhering to the guidelines, the exercise protocol on ExerciseGuide UK provided 1-3 sets of 8-12 repetitions, incorporating the Rate of Perceived Exertion (RPE) for autoregulation, thereby allowing patients to adjust the intensity based on their perceived effort. RPE was set at ~2-5 based on the participants' functional capabilities status. Aerobic training is prescribed at 2-3 sessions per week for durations ranging from 10-40 minutes, including rest breaks where necessary. To ensure continuous adaptation and improvement, the programme was designed to gradually increase in volume until the sixth week. Subsequently, the focus shifts towards increasing the load to maintain intensity, with resistance training sessions occurring 2-3 days per week, emphasising strength and hypertrophy through 2-3 sets of 8-12 repetitions.

5.2.2.3 *Safety and Breathlessness*

Safety was a key component inherited from the previous version of ExerciseGuide. Safety is a crucial concern with any PA or exercise programme and must be addressed thoroughly. Unlike supervised PA, a qualified professional is not there to continually observe PA performance. ExerciseGuide UK adapted and built on the inherited safety information. Information regarding pre-exercise routines (e.g., warm-up, hydration, and clothing) were provided, along with a simple infographic of when to stop exercising immediately (see Figure 21).

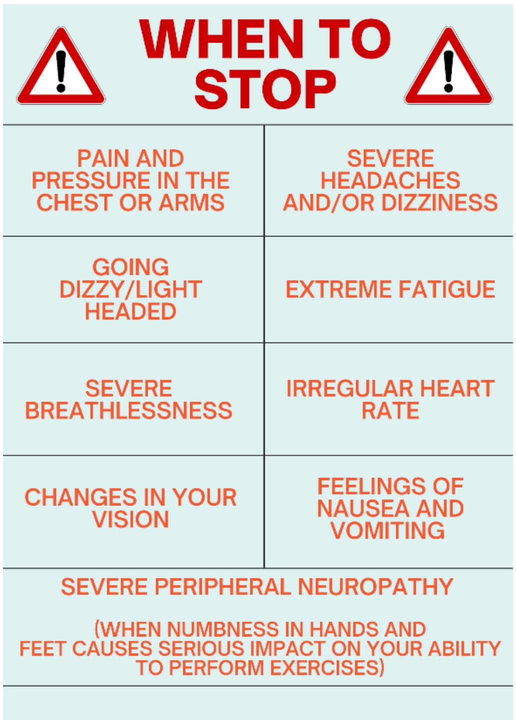


Figure 21: Infographic for when to stop exercising detailed in the pre-exercise safety information on ExerciseGuide UK.

A dedicated module was created for breathlessness which covered a wide range of information pertaining to what breathlessness is, the fight and flight response, anxiety, positions to help and ease breathlessness, and breathing exercises. Videos were included on the website to provide a walkthrough of breathing exercises.

5.2.2.4 *Portability*

The website was adaptable to various digital devices such as mobile phones and tablets (e.g., iPad and Android). Furthermore, modules have a print button located in the lower footer of the pages. This is programmed to prompt the print function of the participant's device automatically.

Following the information gathered from the first PPI workshop, previously established inequalities to eHealth for older adults were identified. Following the identification, efforts were made to address these inequalities within this doctoral research.

5.2.3 Addressing eHealth inequalities in those with and beyond Lung Cancer

It has already been established that those LWBLC have higher unmet symptom burdens than other prevalent cancers. However, several considerations should be discussed regarding this population's engagement with eHealth (see Figure 22). Each of these considerations will be introduced, and their relevance to ExerciseGuide UK will be discussed.

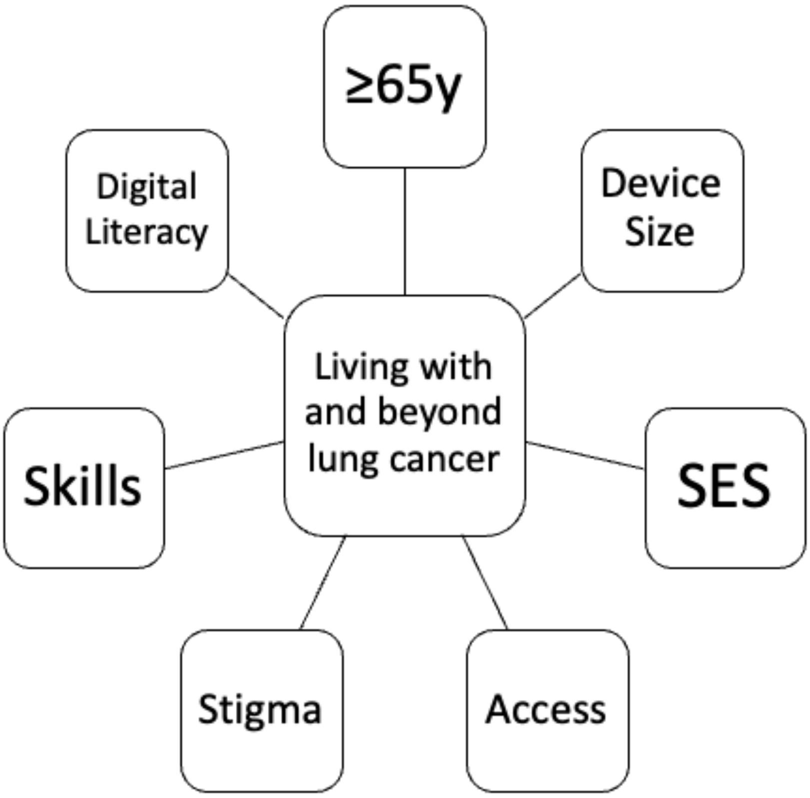


Figure 22: Considerations for digital technology for those living with and beyond lung cancer. SES: Socioeconomic Status

Age is one of the most common barriers to engagement with digital technology, with literature indicating that older individuals, particularly those aged 65 and above, often face barriers due to a lack of familiarity and comfort with these technologies (294, 410, 411). In the UK, a large portion of those newly diagnosed with lung cancer are within the older adult (65y plus) age range (412) (9), demonstrating a need for this population. There are several possible reasons why age presents a barrier to engaging in digital technology. Older adults did not have the level of engagement and exposure to digital technology as younger individuals, often leaving a large gap in their competency and feelings of inadequacy (294).

ExerciseGuide UK was specifically designed for older adults in mind, with features such as a tunnelled approach to help guide participants through the modules, lay language was used throughout with additional support, like step-by-step video instructions, to minimise participants feeling overwhelmed or helpless.

Secondly, the size and accessibility may have an important role, especially for older adults with physical changes and side effects of cancer and its associated treatments, which may impact their ability to engage with smaller devices (413). Screen size is a priority for elderly users (414) ExerciseGuide UK is designed as a website, for larger screens, however it does remain accessible on smaller devices, such as tablets and mobile phones, in order to preserve participant preference However, websites offer greater functionality for this population, given some of the age-related concerns, such as reduced eyesight, dexterity, and sensation in fingertips that make mobile touchscreens difficult to use and navigate (294, 411). Websites can offer larger displays and interfaces, which may accommodate for some of those age-related concerns. Digital health interventions for those LWBLC focused on web-based platforms may help overcome barriers to older adults and those experiencing accelerated ageing.

Socioeconomic status (SES) is another determinant affecting access to digital health resources. Previous studies have demonstrated the associations between low socioeconomic status (SES) and those LWBLC, independent of factors such as smoking behaviour (a major risk of lung cancer) (307). In order to facilitate and promote behaviour change, interventions should be guided by frameworks or models of behaviour change. Key behaviour change frameworks suggest that an individual's capability, opportunity, and motivation to engage with interventions are critical to elicit a behavioural change (415). Those with higher SES may engage in such interventions due to more free time, supportive physical and social factors, and access to resources (gyms, foods, exercise equipment) to facilitate behaviour change and increase PA (416, 417).

Additionally, there is a financial and technological disparity highlighted by the cost of available broadband packages across the UK. In fact, the burden of both internet access and hardware can lead to reduced participation and engagement with the digital technology of those from lower SES (294). The UK's average cost of fixed voice and broadband was £37.25 per month in 2019 (418). Furthermore, this does not specify the quality of the connectivity. Socially deprived areas typically experience slower broadband speeds and coverage (419, 420). Moreover, within Hull and surrounding villages, KCOM has a broadband monopoly. In fact, when searching a popular comparison site (Comparethemarket.com) in February 2022 (421) for major university postcodes in nearby cities, the University of Hull had only one provider (KCOM) with five packages being offered. Whereas Manchester University and Northumbria University had 66 deals with 13 providers, the University of Leeds had 81 deals with 14 different providers. Broadband serving the postcodes for the University of Leeds, Manchester, and Northumbria can be paid monthly for £18 per month, whereas in Hull, the lowest, based on the comparison site, is £24.99. This difference may result in an £83.88 per year difference due to geographical location. ExerciseGuide UK was designed to minimise these disparities where possible, through being highly adaptable, with participants being able to access the platform on whatever device they have. This cross-device compatibility of multiple devices was a priority for ExerciseGuide UK, maximising the likelihood that potential participants would already have access to the intervention through their existing devices without the need to purchase additional technology.

Another consideration is the stigma associated with lung cancer, particularly related to smoking. Cigarette smoking is a major risk for cancer, specifically lung cancer. Data suggests cigarette smoking attributes over in 90% of men and 70% - 80% of women of those who receive a diagnosis of lung cancer (422). However, the association between lung cancer and cigarette smoking has been reported to elicit a public stigma (423, 424). Those who smoke are acting on a behavioural choice and thus may be seen as responsible or possibly deserving of a diagnosis of lung cancer

(424). Stigma pertaining to an individual's health may impact their ability to access treatment and negatively affect behavioural, communication, and psychosocial outcomes over the lung cancer trajectory (423, 424). To reduce any unintended lung cancer stigma, ExerciseGuide UK has been iteratively adapted with a PPI group of those living with and beyond or cared for an individual with lung cancer and went through usability testing. ExerciseGuide UK aimed to include information regarding smoking but not single out those who smoke or provide additional content pertaining to smoking. Recruitment was during oncologist-led outpatient and treatment clinics. The HCPs and clinicians ensured a supportive environment, which the recruiting researcher (JC) echoed.

Moreover, age-related stigma regarding digital technology may have led to older patients declining participation based on their age and their perception of how their age may impact technology engagement. Detailed support was provided for all patients during clinic visits. Those who voiced a lower digital literacy and competency level were provided with a one-to-one discussion immediately following their clinic consultation. Alternatively, follow-up calls were offered to patients if they preferred. JC or the clinical team made no assumptions regarding age or digital literacy during recruitment.

Lastly, digital literacy and skills using digital technology are not uniform across all age groups, with many older adults lacking the foundational skills necessary to engage with digital platforms, such as ExerciseGuide UK (425, 426). Recognising these challenges, ExerciseGuide UK has been designed with user-friendly interfaces and visual aids that simplify navigation and interaction. The platform provided ongoing written support and one-to-one discussions to address further digital literacy, which are a fundamental aspects influencing how individuals access and use digital health resources (427).

Moreover, to enhance usability and accessibility, ExerciseGuide UK also pays attention to the use of symbols, for example, a cross (X) to close a popup or minimise a dropdown box. However, it takes an individual pre-existing knowledge to know the functions of these 'relatively standard symbols'. Those who are not digitally literate, competent or just unaware may experience usability issues if these symbols are used but not understood (428). Therefore, ExerciseGuide UK aimed to address this accessibility barrier over universally accepted symbols by providing written and visual instructions earlier on the website. For example, instead of arrows for going forward and backward, coloured buttons saying "Next" and Previous" were added to all modules.

5.2.4 Patient and Public Involvement: Workshop Two

The second PPI workshop aimed to discuss four main items with the four attending members, 1) patient-facing documents for the feasibility study (study three), 2) Think Aloud interview tasks, 3) website development, and 4) methods of recruitment.

All PPI members were sent the following documents two weeks prior to the workshop to provide feedback on the readability and comprehensibility 1) participant information sheet (PIS), 2) patient informed consent form, and 3) ethics lay summary. In addition, the PPI members were sent the list of proposed activities for the Think Aloud interviews.

A summary of the feedback provided from the PIS, consent form, and ethics lay summary was compiled, and suggested revisions were presented back to the group for agreement. The feedback from the Think Aloud tasks was discussed, and all present PPI members agreed on the final tasks. Following the presentation and final agreements, the PPI workshop transitioned into the second phase, a review of ExerciseGuide UK and a discussion surrounding recruitment methods.

The discussion of ExerciseGuide UK was guided by the following five topics, 1) the PA questionnaire; 2) methods of recruitment; 3) ExerciseGuide UK walkthrough; 4) mental health module; and 5) nutritional information. A summary of the topics discussed with the PPI group and feedback can be found in Appendix Nine (appendix 13.8.2). Each of the five topics will now be discussed in turn.

5.2.4.1 Physical activity questionnaires

A participant's level of PA was noted in the initial PPI workshop as an important outcome to measure prior to engagement in a PA or exercise intervention. The participant's PA level was an outcome that was of interest within this doctoral research as changes in PA behaviour time may provide insight into the longitudinal impact of ExerciseGuide UK. Therefore, the SQUASH (Short QUestionnaire to ASsess Health enhancing physical activity) (429) was chosen in the initial developments. However, uncertainty surrounding the SQUASH's suitability arose. The SQUASH covers four domains of being active, 1) commuting activities (i.e., work or school); 2) leisure time activities; 3) household activities; 4) activity at work or school. Those LWBLC are typically diagnosed later in life (≥65y). Exploring work and school seemed less appropriate. Consequently, the CHAMPS (Community Health Activities Model Program for Seniors) (430) was considered a more appropriate alternative questionnaire. However, the SQUASH was relatively short with the four domains (with ten standard items), whereas the CHAMPS was 41 items. Though the CHAMPS targets older adults, the number of items may be off-putting. Thus, the concern was brought to the PPI group, wherein the PPI group unanimously decided the CHAMPS was more appropriate. The length was noted as a concern but superseded by the level of suitability over the SQUASH within this population.

5.2.4.2 Methods of recruitment

Recruitment within the LWBLC population has demonstrated challenges within the literature (120). Trying to mitigate and address this challenge early in the doctoral research, PPI members were asked about the various methods they would typically receive recruitment material and what would facilitate their engagement in research. Aligned with the research, the PPI group highlighted that their treating physician and HCP team play a major role in trial participation, and the majority would like advice regarding PA (316, 431). Thus, the oncology team would be best suited to facilitating and encouraging trial recruitment. Furthermore, supplementary methods of recruitment stated were social media (e.g., Facebook and Twitter/X), internet forums, support groups, and the MacMillan support services. Though, a lack of access to and awareness of information pertaining to current and ongoing trials was mutually conveyed across the group. Thus, making treating physicians and the HCP team the best recruitment method in the opinion of the PPI group.

5.2.4.3 ExerciseGuide UK walkthrough

ExerciseGuide UK was screen shared (via Zoom) with the PPI group for a walkthrough. The group was guided through the initial *sign-up page*, the *landing page* (known as the homepage or *dashboard*), *Introduction*, *Physical Activity and Exercise Safety, Physical Activity and Exercise Prescription*, *Benefits of Physical Activity*, *Healthy Lifestyles, SMART Goals, Action Planning, Library, Help,* and *Tracking*. Moreover, the website architecture was discussed with the PPI group. A summary of each element discussed with the PPI group throughout the walkthrough will be delineated below.

5.2.4.3.1 Sign-up page

The *sign-up* page received good feedback. Members commented on the simple and minimal design. Members suggested that an image of some form of activity may be beneficial and engaging. The prototype did not have any image layering the sign-up page at this stage. This was something which was planned but not yet completed.

5.2.4.3.2 Landing page

The *landing page* (also known as the *homepage* or *dashboard*) for ExerciseGuide UK received positive feedback. The PPI group members liked the large module boxes and delayed module release (see Figure 23). The PPI group highlighted that the landing page was clear and was not overwhelming.

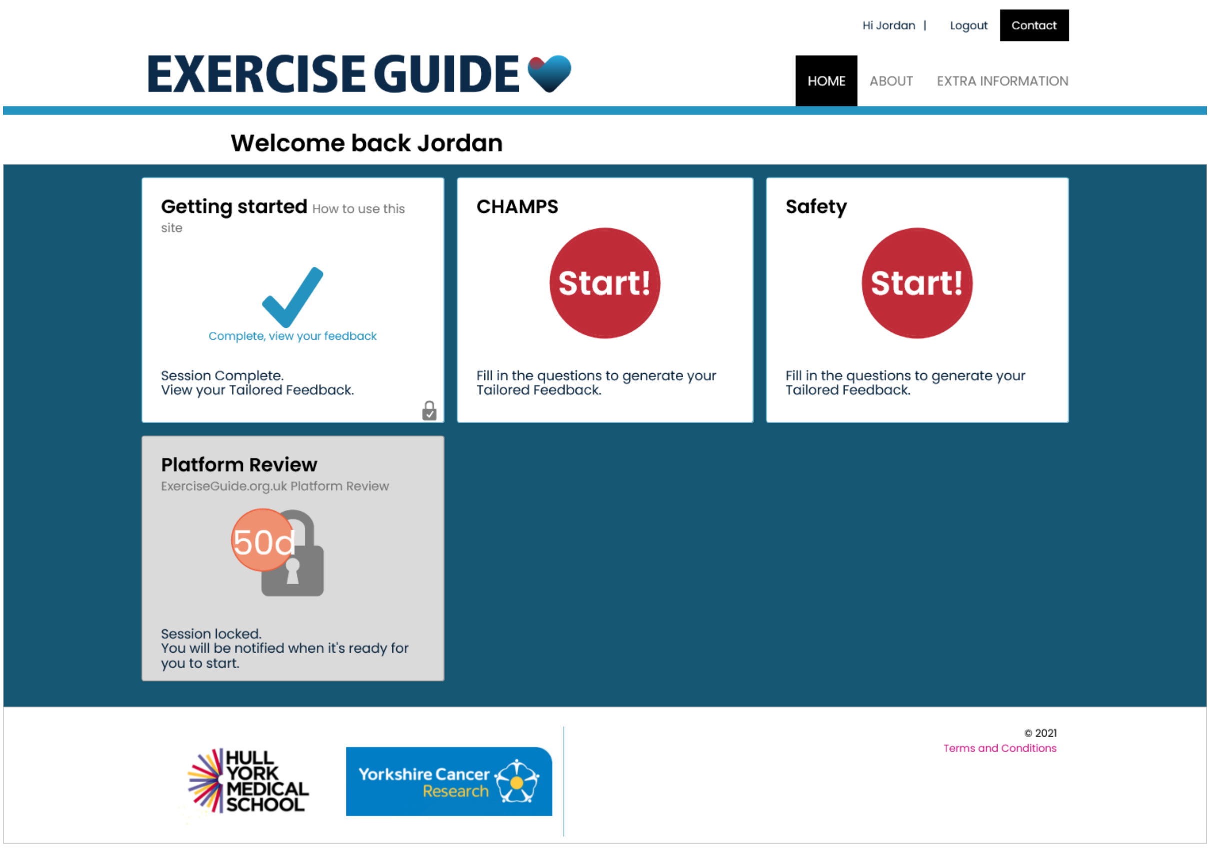


Figure 23: Landing page of ExerciseGuide UK after completing the compulsory baseline questionnaires, 'Safety' and 'Platform Review'.

5.2.4.3.3 Introductory module

An overview of ExerciseGuide UK and advice on how to get started were detailed in this module. Near the end of the module, three videos were proposed, 1) Navigating ExerciseGuide UK; 2) Exercise Plan; 3) How to Contact Us. Though at the point of the second PPI workshop, the videos were incomplete; thus, no feedback was received. The baseline, EORTC-QLQ-30, HADS, and CHAMPS modules disappear after completion. However, the Getting Started module does not disappear throughout the eight weeks to allow participants continuous access.

5.2.4.3.4 Physical activity and exercise prescription

The introduction of the PA programme appeared short with limited information. The PPI members recommended further safety information, and more information to help understanding the exercise prescription was required.

The animations and information pertaining to each strength-based exercise were praised, with members stating they were clear, informative, and understandable. Members stated it could be important to some for the animations to be either none gender-specific or the option for male and female. During the walkthrough, all animations were male based on the administrator's account details.

5.2.4.3.5 Safety

The safety module received good feedback. However, the group suggested that safety information should come before any PA and exercise prescription. During the second workshop, most safety information pertaining to being physically active and engaging in exercise was in a standalone module that proceeded with the exercise module.

5.2.4.3.6 SMART goals and Action Planning

The SMART goals and Action Planning module were available following the safety module. The modules are created independently, but the user is guided through them both combined. PPI members reported positively about the SMART goals information and the website using questions to build the participant's action plan automatically.

5.2.4.3.7 Benefits of physical activity and exercise

The benefits of the PA and exercise module got positive feedback during the workshop. The infographics and figures were highlighted to be clear and engaging. The group members suggested that when providing examples of types of activities for aerobic and strength-related activities, a broader and more inclusive range should be provided, including lighter exercises. The group suggested that a limited number of people may be able to run, cycle, and lift weights but could walk up some stairs, lift a kettle full of water, and walk to the end of their garden. Thus, more appropriate examples were discussed and proposed with the group.

5.2.4.3.8 Healthy lifestyles

Throughout the *Healthy Lifestyle* module walkthrough, the PPI group voiced that more tailoring would be beneficial. A lot of information pertaining to treatment and diet and generic information regarding smoking, alcohol intake, and sleep, which could be better supported and displayed with personalisation.

5.2.4.3.9 Library

The *Library* was explained as a location where supplementary information may be helpful and of interest but was not included in the core modules to keep the modules concise. Members of the PPI group liked the idea of the *Library*, and specific attention was drawn to the page for support groups. The group emphasised the lack of signage to support groups and where to seek further information regarding their diagnosis. Figure 24 shows the original Library page of ExerciseGuide UK.

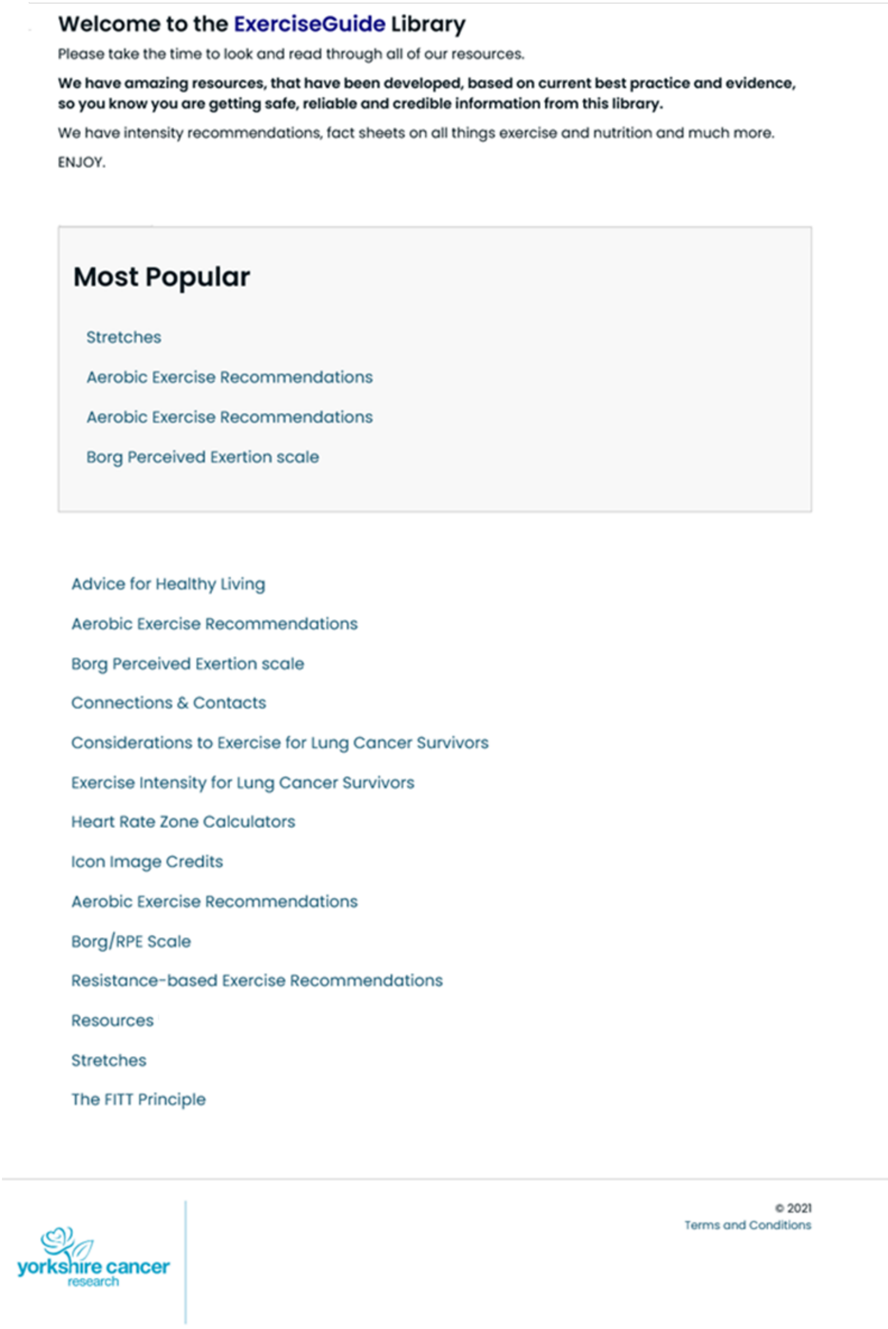


Figure 24: Screenshot of the library after the initial adaption of workshop one for ExerciseGuide UK.

5.2.4.3.10 Help

The help page was well-received by the group. Having an internal messaging system was preferred instead of an external contacting method (e.g., users loading up their personal email and emailing through there).

5.2.4.3.11 Tracking

During the walkthrough, the PPI group liked the idea of a module wherein participants could track their performance and any thoughts they may have. All PPI members commented on the graphs showing metrics relating to symptom tracking and exercise enablers throughout the study as beneficial and useful.

5.2.4.4 Website Architecture

At the end of the walkthrough of the platform, the website's architecture was discussed with the group. Following an explanation of a tunnelled or free-choice architecture, all PPI members agreed a tunnelled approach would be recommended. The tunnelling of the modules was not strict (wherein all modules would lead to one another in a single fashion). Instead, small batches of relevant modules and information are released in an organised and timely approach. This builds on previous research on website usability from Finlay and colleagues (2020) (392) and Evans et al. (382) that usability may be increased on web-based platforms such as ExerciseGuide with the presence of navigation.

5.2.4.5 Mental health module

Receiving a cancer diagnosis can have a wide-ranging and substantial impact on one's mental health, with evidence indicating that the prevalence of anxiety and depression in those diagnosed with cancer is high (432, 433). In comparison to other types of cancer, lung cancer is associated with greater levels of psychological distress (434, 435). Therefore, it was important to explore whether a module dedicated to mental health would be well received and, if so, what content would be most appropriate.

The group was unsure of the specific content which would be best to include and emphasised that the method people use to deal with problems is highly personal, with in-person support being the best option. Thus, the recommended information was information, recourses, and pathways on where to find out information pertaining to mental health and lung cancer.

5.2.4.6 Nutritional information

Nutritional information was included minimally on ExerciseGuide UK with some minor tailoring. Generic advice was provided for how to consume fruit and vegetables (e.g., unpeeled or not raw) and limiting certain foods, such as greasy foods, with two posters regarding the management of diarrhoea and management of nausea and vomiting (see Figure 25).

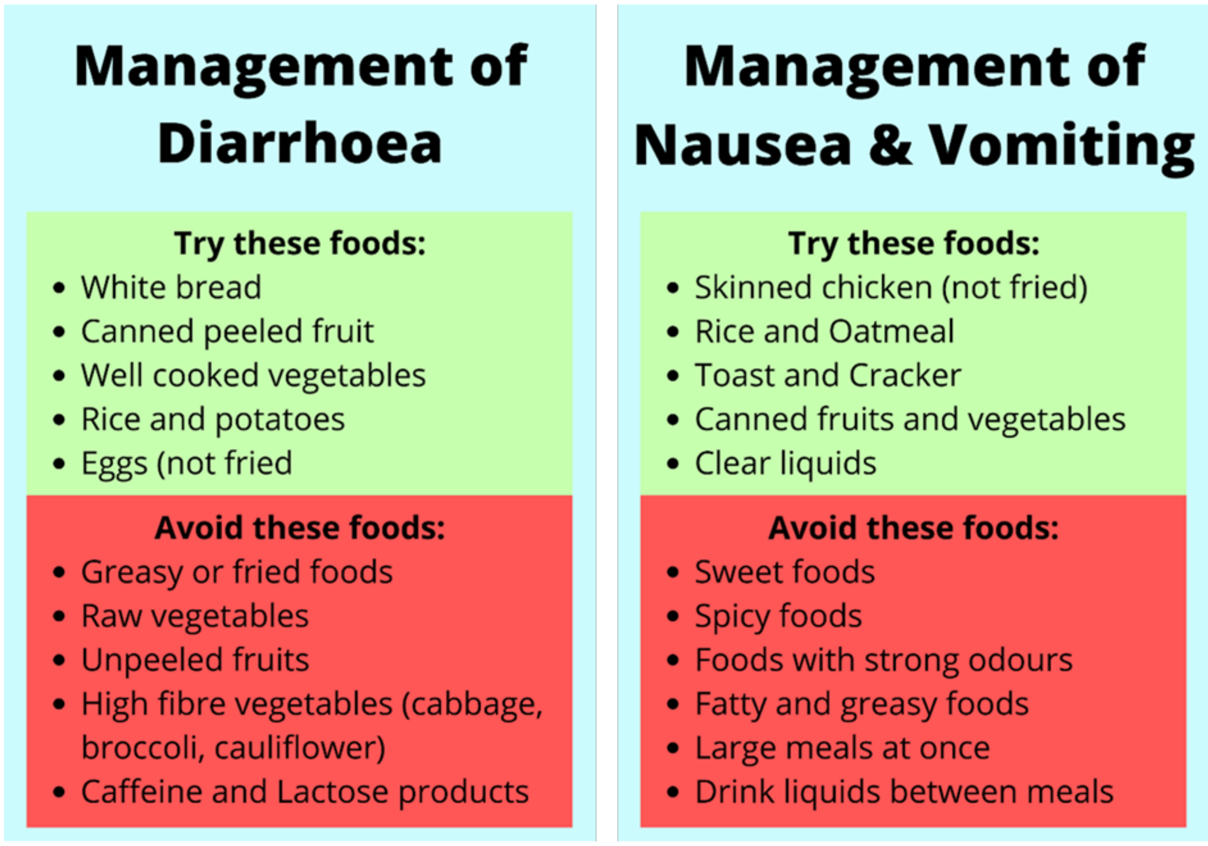


Figure 25: Two posters providing information regarding the management of diarrhoea and management of nausea and vomiting for those living with and beyond cancer.

The members of the PPI group stressed the importance of nutrition throughout their cancer journey. They suggested that generic dietary information which could be tailored based on treatments would be helpful.

When discussing available resources online such as MacMillan: Recipes for people affected by cancer, MacMillan: Diet and food supplements (436), Flavour and Nutrition: Life Kitchen and World Cancer Research Fund (437), and general MacMillan informational booklets (438), members were unaware where and how to find such resources. Therefore, providing the link to open-source documents would be useful.

5.2.5 ExerciseGuide UK Revisions: Round Two

Based on the feedback from the PPI members during workshop two, revisions were made to the website's content. The internal website content was adapted, or new content was developed. The seven major revisions are detailed below.

5.2.5.1 Physical Activity Questionnaires

A module containing the CHAMPS questionnaire was created following the discussion of whether the SQUASH or CHAMPS would be both more appropriate and suitable for those LWBLC. This module followed the EORTC-QLQ-30 and HADS as baseline questionnaires to ExerciseGuide UK.

5.2.5.2 Introductory Module

At the time of the second PPI workshop, the explanatory videos were not complete. The videos were recorded following the revisions carried out within round two. This was to ensure all content was correct at the time of recording. Members within the PPI workshops expressed an interest in more in-depth and advanced information regarding the benefits of PA and exercise for those LWBLC earlier on in the website. Therefore, a figure detailing the depth was added to the introductory module (which is shown in Chapter 1 section 1.8), linked to an open-access research paper detailing PA and exercise benefits for those LWBLC (125).

5.2.5.3 Physical Activity and Safety Modules

The safety module leads directly into the physical activity and exercise module using the tunnelled design. This conditioning ensures users must complete the safety module prior to being prescribed their personalised exercise plan.

5.2.5.4 Benefits of Physical Activity

A more appropriate and wider range of examples for aerobic and strength-based activities were integrated into the online content. The PPI group highlighted that though many individuals with cancer may be able to jog and cycle, those LWBLC may have limited functional capacity. Therefore, examples include walking up a flight of stairs, lifting a kettle full of water, and doing yoga.

5.2.5.5 Healthy Lifestyles

The group highlighted the successful ability of the website to tailor the dietary content based on treatment type, reducing the excess of unwarranted information. However, the group members emphasise the lack of tailoring within subsequent subsections, such as smoking, alcohol, and sleep. Therefore, questions were added to enable code to be implemented, allowing tailored feedback to these given areas.

5.2.5.6 Mental Health

Following the group discussion regarding a dedicated *Mental Health* module, both the research team and the PPI group agreed this module should be developed and included into ExerciseGuide UK. However, the PPI members suggested that tailored content may not be appropriate due to the highly personal nature of mental health. Alternatively, information regarding available resources and pathways was displayed in the module with general information regarding mental health within cancer and specifically lung cancer.

5.2.5.7 Nutritional Information

To support the existing nutrition and dietary information content, links to openly accessible materials were provided. Members of the PPI workshops emphasised the lack of signage and difficulty accessing such information, although highly sought after.

Following the second PPI workshop, a usability study/think aloud interviews was conducted with ExerciseGuide UK at this point.

5.2.6 Usability Study (Think Aloud Interviews)

Examining the usability of interventions and platforms within research has been a standard process for several decades (439). One popular method of exploring the usability of a task, tool, or device is a method known as Think Aloud interviews. There are varying definitions for Think Aloud interviews. Nielsen (2012) defines Think Aloud interviews as:

> *"In a thinking aloud test, you ask test participants to use the system while continuously thinking out loud — that is, simply verbalizing their thoughts as they move through the user interface." (440)*

Whereas the UK Government define the Think Aloud process related to the evaluation of digital technology as:

> *"Think aloud methods ask participants to verbalise what they are thinking and doing as they perform a task using your digital health product or service." (385)*

There is a commonality in both definitions, which are widely used. Both definitions highlight the importance of participants 'verbalising' thoughts while using a device, tool, or platform.

Within this body of research, the definition of Think Aloud interviews has been informed by the previous definitions. The following defines Think Aloud interviews in the context of this doctoral research:

> *Think Aloud interviews involve asking users to verbally express their thought process as they complete tasks on a platform. Researchers record in real-time feedback into usability issues and design concerns as participants walk through the user interface thinking aloud their thoughts and actions.*

However, there are different processes of conducting Think Aloud interviews, each having their own nuances and purposes throughout usability testing. One of the most common is Concurrent Think Aloud (CTA). The CTA approach is the primary method used within the usability testing of web-based platforms to examine a tool or device. Using CTA, users engage with a device and simultaneously verbalise their immediate reactions and thoughts (439). Employing the CTA method to examine a web-based platform's usability has been a popular choice due to its ability to capture reactive information and immediate thought (439). Two variants of Think Aloud interviews are Retrospective Think Aloud (RTA), and Team (also known as constructive interaction) (439)

Despite the immediate verbalisation of thought, RTA requires participants to silently perform tasks or work with a tool, device, or platform and verbalise their thoughts after they watch back their recording. Moreover, Team-based Think Aloud interviews bring two participants together to work through tasks or activities. It has been illustrated that Team-based Think Aloud has been beneficial for evaluating software applications. However, a concern arises regarding when a tool or device has large bodies of textual information. Firstly, reading is inherently personal; individuals read at different paces. Suppose *Participant A* was to verbalise a thought during a reading bout immediately. In that case, this may interrupt *Participant B* and alter any thoughts they may have or are about to have. Therefore, participants would likely read silently and only verbalise concerns that they think warrant discussion.

Additionally, participants may feel embarrassed to verbalise they did not understand something in front of another individual. However, having two participants thinking aloud may elicit additional thoughts from one another. Ultimately, the varying methods of exploring usability may reveal different results. However, the researcher needs to reflect on the tools or devices they wish to examine and then select a suitable Think Aloud method. ExerciseGuide UK does contain, at some points, large bodies of textual data and multiple pages of feedback within a given module.

For this reason, the Team-based Think Aloud approach did not seem suitable. The concept of CTA using a reactive approach (participants see a problem and verbalise it) felt more natural than a reflective approach. Although RTA does have some benefits, such as participants taking time and reflect, possibly providing a more heuristic account or providing those with various language barriers, for example, those who speak in a foreign language, it may find it difficult to verbalise their thoughts in a different language while executing a task (441) Moreover, using an RTA approach may elicit bias due to participants revising or concealing their immediate thoughts for social desirability, observer desirability (e.g. Hawthorne effect), or self-preservation (441). It seemed appropriate to get an immediate reaction from the participants as with web-based platforms, if users do not find what they wish or get frustrated due to issues such as bugs or the user interface, those websites will have a high 'Bounce Rate". The bounce rate refers to users visiting a site and leaving without exploring further due to perceived or existing issues (442). Capturing participants' immediate and reactive feedback was considered important to ensure ExerciseGuide UK did not incur a high 'Bounce Rate". Therefore, a CTA approach was taken. However, efforts were put in place to encourage reflexive or retrospective processing. Solely employing the CTA method may elicit concern over processing large bodies of textual information while maintaining verbal thinking aloud processes (439, 443, 444). In this instance, there may be a decrease in observable problems instead of an increase. Therefore, at the end of a task, participants were given the opportunity to reflect on the content and tasks they had completed prior to moving on to the next task. Allowing time for retrospective and reflexive thoughts aiming to reduce the decrease in observable problems being identified.

5.2.6.1 Methods

The methods for the Think Aloud study are discussed in 4.5.1.

5.2.6.2 Results

5.2.6.3 Participant Characteristics

Seven participants were recruited through the online dissemination of a recruitment flyer. Online dissemination took place on Twitter, Facebook, and emails throughout support groups for those LWBLC. Two males and five females were recruited, covering four regions in England. The mean age of participants was 58y ± 6.2y. All participants had stage IV lung cancer. Self-reported digital competency was wide-ranging across the seven participants, with all participants stating they use digital technology at least once per day, if not multiple times per day. Participant characteristics are presented in Table 11.

Table 11: Think Aloud interview participant characteristics.

Characteristics	N=7
Males/females	2/5
Mean age (SD)	58 (± 6.2)
Region in England	
North West	2
East Midlands	1
South West	2
South East	2
Level of Education	
GCSE, Standard Grade, O-level or equivalent (GNVQ/NVQ Intermediate or Foundation, GSVQ (Level 1 or 2) or RSA Diploma)	1
A-level, Higher Grade, or equivalent (GNVQ/NVQ Advanced, GSVQ/SVQ (Level 3) or RSA Advanced Diploma)	1
HNC, HND, SVQ (Level 4 or 5) or RSA Higher Diploma	1
Postgraduate degree or equivalent	4
Employment Status	
Employed – Full Time	3

Characteristics	N=7
Unemployed - looking for work	1
Retired	3
Cancer stage	
IV	7
Digital Competency	
Not very competent	1
Somewhat competent	2
Pretty competent	2
Highly competent	2
Engagement with digital technology	
Multiple times per day	5
At least once per day	2
Devices used*	
Smartphone	6
Computer/Laptop	7
Tablet	4
Smart TV	5
Smart Watch	1

*Note: GCSE, General Certificate of Secondary Education; O-Level, Ordinary Level; GNVQ, General National Vocational Qualification; NVQ, National Vocational Qualification; RSA, Royal Society of Arts; SVQ, Scottish Vocational Qualification; HNC, Higher National Certificates; HND, Higher National Diplomas. *Participants could have selected multiple devices.*

It is useful to note of the seven participants, there was a fairly even divide among the participant's digital competency, with a median score of three and a range of four (two – five). The digital competency of the sample is presented visually in Figure 26.

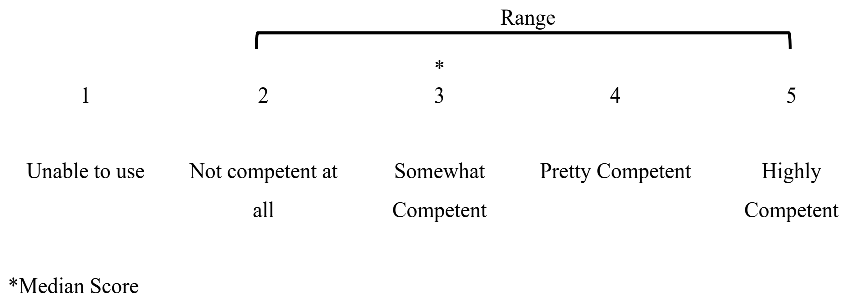


Figure 26: Digital Competency Scale of the seven participants who took part in the Think Aloud interviews, with Median Score and Range

5.2.6.4 Think Aloud Themes

There were six themes inductively generated from the Think Aloud interviews, 1) Functionality, 2) Understanding, 3) Visual, 4) More Information Needed, and 5) Preferential. A breakdown of the themes, their definitions, and the number of occurrences is detailed in

Table 12.

5.2.6.4.1 Theme One: Functionality

Participants of the ExerciseGuide UK Think Aloud study reported several functional issues during their experience with the website. One issue involved navigating from one module to another, such as from the SMART Goals module to the Action Plan. Participants were instructed to click a "Finish" button, which was not always present. When it was present, participants used this appropriately. Additionally, some available buttons, such as the "Show More Information" buttons, did not function properly due to coding errors.

However, most participants found the weekly release of modules and the tunnelled architecture useful and effective. The *Contact Us* email feature which is within the site was also well-received by participants. It was noted that a copy of any message sent through the platform should also be sent to the participant's registered email, providing a backup.

5.2.6.4.2 Theme Two: Understanding/Clarity

The site was thought to be clear, understandable, and inviting during the *Signup* and *Getting Started* module. The information was thought to be concise, which improved the clarity of information.

However, some questions were unclear, especially around the *Exercise Prescription* module. Participants were unsure of what the questions were trying to ask them, and for questions about exercise, they were not sure what was classified as exercise.

In the *SMART Goals* module, the infographics of information, such as the summary of SMART Goals (Specific, Measurable, Attainable, Realistic, Time-Bound Goals), were thought to be a clear way of displaying the information. However, when it was time for participants to complete a text box, some were unsure of the action required as there was no direction or information provided to fill out the text boxes.

Commonly, websites have contact us features, which often reside at the top or bottom of a page. When participants were asked to contact the research team, participants often went to the *About Us* section, thinking contact details for the research team would be located there. This was considered a concern, with no contact information provided there and participants not recognising the presence of a contact button in the top right of the site.

5.2.6.4.3 Theme Three: Visual

Visually the website received some positive feedback and areas of improvement from participants. Some participants found some of the text and figures too small, making them difficult to read. Alternatively, several participants liked the addition of summary videos of large bodies of text and the linked breathing videos, which they found both engaging and helpful. Moreover, the exercise animations were thought to be useful, as they provided an effective demonstration of their prescribed exercises.

5.2.6.4.4 Theme Four: Information Required

Participants' feedback on the level of information provided on the site revealed mixed thoughts. Initially, participants valued the engaging and informative content but expressed a desire for more specificity regarding lung cancer and cancer in general. Questions around the value and purpose of using the site were also raised, as it was perceived that the benefits of participation and exercise were not communicated effectively early on in the site.

Additionally, some statements on the site were considered confusing, as they referred to text not present due to frequent iterations in the content during the site's development. The questions on the site were generally considered good, but some lacked sufficient detail for desired responses. However, the questions and outputs related to values and habits were well received and should have been emphasised more. Finally, participants felt that a module on mindfulness would have added to their experience.

5.2.6.4.5 Theme Five: Preferential

There were some preferential (i.e., participants suggested based of their own preference) suggestions made for ExerciseGuide UK during the Think Aloud interviews. One concern was the use of an example goal focused on calorie restriction. This was thought to be possibly unhelpful, and it may not be a healthy approach, particularly for those undergoing cancer treatments that may cause weight loss. Furthermore, participants noted a lack of inspiration or rationale for participating in the ExerciseGuide UK intervention. Another concern was the structure of questions within the healthy lifestyle module. The first question was regarding smoking history. As the first introduction to a module, these questions were thought to be potentially triggering for some participants who felt a stigma associated with smoking and lung cancer.

On the other hand, participants appreciated email addresses, and contact information was pre-populated email within the *Contact Us* feature. This was thought to reduce effort and lead to a more straightforward communication method with the research team.

Finally, a recommendation was made to integrate a chatbot into ExerciseGuide UK, providing participants an interactive way to seek information or clarification without contacting the research team.

Table 12:Generated themes from Think Aloud interviews of ExerciseGuide UK, their definition, and the number of occurrences of themes within the positive and negative comments.

Theme	**Definition**	**Total Number of Comments**	**Number of Positive Comments (%)***	**Number of Negative Comments (%)***
Functionality	The extent to which the participants were able to navigate through the website as intended.	18	2 (9.09%)	6 (14.63%)
Understanding/Clarity	The extent to which the participants were able to understand the content or required action.	10	12 (54.55%)	10 (24.39%)
Visual	How an individual felt about the visual components of the website.	5	5 (22.73%)	5 (12.39%)
Information Required	The level of information required to complete a task or appropriately engage with the website.	12	2 (9.09%)	12 (29.27%)
Preferential	The participants personal thoughts based on their personal preferences.	8	1 (4.55%)	8 (19.51%)
Total		**63**	**22**	**41**

Note: * = "Displaying the distribution of themes between positive and negative comments, with the percentage of themes within the positive category and the percentage of themes within the negative category presented separately

5.2.6.5 System Usability Score

After completing the interviews, participants were asked to complete the SUS online via Qualtrics independently. The SUS was sent to the participants via email they provided during the consenting procedure. Five of the seven participants (71%) reported they would feel confident using ExerciseGuide UK, with six of the seven (86%) stating they would imagine that most people would learn to use ExerciseGuide UK very quickly. Six of the seven (86%) participants reported they would not need to learn a lot of things before they would get going with ExerciseGuide UK. A breakdown of the overall reporting per item is detailed in Appendix 11 (appendix 13.10).

Overall, ExerciseGuide UK was rated ‘Excellent’ four times (57%), ‘Good’ one time (14%), ‘OK’ one time (14%), and ‘Awful’ one time (14%). The SUS score and rating for each participant are presented in Table 13.

The mean SUS score was 72 (± 25), achieving higher than the satisfactory score derived from the literature (≥ 68%) for usability (388, 393).

Table 13: Overall SUS score and rank per participant for the Think Aloud interviews.

Participant	SUS Score	Rating*
1	87.5	Excellent
2	75	Good
3	67.5	Ok
4	17.5	Awful
5	90	Excellent
6	85	Excellent
7	82.5	Excellent

**Rating: >80.3, Excellent; 68 – 80.3, Good; 68, Okay; 51 – 68, Poor; <51 Awful. SUS: Systems Usability Score.*

5.2.6.6 *Summary of Think Aloud Findings*

Conducting Think Aloud interviews with participants LWBLC provided a useful assessment of the site's usability before launching a larger trial.

Using the SUS, ExerciseGuide UK was rated 'Good' or 'Excellent' by 71% of participants. Findings from the ExerciseGuide UK Think Aloud study align with previous evidence that online supportive care for those LWBLC appears acceptable (3). However, results should be taken with caution in relation to age. Age is an important caveat to both the findings of the Think Aloud study and previous literature. In the UK, 44% of those diagnosed with lung cancer are aged 75y or older (9) . Though, within this study, the mean age of participants was 58y ± 6.2. Furthermore, in a review examining the feasibility, acceptability, and efficacy of online supportive care for those LWBLC, across eight studies, the mean age was 61y ± 5.6y (3). Though roughly 66% of those diagnosed with lung cancer are below 75y, evidence suggests older adults (≥ 65y) are often underrepresented in oncological research (293, 445).

Having recruited a cohort of adults not classified as elderly means usability or accessibility concerns for the website may not have been captured. Older adults are often a group that is reported to face more challenges with the accessibility of digital technologies and digital interventions due to the perception they have low digital literacy skills and a reluctance to use technology. By not capturing the views of older adults in the Think Aloud interview sample, important information regarding the usability and, more specifically, the support needs of this group for using ExerciseGuide UK may not have been captured.

In addition to the concerns about age, the level of digital literacy and engagement with the technology of the sample should be highlighted. During the baseline assessment, participants were asked to rate their digital literacy on a five-point Likert scale (see Figure 26). Participants reported a median digital literacy score of three (range: two – five). In addition, five of the seven participants reported they use digital technology multiple times per day, with two reporting they use it at least once per day. Although there was an even range of self-reported digital literacy, the high level of engagement may indicate participants are more literate than they perceive. If ExerciseGuide UK was designed and the usability was assessed by those with a good comprehension of digital technology, there may be elements that unintendedly result in missing potential insights to promote engagement or user experience from those with limited technology experience.

The results from the Think Aloud interviews were summarised and presented to the PPI group for review and further revisions. Collaborating with the PPI group to determine the need for revisions and use a collaborative approach to ensure clarity, comprehensiveness, and suitability in the revisions made. Similar to the early development of ExerciseGuide, the PBA encourages grounding changes with experience from those the intervention is aimed at, in this instance, lung cancer.

The process of discussing and agreeing on the proposed revisions will now be delineated.

5.3 Patient and Public Involvement Workshop Three

The aim of the third Patient and Public Involvement (PPI) workshop three was to present suggested revisions for the usability Think Aloud study and collaboratively discuss potential revisions. The workshop was conducted via Zoom with three volunteers. The session was recorded with verbal consent from the volunteers. The recordings allowed the research team to refer back to ensure accurate decisions were captured and implemented. A PowerPoint (Microsoft Office, Version: 16.96.1, 2023) was created to present the critical feedback and proposed revisions initially suggested by the doctoral researcher.

A method of prioritising revisions was established before the workshop. The model chosen for this was the Must, Should, Could, Would (MoSCoW) criteria (446). The MoSCoW model is a simple tool often used in developing digital interventions (447). The MoSCoW model is considered effective for communicating priorities across team members (446). The revisions were prioritised using the MoSCoW model based on if negative comments were likely to impact components of behaviour change or a precursor to behaviour change. These changes include but are not limited to engagement, persuasiveness, motivation, acceptability, and feasibility (448). Therefore, prioritising the components was vital to address those most essential to the intervention and possible impacts on behavioural change (449, 450). The MoSCoW model and definitions can be found in Appendix 11 (13.11).

Of the 41 comments negative comments recorded from the Think Aloud interviews, 24 (with suggested revisions from the doctoral researcher) were presented and discussed with the PPI group. The remaining 17 comments were not discussed with the group due to requiring fundamental changes to the code or suggestions that were unachievable at the given time. Therefore, it was decided to focus on the 24 comments to the PPI group to best utilise time and effort on the comments which would benefit most from PPI input.

The comments discussed with the PPI group can be seen in the Table of Change (see appendix 13.2), with all items discussed stated in the *Agreed Change* column.

Table 14 below provides a summary of the themes for only the negative comments.

Table 14: The number of critical occurrences within a theme was recorded.

Theme	Count (%)
Information Required	12 (24.39%)
Understanding and Clarity	10 (29.27%)
Functionality	6 (14.63%)
Preferences	8 (19.51%)
Visual	5 (12.20%)
Total	**41**

The rationale behind providing the initial revisions from the doctoral researcher was two-fold. Firstly, proposing changes can reduce the time spent developing new revising methods. If an initial change is proposed, it will be a possible revision which can either be agreed upon or lay the groundwork for further revision. Secondly, it was worth exploring whether the revisions suggested by the researcher responsible for the website's content were relevant and appropriate to the target population. This aims to reduce the potential repeat of usability errors from what the research team perceive may work. In fact, of the initially suggested revisions from the doctoral researcher, the PPI group disagreed with 56%.

5.4 PPI Reporting

5.4.1 PPI Background

PPI in health and social care research has become an important priority in recent years (451). Healthcare systems worldwide recognise the need to include patients and the public in the design and conduct of research studies (452). Historically, research was conducted "on" patients without much consideration for their preferences or perspectives. However, there is a growing understanding that incorporating insights from patients and the public can improve health research's quality, relevance, and impact (451, 453).

The underlying rationale for PPI is that patients and the public have experiential knowledge of living with a health condition that provides a unique and valuable contribution to the research process. Their involvement can help ensure that research that is usable, understandable, and relevant for potential participants. There are good standards of practice within the UK for PPI, such as Inclusive Opportunities, Working Together, Support and Learning, Governance, Communication, and Impact.

In the UK, major funders of health research, such as the National Institute for Health Research, have made PPI a requirement for funding. Policy initiatives such as INVOLVE have also promoted greater public involvement in the NHS. Moreover, Local INVOLVE hubs have been set up, with the Hull York Medical School (HYMS) being fortunate to have their own INVOLVE PPI hub. However, progress is still being made in meaningfully and consistently integrating PPI across different health research disciplines. There are also questions about how to evaluate the impact and outcomes of PPI. Nevertheless, the field is rapidly evolving with an increasing commitment to patient-focused research.

5.4.2 Summary Purpose of PPI

Within the adaption and redevelopment of ExerciseGuide UK, PPI played a critical role. Three online PPI workshops were conducted via Zoom over the course of iteration of ExerciseGuide UK. Participants were individuals living with lung cancer or those who cared for someone with lung cancer, providing crucial lived experiences and perspectives.

The aim of the initial workshop was to explore the views and understanding of physical activity (PA) and digital technology for those LWBLC and discuss the potential design, important features, and content for ExerciseGuide UK. The second PPI workshop aimed to discuss four main items with the four attending members, 1) patient-facing documents for the feasibility study (study three), 2) Think Aloud interview tasks, 3) website development, and 4) methods of recruitment. Between workshops two and three, a Think Aloud usability study was conducted. The results from this usability study were presented back to the PPI group at workshop three, before making any revisions. This enabled participants to actively evaluate and inform changes to optimise app usability and user experience. In the third workshop, the updated prototype was presented for final, participatory decisions on refining app content and functionality.

Overall, the iterative, interactive PPI process placed patients at the centre of co-creating an intervention tailored to their needs and priorities. The PPI group became part of the research team. The virtual workshops provided flexible involvement, while the usability study empowered participants to directly shape site improvements using their lived expertise. This PPI integration enhanced the quality and relevance of ExerciseGuide through collaborative development.

To promote transparency of the PPI conducted throughout this doctoral research, the PPI process has been reported in detail below.

5.4.3 Guidance for Reporting Involvement of Patients and the Public and Evaluation

PPI is a tertiary aspect of the thesis opposed to a primary focus of the adaption of ExerciseGuide UK. Numerous standard reporting guidelines have been developed, such as Consolidated Standards of Reporting Trials (CONSORT) and Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT). In 2011, Staniszewska et al. developed the first guidance for reporting PPI, the Guidance for Reporting Involvement of Patients and the Public (GRIPP) (Staniszewska et al., 2011). Though, this guidance lacked input from the wider academic and PPI community, which is acknowledged as a vital step in developing guidance (Moher et al., 2010). Therefore, in 2017, Staniszewska et al. achieved international consensus and developed the GRIPP2 (Staniszewska et al., 2017). The GRIPP2 comes in long-form (GRIPP2-LF), comprised of 34 items and short-form (GRIPP2-SF), comprised of five items. The GRIPP2-SF will be used as a checklist within this thesis. The short form can be found in Table 15**Error! Reference source not found.**. The six domains presented by UK Standards for Public Involvement will be discussed for the PPI conducted as part of this doctoral degree.

5.4.3.1 GRIPP2-SF

The GRIPP2-SF was used to illustrate key items of the PPI workshops. The use of the GRIPP2-SF was to ensure this doctoral thesis met the international criteria to promote transparency and over quality of PPI. In this thesis, the GRIPP2-SF was used retrospectively to ensure quality of the PPI and contribute to impact analysis.

Table 15: GRIPP2 short form (454)

Section and topic	Item	Reported in chapter
1: Aim	Report the aim of PPI in the study	Workshop One, Two, and Three: Chapter 5
2: Methods	Provide a clear description of the methods used for PPI in the study	Workshop One, Two, and Three: Chapter 5
3: Study results	Outcomes — Report the results of PPI in the study, including both positive and negative outcomes	Workshop One, Two, and Three: Chapter 5
4: Discussion and conclusions	Outcomes — Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	Workshop One, Two, and Three: Chapter 5
5: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	Workshop One, Two, and Three: Chapter 5: Section 5.4.4 - 5.4.5
Note: PPI: Patient and Public Involvement		

5.4.4 UK Standards for Public Involvement

The UK Standards for Public Involvement have need developed and designed to enhance the quality, reporting, and consistency of PPI within research.

Patient and public involvement in research can be defined according to the UK Standards for Public Involvement as:

> *"Research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them." (455)*

Six standards create the UK Standards for Public Involvement. Each standard will be delineated below with reference to the three workshops as part of this doctoral degree:

5.4.4.1 Inclusive Opportunities

The UK Standards for Public Involvement state that to achieve inclusive opportunities, researchers must:

> *"Offer public involvement opportunities that are accessible and that reach people and groups according to research needs"* (456)

Accessibility was a core aspect addressed in the development of the PPI workshops. Due to the COVID-19 pandemic, workshops were transitioned from in-person to online. Of all the existing online video and teleconferencing software available, Zoom (institutional access via the University of York) was used due to no sign-up or registration required. Moreover, individuals had the opportunity to call in via telephone if videoconferencing was not possible for them. In order to mitigate any out-of-pocket expenses, volunteers were able to reclaim expenses for participation in the workshops. To facilitate the availability of volunteers, some sessions were held within two parts. Information flyers for the PPI were disseminated via social media (e.g., Twitter and Facebook), directly to support groups for those LWBLC, and through a local PPI network (Involve Hull). The shift to online recruitment and delivery methods due to the COVID-19 pandemic meant that those who did not have internet access or were not comfortable with online meetings might have been excluded.

5.4.4.2 Working Together

As part of the 'Working Together' standard, the UK Standards for Public Involvement states researchers must:

> *"Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships" (456)*

Throughout this doctoral degree, a focus has been to involve those with lived experiences of LWBLC. This follows the guidance put forward by the PBA and creates a critical component of the adaptation of ExerciseGuide. Following the first two workshops, a summary document was provided to all volunteers with a traffic light depiction of what we can, would like to, and cannot do to the website based on their feedback (see appendix nine (13.8).

With the swift transition to delivering the workshops online instead of in-person, the planned activities were reviewed with the HYMS PPI coordinator (HR) supporting this PPI. A variety of activities were planned to promote different working methods, such as group discussions, games, and drawing exercises.

Before engaging in any activities, time was spent getting to know the volunteer members. All PPI volunteers were given the opportunity to meet with JC prior to the workshops to discuss the nature and rationale behind the PPI for this research. This initial conversation aimed to provide potential volunteers with all relevant information to decide about being involved and build a rapport with them prior to meeting other members. Ongoing communication with the PPI members was a priority within the design and approach of workshops. Workshops were often months apart, and concern was noted regarding potential dropouts. JC provided a bi-monthly update to all PPI members to ensure communication was provided to all PPI members.

The efforts made to create and facilitate a comfortable and safe space were paramount to promoting collaboration, not only among PPI members but also with the research team. Moreover, some PPI members agreed to continue working with the research team on additional studies (CanBenefit II and CANFit).

5.4.4.3 Support and Learning

As part of the 'Support and Learning' standard, the UK Standards for Public Involvement states researchers must

> *"Offer and promote support and learning opportunities that build confidence and skills for public involvement in research" (456)*

Supporting those interested in being a part of the PPI workshops was a primary aim of the research team and PPI coordinator. Initially, the PPI workshops were planned to be conducted face-to-face at either the Allam Medical Building at the University of Hull or Castle Hill Hospital. Funds were secured through the PPI coordinate at HYMS to reduce financial loss due to involvement in PPI (e.g., mileage and parking). However, due to COVID-19, the PPI swiftly transitioned to online delivery via Zoom.

However, alternative methods of involvement were offered, such as telephone or mailing interested volunteers. Though, digital technology, telephones, and mailing all have potential costs. Therefore, to reduce any financial concerns, those involved in the Zoom workshops were able to submit a reimbursement form for data usage (broadband or mobile data) and supplementary costs (e.g., childminding). For those engaging via telephone, call costs could be reimbursed. A completed return envelope would be included for those who engaged via mailouts. Offering alternative methods of involvement with reimbursements aimed to allow anyone interested to take part by reducing potential barriers. Furthermore, emotional support for PPI members was a critical component of the planning and delivery of all workshops.

Discussing cancer can elicit a vast array of emotions for those living with or affected by the disease. Cancer is globally a leading cause of death, with symptoms including cancer-related fatigue, pain, and an overall reduction in QoL. Moreover, cancer may lead to psychological impacts such as depression and anxiety. However, those LWBLC are reported to have higher unmet supportive care needs and physical impairments than those with other common cancer (e.g., prostate, breast, skin, and bowel cancers) (457). Hence, discussing lung cancer may have been a sensitive and emotional topic for some. To promote emotional support, PPI members were informed that following any workshop, they were able to contact the facilitator (JC) to discuss any support needs further.

Additionally, members were informed that if they needed time away from any conversation, they were able to mute their disable their microphones and cameras (if on Zoom) or request some time (if on the phone) to collect their thoughts before either addressing the topic which led to the emotional response or progressing to the next topic. Lastly, an outline of the sessions was disseminated to the members at least one week prior to the workshop. The outline illustrated the topics planned for discussion and some tasks. Members were informed if they would like any additional information regarding a topic or task to contact the PPI facilitator (JC). This aimed to reduce any unexpected topics of discussion which may cause distress.

The purpose of the PPI was to explore the views and thoughts of those living with and affected by lung cancer on digital technology and physical activity on a broad level and working towards the design of an intervention and iterative adaptation of

ExerciseGuide UK. In addition to reducing potential barriers and ensuring emotional support, it was an important aim of the PPI not purely to seek information but to provide a mutually informative learning and sharing environment. Although there was an overarching aim to the PPI, it was important to create an environment where individuals could speak freely and learn. This was implemented into the workshop's presentations, where information was not solely sought out but shared with PPI members.

5.4.4.4 Governance

In order to achieve governance through PPI, the UK Standards for Public Involvement state researchers must:

> *"Involve the public in research management, regulation, leadership and decision making" (456)*

This doctoral degree is funded through a Studentship as part of the TRANSFORM endowment from Yorkshire Cancer Research. Within this endowment, funds have been allocated for PPI. The PPI funds provided the opportunity to provide a budget for expenses (e.g., broadband or travel costs) and fees (e.g., thank you payments) for all volunteers.

PPI within our research institute is overseen by a steering committee, which regularly reviews our strategy and action plan for public involvement. The approach to PPI followed in this doctoral study was based on our wider strategy, supported by our PPI Coordinator. Furthermore, each PPI workshop conducted throughout this doctoral degree was followed by a reflective meeting. Summary notes were formed and disseminated to the PPI members during this meeting. Moreover, surveys via Qualtrics were sent to the PPI members to promote feedback.

5.4.4.5 Communications

The UK Standards for Public Involvement states to achieve the standard of 'Communication' states researchers must:

> *"Use plain language for well-timed and relevant communications, as part of involvement plans and activities" (456)*

The recourses and content developed for the PPI workshops used lay language, and definitions and examples were provided where the complex language was used. Outlines of the workshops were sent to PPI members one week prior to our meeting, and the resources were available upon request. Following the first and second PPI workshops, members were sent a questionnaire via Qualtrics to report back on the workshops. This feedback was anonymous and used to revise the subsequent workshops.

5.4.4.6 Impact

The last of the six standards set out by the UK Standards for Public involvement is ‘Impact’. In order to achieve impact, researchers must:

> *“Seek improvement by identifying and sharing the difference that public involvement makes to research” (456)*

Within this doctoral thesis, the aims and methods of PPI has been clearly delineated, and the outputs from the first and second workshop are presented in appendix eight (see appendix 13.8. The outputs from workshop three comprise of the accepted revisions detailed in the table of change (see appendix two (13.2)). Throughout the iterative development process, the accepted revisions were acted on and demonstrated back to the PPI group and the changes not accepted were reported back with a reason. In addition to PPI being a pivotal component of this doctoral research, the impact on the PPI members was positive. During feedback and discussions, PPI members referenced their satisfaction and interest in being involved in research design and adaption. Moreover, I have learned a lot from facilitating the workshops with those living with and affected by lung cancer.

5.4.4.6.1 PPI Group Reflection

Members of the ExerciseGuide UK PPI group commented they enjoyed to PPI throughout the development of ExerciseGuide UK. Members of the group highlighted that participating in PPI itself had expanded their understanding and appreciate of how PPI can be carried out in health research.

In addition to contributing their voice and experience, they felt confident and empowered to help shape the research, ensuring it was appropriate, relevant, and meaningful. Moreover, two PPI members commented that focusing on lung cancer for ExerciseGuide UK positively influenced their perceptions and experience of lung cancer.

This collaboration between the doctoral researcher and the PPI group provided insights that advanced this research while simultaneously educating and uplifting the PPI members. Promoting an environment wherein members are given the space to share the voice of lived experience to contribute underscores the reciprocal nature of meaningful PPI, through acknowledging PPI members have expertise which the research team may not.

5.4.4.6.1.1 Doctoral Student Reflection

Patient and public involvement (PPI) was integral to the redevelopment of ExerciseGuide into ExerciseGuide UK and the developing of new content tailored for those living with and beyond lung cancer. I initially revised ExerciseGuide to align with the most recent research on healthy lifestyles and behaviour change for the intended demographic (those LWBLC). In retrospect, creating a PPI group before starting the redevelopment would have allowed for a more collaborative, participatory approach from the beginning. The lived experiences of patients and carers may have led to selecting the most important material and features to develop. By concentrating on the components consumers believed to be most valuable and useable, efficiency may have been improved. Once an initial ExerciseGuide UK prototype was ready, it was presented to the PPI group for comments. While earlier involvement would have been ideal, the PPI contributions still provided critical insights to enhance ExerciseGuide UK's acceptability, relevance and usability for those LWBLC.

As a doctoral student, seeking advice from supervisors and academics' is typical. However, seeking advice from PPI members is often less typical at this level. Throughout the first presentation of ExerciseGuide UK to the PPI group, it was challenging to hear those intended target users critiquing ExerciseGuide UK following extensive efforts to redevelop it. Integrating lived experience benefits research by generating more relevant, appropriate, and user-friendly designs. Furthermore, it provides invaluable learning for emerging researchers, such as doctoral students, on partnering with patients and involving them in the research process. In the case of ExerciseGuide UK, the feedback gained from the PPI group helped create a user-friendly and relevant website and accelerated my learning as a doctoral student. Although initially challenging to hear, including the PPI group within a user-centred design process was highly valuable.

5.4.5 Summary of PPI Evaluation

Patient and public involvement has been a core component of this doctoral degree. PPI has had a substantial impact on this research and the adaption of ExerciseGuide UK. The final standard of the UK Standards for Public Involvement is ‘Impact’. Throughout this chapter, the impact of PPI has been illustrated. However, importantly, this chapter has allowed reflection on the practice of PPI in the adaption of ExerciseGuide UK and the development of interventions. The PPI members throughout this doctoral degree brought a wealth of knowledge and experience that someone who has not lived with lung cancer would personally relate to. A collaborative decision-making process with the PPI members was taken for the final revisions to ensure the changes proposed from the Think Aloud interviews were appropriate to address the comments made.

Following the evaluation of insights gathered from the PPI, attention can move to the summary of the final prototype of ExerciseGuide UK. ExerciseGuide UK has been literately developed with and shaped by feedback and form the usability participants and the PPI group.

5.5 Summary of Final ExerciseGuide UK Prototype

Following the agreed changes with the PPI group and research team, the final prototype of ExerciseGuide UK was created. The final version consisted of 18 modules which covered PA and safety, self-monitoring, healthy lifestyle resources, and supplementary information. Behaviour change techniques and mechanisms of action were integrated into modules were possible to promote behaviour change. A mechanism of action refers to the underlying mechanisms that impact behaviour (458). See Table 16 for a list of all modules, tailoring process, and mechanisms of action.

Table 16: List of all modules and description, tailoring process, and mechanism of action for ExerciseGuide UK.

Module	Module Description	Tailoring	Mechanism of Action	Mapped to BCT[*]	Application in ExerciseGuide UK
Getting Started	Introductory module to the website. Demonstrating how to use and navigate the website.	No tailoring	• Knowledge • Self-Efficacy	• Health consequences (BCT 5.1)	ExerciseGuide UK utilised videos and reinforcing messages to build Knowledge (MoA) and enhance Self-Efficacy (MoA), applying Information about health consequences (BCT 5.1) to demonstrate app usage and benefits
Physical Activity Programme	Provide a personally tailored physical activity programme in two sections. Section one will cover week one to week three. Section two will cover week four to week eight. Additionally, introductory safety information is provided.	Tailoring was based on pre-set questions which covered prior physical activity and exercise experience, physical health limitations.	• Knowledge • Self-Efficacy • Intentions	• Goal setting: behaviour (BCT 1.1) • Problem Solving (BCT 1.2) • Goal setting outcome (BCT 1.3) • Health consequences BCT 5.1) • Instruction on how to perform the behaviour (BCT 4.1)	Personalised exercise programmes were designed to increase Knowledge, Self-Efficacy, and Intentions (MoAs) through Goal setting (BCT 1.1), Action planning (BCT 1.2), and Instruction on how to perform the behaviour (BCT 4.1)

Module	Module Description	Tailoring	Mechanism of Action	Mapped to BCT[*]	Application in ExerciseGuide UK
SMART Goals	Provide information regarding SMART goals. Linked to the Action Plan. Participants will set their own SMART goal.	Personalised introduction with messaged based on previous goal setting habits.	• Knowledge • Goals/Behavioural Regulation • Intentions • Motivation	• Goal setting: behaviour (BCT 1.1) • Problem Solving (BCT 1.2) • Goal setting outcome (BCT 1.3).	Educational content on SMART goals aimed to enhance Knowledge, Goals/Behavioural Regulation, and Motivations (MoAs) using Goal setting (BCTs 1.1, 1.3) and Problem solving (BCT 1.2)
Action Plan	Supported by the SMART goals module, the Action Plan guides participants to set a personally relevant and meaning plan to achieve their SMART Goal.	Not tailored. Participants are guided to set an Action Plan with specific questions. Ultimately setting a personalised action plan.	• Goals/Behavioural Regulation • Intentions • Motivation	• Goal setting: behaviour (BCT 1.1) • Action planning (BCT 1.4) • Self-monitoring of behaviour (BCT 2.3) • Feedback on behaviour (BCT 2.2) • Intrinsic motivation (BCT 10.3)	Interactive SMART goal setting enhanced Knowledge and Motivations (MoAs) via Goal setting (BCT 1.1) and Adding objects to the environment (BCT 12.5) for tangible action planning
Exercise Safety	Provide safety information for those LWBLC regarding being	Further in-depth guidance is provided for specific health-	• Knowledge • Self-Efficacy • Beliefs about Capabilities • Needs	• Health consequences (BCT 5.1)	Safety tips increased Knowledge and Self-Efficacy (MoAs) through Information about health

Module	Module Description	Tailoring	Mechanism of Action	Mapped to BCT♦	Application in ExerciseGuide UK
	physically active and engaging in exercise.	and cancer-related concerns.	• Perceived Susceptibility/Vulnerability	• Persuasion to boost self-efficacy (BCT 15.1) • Problem solving (BCT 1.2)	consequences (BCT 5.1) and self-efficacy (BCT 15.3) for safe exercise practices
Exercise Benefits	Provide informative content surrounding benefits of physical activity for those LWBLC.	Health issues and cancer-related side effects which may be improved via physical activity and exercise.	• Knowledge • Optimism • Self-Efficacy • Intentions • Motivation • Beliefs about Consequences	• Health consequences (BCT 5.1) • Encouraging about past success (BCT 15.2) • Intrinsic motivation (BCT 10.3) • Material reward (BCT 10.2) • Information about emotional consequences (BCT 5.6) • Information about health consequences (BCT 5.1) • Information about social and environmental	Module to discuss exercise benefits aimed to enhance Knowledge, Optimism, and Self-Efficacy (MoAs) via Information about health consequences (BCT 5.1) and Information about emotional consequences (BCT 5.6).

Module	Module Description	Tailoring	Mechanism of Action	Mapped to BCT*	Application in ExerciseGuide UK
				consequences (BCT 5.3)	
Motivation	Content surrounding motivation, barriers and enablers to physical activity, and habit formation.	Identify and assistive feedback on specific barriers to physical activity and exercise.	• Emotion • Attitude towards the Behaviour • Values • Motivation • Automaticity	• Regulation of emotions (BCT 11.2), • Stress management (BCT 11.3) • Pros and cons (BCT 9.1) • Values clarification (BCT 13.1) • Prompts and cues (BCT 7.1) • Intrinsic motivation (BCT 10.3)	Motivational strategies addressed Emotion and Attitude towards the behaviour (MoAs) through Reducing negative emotions (BCT 11.2) and Identification of self as a role model (BCT 13.1).
Tracking Module	Provides an opportunity for self-monitoring of exercise and healthy lifestyle behaviours and outcomes.	No tailoring	• General Attitudes/Beliefs • Self-regulation	• Persuasive communication (BCT 5.4) • Information about emotional consequences (BCT 5.6) • Self-monitoring of behaviour (BCT 2.3)	Weekly tracking fostered Self-Regulation (MoA) using Feedback on behaviour (BCT 2.2) and Self-monitoring of behaviour (BCT 2.3) via visual progress graphs.

Module	Module Description	Tailoring	Mechanism of Action	Mapped to BCT[*]	Application in ExerciseGuide UK
				• Feedback on behaviour (BCT 2.2)	
Other Activities	Covers information regarding what is physical activity, exercise, and physical fitness. Further information regarding non-conventional activities and exercises.	Tailored information provided around methods of getting in 'other' types of activities within their daily lives.	• Knowledge • Optimism • Self-Efficacy • Intentions	• Instruction on how to perform the behaviour (BCT 4.1) • Health consequences (BCT 5.1) • Reduce negative emotions (BCT 11.2)	Expanding exercise understanding increased Knowledge and Self-Efficacy (MoAs) with Instruction on how to perform behaviour (BCT 4.1) and Reducing negative emotions (BCT 11.2)
Health Lifestyles	Provide informative content, both generally and lung cancer specific regarding lifestyle factors which may increase health-related quality of life.	Tailored information based on treatment type and lifestyle habits (smoking, alcohol, sleep, activity minutes), and personal values	• Knowledge • Optimism • Self-Efficacy • Intentions • Motivation • Beliefs about Consequences	• Instruction on how to perform the behaviour (BCT 4.1) • Health consequences (BCT 5.1) • Information about emotional consequences (BCT 5.6)	Lifestyle advice was provided to boost Knowledge, Optimism, and Self-Efficacy (MoAs) using Information about health consequences (BCT 5.1) and Emotional consequences (BCT 5.6)
Breathlessness	Provide foundational information of what is breathlessness, causes, and exercises to help	No tailoring	• Knowledge • Self-Efficacy	• Instruction on how to perform the behaviour (BCT 4.1)	Information on breathlessness aimed to increase Knowledge and Self-Efficacy (MoAs) through Instruction on how

Module	Module Description	Tailoring	Mechanism of Action	Mapped to BCT[•]	Application in ExerciseGuide UK
	(both video and written demonstrations).			• Health consequences (BCT 5.1) • Information about emotional consequences (BCT 5.6)	to perform the behaviour (BCT 4.1) and Information about health consequences (BCT 5.1)
Mental Health	Provides an introduction to mental health and lung cancer. Additionally, this module provides multiple links to external sources which discuss lung cancer and mental health related factors.	No tailoring	• Knowledge • Signage and Support	• Social support (unspecified) (BCT 3.1) • Social support (practical) (BCT 3.2) • Prompts/cues (BCT 7.1) • Reduce negative emotions (BCT 11.2)	Mental health resources were linked to Knowledge and Support (MoAs) via Social support (unspecified) (BCT 3.1) and Prompts/cues (BCT 7.1) to encourage engagement with supportive materials

Note: LWBLC: Living with and beyond lung cancer; SMART: Specific, Measurable, Attainable, Realistic, Time-Bound.

[•]BCT; Behaviour Change Techniques taken from the The Behavior Change Technique Taxonomy (v1) of 93 Hierarchically Clustered Techniques (459)

Throughout the 18 modules, information is provided in small portions to promote short reading times and increased levels of attention. Vercruyssen (1996) has reported older adults may have difficulties maintaining attention over longer periods of time (460). Given the nature of those LWBLC being older adults, this recommendation was implemented into ExerciseGuide UK. Though, there relevant information does exist which can complement the information presented in the core 18 modules. Thus, hyperlinks were used to allow referencing to external sources. Furthermore, additional resources which were excluded from the core 18 modules but were thought to be useful and complementary were stored in the *Extra Information* section. There were 16 pages provided in the *Extra Information* page. A list of these modules can be found in appendix 13 (see appendix 13.12).

5.6 Summary of Chapter Five

This chapter provides an overview of the initial adaptation process and subsequent usability testing of the ExerciseGuide UK platform through Think Aloud interviews.

The first PPI workshop explored three main themes concerning PA, lung cancer, and digital technology: 1) PA and exercise knowledge, 2) barriers and facilitators to PA, exercise, and digital technology, and 3) website design and features. This workshop's insights provided the foundations for the early adaptation of ExerciseGuide UK. During this phase, key inequalities in eHealth for those LWBLC were identified and discussed.

Subsequently, a second PPI workshop was held to review the adaptations made to ExerciseGuide based on the initial feedback. Five key themes were explored during this workshop: 1) the PA questionnaire, 2) methods of recruitment, 3) ExerciseGuide UK walkthrough and website architecture, 4) mental health module, and 5) nutritional information. Additionally, feedback was gathered from the PPI group on four ethics documents between the two workshops (the ethics lay summary, Think Aloud tasks, participant information sheet, and participant informed consent form).

The primary aim of the subsequent Think Aloud interviews was to understand ExerciseGuide UK's usability during its iterative development. Seven participants completed the interviews via Zoom, using screen sharing. As demonstrated by the researcher, they performed a practice run to familiarise themselves with thinking aloud, followed by completing six predefined tasks and one open-choice task related to using ExerciseGuide UK. These tasks were previously agreed upon with the PPI group.

Key insights from these interviews informed the design of ExerciseGuide UK. It was rated as usable, surpassing the predefined usability threshold of 68 with a system usability score of 72. Five key themes emerged: 1) functionality, 2) understanding/clarity, 3) visual design, 4) needed information, and 5) preferences. Common usability issues identified included small images, unclear naming, and the need for easier contact with the research team.

The findings were presented back to the PPI group, int he third and final PPI workshop, for a collaborative discussion on possible iterations. The researcher suggested changes based on each comment from the group, and together, they decided which changes to implement. The benefits of using Think Aloud interviews included real-time usability analysis, engagement with real use, concurrent and retrospective thinking aloud, visual context, and collaboration with the PPI group. Overall, this method provided essential insights that directly influenced iterative improvements to the design and usability of ExerciseGuide UK.

Chapter 6 Feasibility and Acceptability of ExerciseGuide UK for those Living with and Beyond Lung Cancer: A Mixed-Methods Study

6.1 Introduction

This chapter will report the introduce the examination of the feasibility and acceptability of ExerciseGuide UK. The methods for this study are presented in Chapter 4 (section 4.5.2).

The two subsequent chapters (Chapter 7 and Chapter 8) will discuss the quantitative and qualitative findings separately. Chapter 7 will examine the feasibility data, to give insight into whether those living with and beyond lung cancer (LWBLC) were willing and able to use a digital-based platform to perform home-based tailored physical activity (PA) and complete supplementary modules. Chapter 8 will explore the acceptability data, to provide a better understanding of the thoughts, beliefs, and feelings of those who used the platform. Moreover, website engagement data was collected to explore the extent participants engaged with the website and modules. In addition, patient-reported outcomes were explored to see if it was feasible and acceptable to collect such data online and if any signal of change was observable between pre- and post-intervention timepoints. Finally, all participants were offered to participate in post-intervention interviews, to capture data pertaining to the participants' experience using ExerciseGuide UK.

Following Chapter 7 and Chapter 8, Chapter 9 will integrate the feasibility and acceptability findings, with outcomes reported throughout this thesis and the wider literature to answer the overarching research questions stated in Chapter 4 (section 4.1). Finally, Chapter 10 will summarise and conclude this body of doctoral research, providing the foundation for the next key research stages.

However, before discussing the quantitative and qualitative data, Table 17 explains what is meant my *feasibility* and *acceptability* for this study and how they are related to the thesis questions.

Table 17: The operational definition of feasibility and acceptability based on the Implementation Outcomes Framework(317) and their application within the the feasibility and acceptability study of ExerciseGuide UK.

Term	**Implementation Outcomes Framework definition**	**Operational definition applied to this doctoral degree**	**Example within Thesis**	**Question within Thesis**
Feasibility	The extent to which a new treatment or an innovation can be successfully used or carried out within a given agency or setting.	Feasibility was examined by evaluating various practical aspects of implementing ExerciseGuide within the target setting. This involved analysing metrics that reflect the operational capacity to execute the intervention as planned.	• Eligible ratio of recruitment: Analysed to determine the feasibility of recruiting participants • Retention rate: Measured to assess whether participants stayed engaged with the treatment over the study period • Recruitment rate: Evaluated the rate of enrolling participants as an indicator of feasibility	• Is the ExerciseGuide UK feasible for those LWBLC in the UK? • What barriers exist for those LWBLC to engage in an online tailored physical activity platform?
Acceptability	The perception among implementation stakeholders that a given treatment, service, practice, or innovation is agreeable,	Acceptability was evaluated by collecting quantitative and qualitative data on participants' perceptions regarding ExerciseGuide UK. This aimed to gauge the approval and satisfaction of participants with ExerciseGuide UK.	• Engagement with ExerciseGuide UK: Investigated how those LWBLC interacted with the platform, reflecting their acceptance • Perceptions of ExerciseGuide UK: Explored thoughts, beliefs, and feelings of participants about using the platform, indicating their psychological and emotional acceptance	• Is ExerciseGuide UK acceptable for those LWBLC in the UK? • What barriers exist for those LWBLC to engage in an online tailored physical activity platform?

Term	Implementation Outcomes Framework definition	Operational definition applied to this doctoral degree	Example within Thesis	Question within Thesis
	palatable, or satisfactory.		• Impact of tailored physical activity programme: Assessed the acceptability based on perceived benefits and satisfaction with the programme for LWBLC • Perceived usability of ExerciseGuide UK: Explored how user-friendly LWBLC found the platform, which reflects its practical acceptability	

Note: LWBLC, Living with and beyond lung cancer

6.2 Feasibility and Acceptability Results

The results for the feasibility and acceptability of ExerciseGuide UK is presented in the two following chapters. The chapters will independently cover the Quantitative (Chapter 7) and Qualitative (Chapter 8) data with a discussion and integration of overall findings in Chapter 9.

Chapter 7 Quantitative Results of Feasibility and Acceptability of ExerciseGuide UK

7.1 Introduction

This chapter will report the quantitative data on the feasibility and acceptability of the ExerciseGuide UK study. In addition to feasibility, Patient Reported Outcomes (PROs) are referred to as pilot effectiveness data for future research. PRO data can be found in Appendix Nineteen (13.18). The feasibility data provided insight into whether those living with and beyond lung cancer (LWBLC) were willing and able to use a digital-based platform to participate in a home-based tailored physical activity (PA) and complete supplementary modules. Quantitative acceptability data was valuable in ascertaining the thoughts, beliefs, and feelings of those who used the platform. Moreover, website analytic data was collected to explore engagement data to explore the extent to which participants engaged with the website and specific modules. In addition, PROs were explored to see if it would be feasible to do within this population using ExerciseGuide UK.

7.2 Results

7.2.1 Participant Characteristics

One hundred and thirty patients LWBLC were screened for eligibility within clinic between January 2022 and May 2022. Of those 130, 59 were eligible for participation. Of the 59 eligible participants, 18 were consented to participate to the ExerciseGuide UK study. Participant characteristics are presented in Table 18. The participant flow throughout ExerciseGuide UK is presented in Chapter 4 above (see Figure 10**Error! Reference source not found.**).

Participants had a mean age of 65y ± 14.42y, with 10 participants registering as male (55.56%) and eight registering as female (44.46%). All participants where White British. The majority (83.3%) of participants where currently receiving treatment at the point of completing baseline measures. Current treatments were recorded for both sequential and concurrent treatments, with surgery being recorded if recent. There was little variation in treatment types, with eight (44.4%) receiving immunotherapy, seven (38.9%) receiving surgery, six (33.3%), receiving radiotherapy, five receiving chemotherapy (27.8%), and five receiving targeted drug therapy (27.8%).

Table 18: Participant Characteristics

	Total (n=18)
Age	65 (±14.42)
Height (cm)	172.24 (±10.58)
Weight (kg)	86 (±23.57)
Sex	
Male	10 (55.56%)
Female	8 (44.44%)
Ethnicity	
White British	18 (100%)
Relationship Status	
Married / Common Law	12 (66.7%)
In a relationship (not living together)	1 (5.6%)
Single / Never married	1 (5.6%)
Divorced / Separated	2 (11.1%)
Widowed	2 (11.1%)
Employment	
Employed (Full Time)	3 (16.7%)
Employed (Part Time)	1 (5.6%)
Employed (Casually)	0 (0%)
Currently Unemployed	0 (0%)
Retired	14 (77.8%)
Student	0 (0%)
Homemaker	0 (0%)
Currently on Disability	0 (0%)
Cancer Stage	
Stage I	0 (0%)
Stage II	2 (11.1%)
Stage III	2 (11.1%)
Stage IV	3 (16.7%)
Do not know	11 (61.1%)
Currently Receiving Treatment	
Yes	15 (83.3%)
Current Treatments	
Chemotherapy	5 (27.8%)
Immunotherapy	8 (44.4%)
Surgery	7 (38.9%)
Targeted Drug Treatment	5 (27.8%)
Radiotherapy	6 (33.3%)
Previous Treatments	
Chemotherapy	7 (38.9%)
Immunotherapy	6 (33.3%)
Surgery	8 (44.4%)
Targeted Drug Treatment	3 (16.7%)
Radiotherapy	6 (33.3%)
Comorbidities	

	Total (n=18)
Lung Disease	15 (83.3%)
Diabetes	11 (61.1%)
High Blood Pressure	13 (72.2%)
High Blood Cholesterol	12 (66.7%)
Arthritis	15 (83.3%)
Stroke	8 (44.4%)
Other Cancers	11 (61.1%)
Angina	9 (50%)
Depression	10 (55.6%)
Lymphedema	8 (44.4%)
Poor circulation to legs or feet	11 (61.1%)
Smoking Status	
Never Smoker	4 (22.2%)
Occasional Smoker	1 (5.6%)
Ex-Smoker	13 (72.2%)
Self-Reported Overall Health Rating	
Poor	2 (11.1%)
Fair	8 (44.4%)
Good	6 (33.3%)
Very Good	2 (11.1%)

Data are presented in *n* (%) or mean (SD).

7.2.2 Intervention Feasibility

7.2.2.1 Recruitment and Eligible:consent ratio

Of the fifty-nine eligible patients approached, eighteen provided written informed consent, demonstrating a 30.5% consent rate. The Screen:Consent ratio was 3.3:1 (see Table 19).

Table 19: Screened:consent ratio of patients seen in clinic by the doctoral researcher.

Total Screened*	Screened	Recruited and consented	Screened:Consent Ratio	Consent Rate Percentage (%)
130	59	18	3.3:1	30.5

**Total patients screened only refers to patients who were screened for eligibility in their first instance.*

7.2.2.1.1 Ineligibility

Seventy-one patients were deemed ineligible for the study. The reasons for ineligibility are recorded in Table 20.

Table 20: Reasons noted for ineligibility of those seen in clinic by the doctoral researcher.

Reason Recorded	**Number of patients (%)**
Too frail and/or weak to participate in a physical activity study based on clinician judgement	29 (40.85%)
Was not able to read and/or write in English	3 (4.23%)
Heart issue impairing physical activity	1 (1.41%)
Did not have Lung Cancer	5 (7.04%)
Patient reported no access to digital technology	18 (25.35%)
Bone Mets	8 (11.27%)
Currently in a trial which precluded involvement in additional trials.	5 (7.04%)
Recent Stoke (<1y)	1 (1.41%)
Recent Heart Attack (<1y)	1 (1.41%)
Total	71 (100%)

Forty-one of the 59 eligible patients declined to participate. All patients were asked to provide a reason for non-participation. Ten patients did not wish to provide a reason for their decision to not enrol. The second and third most commonly provided reason, behind not wishing to disclose a reason, where patients felt "too weak and frail" (21.95%) and "Did not want to use digital technology" (19.51%). A summary of the reasons for decline are detailed in Table 21 below.

Table 21: Overall themes for eligible patients who declined to enrol into the ExerciseGuide UK study.

Reason Recorded	**Number of patients (%)**
Did not wish to provide a reason	10 (24.39%)
Too weak and frail	9 (21.95%)
Already active enough	3 (7.32%)
Too frail and worried about performing physical activities	1 (2.44%
Did not want to use digital technology	8 (19.51%)
Too much currently going on	5 (12.20%)
Wants to enjoy life and does not want to be involved in research study for physical activity	2 (4.88%)
Did not reply to follow up attempts	2 (4.88%)
Was not interested in the study	1 (2.44%
Total	41 (100%)

7.2.2.2 Retention

Of the 18 individuals recruited to the ExerciseGuide UK study, four did not complete the study duration, leading to a retention rate of 66.67%. This did not meet the pre-defined criteria set out in this thesis of 85%. However, it is important to note the small sample size. This highlights the impact of even a few dropouts on overall retention percentages. Specifically, three participants died during the study, and one participant withdrew due to a change in treatment and associated side effects, leading to an overwhelming situation. Despite these challenges, most participants who remained in the study expressed positive feedback regarding ExerciseGuide UK's usability and engagement. This suggests that, while the retention rate was affected by circumstances largely beyond the control of the study design, ExerciseGuide UK was generally well-received by those who could continue its use. These findings underscore the importance of considering the specific health challenges this population faces, as it has already been stated that this population has a substantial unmet symptom burden when interpreting retention rates in feasibility studies.

7.2.2.3 Quantitative Acceptability

Intervention acceptability was analysed both quantitatively and qualitatively. In this chapter, there will be a quantitative focus. The successive chapter (Chapter 8) will discuss the qualitative results.

The acceptability was explored by collecting the Systems Usability Scale (SUS) and a platform review questionnaire post study.

7.2.2.3.1 System Usability Scale Results

The Systems Usability Scale (SUS) is a widely used metric for assessing the usability of a platform, with a score of 68% generally considered the threshold for acceptable usability. ExerciseGuide UK achieved a SUS score of 72.12% (± 14.15), indicating that it met the basic criteria for usability. However, it's important to note that this evaluation was based on a relatively small sample size of 13 participants. The distribution of scores was as follows. Summarised SUS data can be found in Table 22. A breakdown of each participant's score and adjective rating can be found in appendix 16 (see appendix 13.16). Of the 13 participants, two scored ExerciseGuide UK 'Excellent', seven scored it 'Good, two scored it 'Poor', and two scored it 'Awful'.

Table 22: System Usability Scale Score post-ExerciseGuide UK.

Adjective Rating (Grade)	Score Count (%)	SUS Scoring Threshold
Excellent (A)	2 (15.38%)	>80.3
Good (B)	6 (53.58%)	68 – 80.3
Ok (C)	0 (0%)	68

Poor (D)	2 (15.38%)	51 – 68
Awful (F)	2 (15.38%)	<51

While the overall SUS score suggests ExerciseGuide UK was usable, the small sample size and the lack of assessment of participants' digital literacy or competency prior to their engagement are important limitations to consider. The Think Aloud study conducted during the design phase gathered information on digital literacy, which provided valuable insights into how participants' competencies may have affected their experience. Including such an assessment in this post-study evaluation could have helped understand whether digital literacy influenced the usability ratings, particularly given the divided nature of the feedback.

The higher usability score is encouraging, yet the mixed individual ratings highlight the need for further exploration into user characteristics and their impact on usability perceptions. This would allow for targeted improvements and a more inclusive design that meets the individual users' needs with varying levels of digital literacy.

7.2.2.3.2 Post-Study Questionnaire: Platform Review

During the final module, participants were encouraged to complete an evaluation of the platform via an integrated questionnaire. Questions were modelled off a previous iteration of ExerciseGuide (461) and the SUS to make questions more relevant and explicit to ExerciseGuide UK.

When asked to rate statements from one to five (strongly disagree to strongly agree), ExerciseGuide UK consistently received high scores for aspects which would be considered important for acceptability (date given in mean scores (± standard deviation)). For example, participants reported they found the exercise prescription relevant (4.15 ± 0.99), easy to understand (4.38 ± 0.65), useful 4.23 ± 0.73), and to be of personal benefit 4.38 ± 0.65).

Moreover, the majority of participants reported ExerciseGuide UK did not evoke negative emotions (1.54 ± 0.78) and when asked whether ExerciseGuide UK added burden to them personally, the majority strongly disagreed (1.62 ± 0.65).

Although ExerciseGuide UK received positive scores, participants were mixed if they would like to continue to use ExerciseGuide UK (3.54 ± 1.33). However, the majority did suggest ExerciseGuide UK would add value to cancer care and services (4.08 ± 0.86) and would be easily integrated into routine care for those receiving a diagnosis of lung cancer (4.23 ± 0.83).

A breakdown of all statements asked with mean score (± standard deviation, median score, and range is presented in Table 23.

Table 23: Platform review summary of ExerciseGuide UK (n=13)

Statement	**Mean Score (SD)**	**Median Score**	**Range**
The ExerciseGuide.org.uk website was credible	4.38 (± 0.65)	4	3 – 5
The ExerciseGuide.org.uk website was relevant to me personally	4.15 (± 0.99)	4	2 – 5
The ExerciseGuide.org.uk website met my expectations	3.85 (± 1.07)	4	1 – 5
The ExerciseGuide.org.uk website content was easy to understand	4.38 (± 0.65)	4	3 – 5
The ExerciseGuide.org.uk website was interesting	4.23 (± 0.73)	4	3 – 5
The ExerciseGuide.org.uk website was easy to use and navigate	4 (± 1.15)	4	1 – 5
The ExerciseGuide.org.uk website was unnecessarily complex	2.15 (± 1.14)	2	1 – 4
The ExerciseGuide.org.uk website features were well integrated	3.92 (± 0.64)	4	3 – 5
The ExerciseGuide.org.uk website was presented professionally, with appropriate content, colour, and images	4.15 (± 0.69)	4	3 – 5
The ExerciseGuide.org.uk website was of benefit to me	4.38 (± 0.65)	4	3 – 5
The ExerciseGuide.org.uk website evoked negative emotions	1.54 (± 0.78)	1	1 – 3
The modules were useful to me	4.23 (± 0.73)	4	3 – 5
The action planning tool / activity was useful to me	4.08 (± 0.64)	4	3 – 5
The resources Extra Information/Library was useful to me	3.77 (± 1.09)	4	1 – 5
The ExerciseGuide.org.uk website helped me to identify my physical activity goals	4.38 (± 0.65)	4	3 – 5
The ExerciseGuide.org.uk website has changed my attitude toward participating in physical activity throughout the cancer journey	3.77 (± 0.93)	4	2 – 5
The ExerciseGuide.org.uk website has increased my confidence to participate in physical activity	4.08 (± 0.86)	4	3 – 5
The ExerciseGuide.org.uk website added additional burden on me personally	1.62 (± 0.65)	2	1 – 3
The ExerciseGuide.org.uk website is something I would like to continue to use on a regular basis	3.54 (± 1.33)	4	1 – 5
The ExerciseGuide.org.uk website added (or would add if you are post treatment) value to my cancer care and service	4.08 (± 0.86)	4	3 – 5

Statement	Mean Score (SD)	Median Score	Range
The ExerciseGuide.org.uk website could be easily integrated into a part of routine care for individuals receiving a lung cancer diagnosis	4.23 (± 0.83)	4	2 – 5

Note: Mean values are given Mean (± Standard Deviation). Participants were asked to rate the statements on a scale of 1 – 5 (1 = Strongly Disagree - 5 = Strongly Agree).

7.2.2.4 Website Usage

Website engagement data was collected for 16 of 18 participants. The two without data likely due to participants having tracking-blocking software installed on their device or website browser. All participants were given the same level of access to all modules. All participants were given the same level of access to all modules, and the engagement data is summarised in

Table 24.

All participants viewed the *Getting Started*, *Physical Activity Safety*, and weeks one to three *Exercise Prescription* modules. However, this is not unsurprising due to the tunnelled approach of modules. Participants were unable to unlock the *Exercise Prescription* module without first completing the *Getting Started* and *Physical Activity Safety* modules. Following the unlocking of the initial *Exercise Prescription* module, the number of participants views declined. However, it is important to note, all four dropouts occurred between weeks two and three. Dropouts occurring between these time points mean not all modules would have been viewed, and thus not the full site being evaluated by all participants.

The total number of times a feedback section within a module was viewed (i.e., the content a participant sees within a module) is presented in

Table 24 to examine the number of times participants viewed/engaged with a specific module. Though, caution must be taken when interpreting this data due to its granularity. The data is illustrating if a participant enters that module at any time during a given day. However, the data does not reflect if a participant enters the module multiple times per day. Within analytics, often "Page Views" are used as the metric to illustrate the number of times a patient views a module, however, this is often inflated due to a module possibly having multiped pages. An automatic trigger for "Page Views" based on Google Analytics 4 (GA4) parameters is as followed:

"Each time the page loads or the browser history state is changed by the active site" (462)

Therefore, if a module has multiple pages, the page views will be a summary of the pages viewed within the module, not reflecting the number of times a module is viewed. The Exercise Plan for weeks one to three had the highest number of views (50), indicating strong interest in early-stage exercise planning. The *Introduction* module and *Exercise Plan* for weeks four to eight also received substantial views (30 each), suggesting these are key areas for user engagement. However, modules like *Goal Setting, Action Plan, Breathlessness,* and others had significantly fewer views, with some modules being viewed by less than 70% of participants. This trend may indicate either a lack of interest in these modules or barriers to continued engagement. The average total time spent in modules varied widely. For example, participants spent an average of 16.51 (± 21.77) minutes in the *Exercise Prescription* (weeks 1-3) module but only 1.95 (± 2.86) minutes in the Goal Setting module. This variation suggests differing levels of perceived importance or difficulty among the modules. The standard deviations for time spent in some modules highlight the large variability in how different participants engaged with the content. This may be a reflection on the diverse user needs and preferences or varying levels of prior knowledge and interest.

As highlighted above, the data on the number of times feedback sections were viewed indicates that some modules were revisited multiple times, although the exact number of unique entries per day is unclear. For example, the *Exercise Plan* for weeks 1-3 had 50 views, suggesting it was a frequently revisited resource. Given the limitations of the data collection method, which tracks page views rather than unique sessions, the actual engagement may be overestimated if participants revisited pages multiple times in one session. The dropout of four participants during the second and third weeks critically impacts the overall engagement data. These dropouts mean that not all participants evaluated ExerciseGuide UK, which could skew the feedback and engagement data.

Table 24: ExerciseGuide UK Website Engagement

Module/Questionnaire Name	**Participants Active**	**Modules Viewed**		**Average Total Time in Module (mins)**		**Total Number of Times Feedback Section Viewed**	**Module Rating**		
	N	N	%	M*	SD	N	N	Median Score	Range
Information Modules									
Getting Started	16	16	100	6.71	10.26	30	HM	HM	HM
Physical Activity Safety	16	16	100	4.95	4.74	24	HM	HM	HM
Exercise Prescription (weeks 1-3)	16	16	100	16.51	21.77	50	6	5	1
Goal Setting	16	13	81.25	1.95	2.86	17	HM	HM	HM
Action Plan	16	11	68.75	8.13	8.90	15	NR	NR	NR
Breathlessness	16	12	75	6.87	9.19	21	6	4.5	1
Physical Activity Benefits	16	11	68.75	5.25	4.91	13	5	4	2
Other Activities	16	11	68.75	7.03	5.46	13	7	4	2
Health Lifestyle	16	10	62.5	7.35	4.07	11	7	4	1
Mental Health	16	10	62.5	2.75	2.31	12	6	4	2
Motivation	16	11	68.75	6.03	6.04	17	6	4.5	4
Tracking	16	10	62.5	9.95	6.64	18	NR	NR	NR
Exercise Prescription (weeks 4-8)	16	11	68.75	5.16	6.36	30			
Questionnaire Modules									
Baseline Demographics	16	16	100	18.61	13.92	NF	HM	HM	HM

Module/Questionnaire Name	Participants Active	Modules Viewed		Average Total Time in Module (mins)		Total Number of Times Feedback Section Viewed	Module Rating		
European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire (EORTC-QLQ-30)									
Baseline	16	16	100	5.48	2.76	NF	HM	HM	HM
Post-Intervention	14	10	71.4			NF	HM	HM	HM
Hospital Anxiety Depression Scale (HADS)									
Baseline	16	16	100	3.17	2.24	NF	HM	HM	HM
Post-Intervention	14	10	71.4	2.64	1.14	NF	HM	HM	HM
Community Healthy Activities Model Program for Seniors (CHAMPS)									
Baseline	16	14	87.5	8.53	4.96	NF	HM	HM	HM
Post-Intervention*	16*	11*	68.6*	NR	NR	NF	NR	NR	NR
Post-Study Platform Review									
Platform Review	14	13	92.9	11.58	8.30	NF	HM	HM	HM

N= Number; M = Mean; SD = Standard Deviation; NR = Not Recorded; HM = Hierarchy Module. NF = No Feedback Item; *Data from Qualtrics not obtained from ExerciseGuide UK three months following completion.

Chapter 8 Qualitative Results of Feasibility and Acceptability of ExerciseGuide UK

8.1 Introduction

Chapter 8 will explore the post-study qualitative findings from the ExerciseGuide UK study for those living with and beyond lung cancer (LWBLC), which cover the three following research questions of this doctoral research:

1) Is an online tailored physical activity platform feasible for those LWBLC?
2) Is an online tailored physical activity platform acceptable for those LWBLC?
3) What barriers exist for those LWBLC to engage in an online tailored physical activity platform?

Conducting interviews to obtain qualitative data to explore the acceptability of ExerciseGuide UK from the participant's perspective was crucial, as it allowed for an in-depth understanding of their thoughts and feelings regarding their engagement. By exploring the qualitative data, it is possible to delve into the 'why' participants did or did not engage in ExerciseGuide UK, which quantitative data may not fully capture independently. Through exploring nuanced and rich insights directly from the participants who used ExerciseGuide UK, qualitative analysis provided the opportunity to identify key considerations which worked, and which may need further development. By combining qualitative data with quantitative evaluation, a more comprehensive and meaningful assessment of ExerciseGuide UK's acceptability is possible. Therefore, this chapter will focus solely on the qualitative data from the ExerciseGuide UK post-study interviews, presenting themes through Thematic Analysis using a conceptual framework, The Theoretical Framework of Acceptability (TFA) (v2) (400).

A conceptual framework is a set of interconnected thoughts, theories, or concepts which support the organising and informing the process of analysis (463). Sekhon and colleagues (2017) developed the TFA through an iterative process using both inductive and deductive approaches. Sekhon and colleagues (2017) claim theoretical constructs from behaviour change literature, such as the Theory of Planned Behaviour, were used during the iterative inductive and deductive process, which allowed for a parsimonious set of clearly defined constructs to be developed.

Sekhon and colleagues (2017) suggest the TFA that the framework enables a multi-faceted understanding of acceptability(400). The framework has been used by Paskins et al., (2020) (464), Pavlova et al., (2020) (465), Chen et al., (2023) (466), and Paynter et al., (2023) (467), in topics such as pharmacological, PA, maternity care, and surgical trials, respectively.

The TFA (v2), is comprised of seven constructs, which are as followed: 1) Affective Attitude, 2) Burden, 3) Ethicality, 4) Intervention Coherence, 5) Opportunity Cost, 6) Perceived Effectiveness, and 7) Self-efficacy (400).

However, during analysis, it became evident that participants did not discuss the compromises they made for taking part in the ExerciseGuide UK programme. In contrast, their discussions focused around the importance and value they attributed to exercise, aligning more on Ethicality. Consequently, the Opportunity Cost construct was removed. Furthermore, the barriers which were frequently discussed by participants more closely aligned with the Burden construct. Thus, by excluding Opportunity Cost from the analysis, it facilitated a deeper exploration of the findings that were directly related to the research questions.

As the thematic analysis progressed from phase two (generating initial codes), to phases three and four (searching for and reviewing themes) the importance of how users interacted with ExerciseGuide UK was apparent. This evolving understanding culminated in the recognition of varied engagement patterns among participants. To capture this varied engagement, a new construct titled Flexibility was conceptualised. This development underscores a shift towards inductive analysis, as it emerged directly from the data rather than being predetermined by theoretical constructs. However, it's important to note that the remaining constructs remained intact and aligned with the deductive aspect of the analysis process. By acknowledging and integrating both deductive and inductive methods, I was able to develop a nuanced and comprehensive understanding of feasibility and acceptability.

A modified TFA is presented in Figure 27.

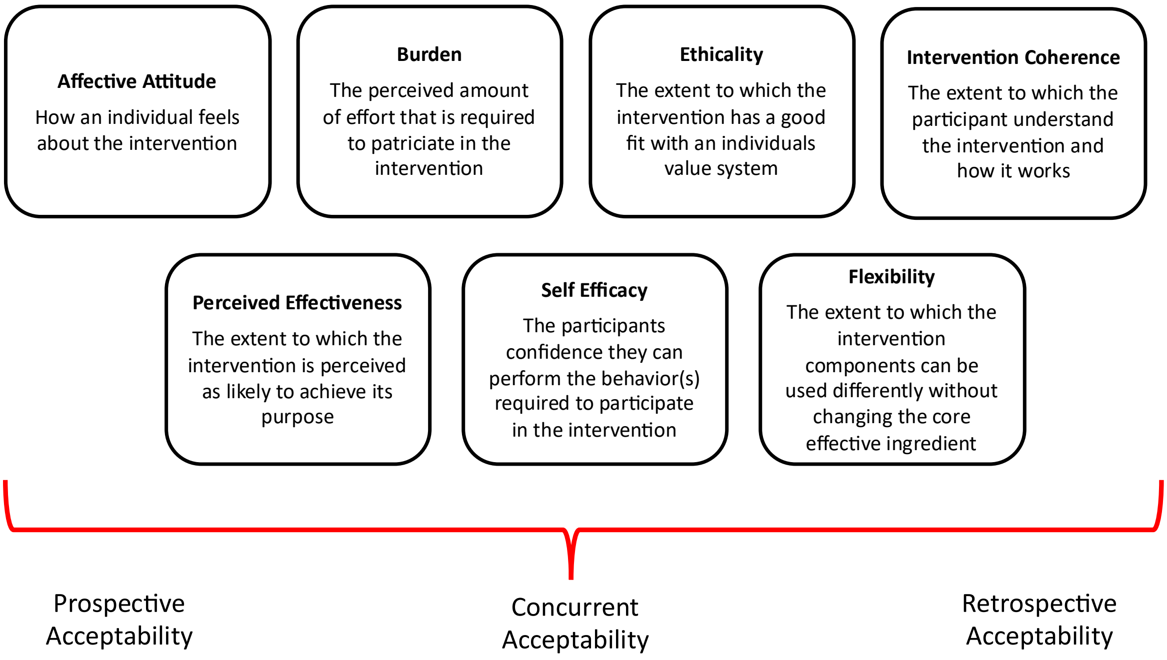


Figure 27: A modified theoretical framework of acceptability (v2) of the constructs used within the analysis of the acceptability of ExerciseGuide UK.

The data within the thematic analysis report will now be discussed, guided by the modified TFA, as presented above in Figure 27.

8.2 Thematic Analysis Report

There were seven constructs which covered seven themes and 22 subthemes within the interview findings. A list of the constructs, themes, and subthemes is presented below in

Table 25. The TFA suggests acceptability can be assessed from two temporal perspectives, prospectively and retrospectively. Prospectively perspective refers to participants *looking forward*, in essence, anticipated acceptability of an intervention. Whereas the retrospective perspective refers to participants looking back, essentially, their experience of an intervention. Both temporal perspectives can be viewed from three time points in relation to when the intervention based on the period of the intervention. The time points are 1) Prospective Acceptability (i.e., prior to commencement of intervention), 2) Concurrent Acceptability (i.e., during the active intervention), and 3) Retrospective Acceptability (i.e., following completion of the

intervention). The time points can be observed under the constructs in Figure 27. However, the interview data that has been guided by the TFA was only collected post-study, resulting in participating reflecting on their engagement. Therefore, all time points will be discussed from a retrospective lens. Nevertheless, the views from the participants, which were collected retrospectively, will be discussed based on the time point they are referring to. For example, decisions for participation (prospective acceptability), thoughts during the intervention, such as using ExerciseGuide UK) (concurrent acceptability), and thoughts looking back since completion and continuation (retrospective acceptability).

Within the qualitative analysis, thematic analysis was used to analyse the data, following Braun and Clarke's six-phase framework. To ensure the reliability and validity of the findings, a rigorous coding process was adopted, which involved multiple coders. Initially, two primary coders (JC and MP) independently reviewed a subset of the transcripts to identify preliminary themes and sub-themes. This initial coding phase was followed by a series of collaborative meetings between the two coders to discuss their findings, discuss any differences, and refine the themes and sub-themes. In the event there were any disagreements persisted, a third coder (CF) was included to provide an additional perspective and enable a consensus to be reached. This multi-coder approach not only enhanced the credibility and dependability of the thematic analysis but also ensured a robust and thorough interpretation of the data.

A combined deductive-inductive approach to thematic analysis was utilised for this data. Initially, a deductive framework was utilised, based on the constructs of the Theoretical Framework of Acceptability, to guide the analysis. This allowed a systematic exploration of predefined constructs related to the acceptability of ExerciseGuide UK. Concurrently, an inductive approach was adopted to identify themes that were identified directly from the data, which were not covered by the initial framework. This combined approach ensured a comprehensive and nuanced understanding of the data, ensuring findings were captured, both anticipated and unanticipated aspects of participants' experiences. For instance, the theme of Flexibility, which was not originally part of the TFA but was observed inductively from the data analysis, highlighting the need for adaptable intervention components.

The analysis is presented using each of the TFA constructs in sequence, which will be referred to as themes in this chapter, to build a multifaceted understanding of acceptability. Throughout this chapter, quotes from interviews will be included. An *R* or *P* will be used throughout the quotes to identify whether the researcher (*R*) or participant (*P*) was speaking.

Table 25: Themes and sub-themes identified within the ExerciseGuide UK post-study interviews.

Theme	Sub-Theme	
Affective Attitude	• Exercise Experience • Emotional Engagement	• Website Evaluation
Burden	• Physical and Cognitive Challenges • Digital Literacy and Perceived Complexity • Motivation, Resilience, and Empowerment	• User Experience and Navigation East • Access to Supplementary Resources and Tracking • Work Commitments and Time Management
Ethicality	• Alignment with Personal Values and Goals	• Desire for Improvement and Empowerment
Flexibility	• Adaptability of Exercise Materials	• Preferences for Tracking
Intervention Coherence	• Goal Setting • Exercise Efficacy and Adaptation	• Website Architecture
Perceived Effectiveness	• Website Effectiveness and User Engagement • Tailoring, Personalisation, and Check-Ins	• Physical and Psychological Benefits • Managing Breathlessness
Self-Efficacy	• Digital Confidence	• Exercise Confidence

8.2.1 Theme One: Affective Attitude

The first theme to be explored is the Affective Attitude theme. Affective Attitude can be defined as:

> *"How an individual feels about the intervention" (400)*

When exploring the acceptability of a personalised physical activity (PA) intervention delivered by a website, it is important to consider how an individual feels about their engagement, which could influence their acceptance of the intervention. For example, how a participant perceives the website and participating in an exercise intervention. Understanding whether participants have positive affective attitudes to the PA programme provided via a website (in this thesis, ExerciseGuide UK) and how they perceive that information (e.g., user-friendly, informative, or appropriate), may lead to higher chance of sustained engagement.

8.2.1.1 Sub Theme One: Exercise Experience

Many participants expressed genuine enjoyment and enthusiasm for the exercises, emphasising the positive impact on their overall satisfaction with the intervention. They described feeling motivated, energised and even uplifted after completing the exercises. Factors such as the variety of exercises offered, the accessibility of the programme, and the perceived benefits of regular PA contributed to their enjoyment. Participants found pleasure in engaging with the exercises, which fostered a sense of fulfilment and motivation. For example,

> *P: I think it's just that enjoyment of doing it [exercises], and I do feel it has. I've noticed that. It is. It is improving some muscle in my legs which I lost quite a lot of. Yeah, I just find it enjoyable to do.*
>
> *(Participant: 002, 75y)*

> *P: I actually look forward to doing my exercises… Well, to be honest, all the time I've been in this, I've enjoyed, you know, doing the exercises.*
>
> *(Participant: 013, 70y)*

Conversely, participants who encountered difficulties or discomfort during the exercises expressed lower levels of satisfaction and exhibited reluctance towards continued engagement. Some reported feeling frustrated or demotivated when they struggled with certain exercises, some even voiced they only engaged due to a family members input:

> *P: Yeah, I'm not particularly into exercise…I think if my wife wasn't still behind me, I don't think I would have done it.*

(Participant: 008, 74y)

These negative experiences may have hindered their ability to fully engage with the intervention and adhere to the prescribed exercise programme.

However, it's noteworthy that participants who found the exercises enjoyable and expressed enthusiasm demonstrated greater commitment and adherence to the programme. This highlights the impact of enjoyment on fostering positive outcomes.

Moreover, the evident connection between enjoyment of the exercises and adherence underscores the pivotal role of emotional engagement in participants' commitment to the exercise programme.

Participants' motivation to continue engaging in the intervention was closely tied to their perceived benefits and emotional well-being. Feeling good and experiencing positive outcomes served as strong motivators for sustaining their exercise prescription. Participants expressed a willingness to continue exercising as long as they felt the benefits outweighed the challenges:

> *R: Do you think this [exercise] is something that you would keep doing in the future?*
>
> *P: yes, yeah, certainly. You know, maintaining the level I'm at certainly depending whether I want to go further. The scheme [exercise plan] I have at the moment I'm very comfortable with, and I'll keep on going, you know, getting on the carpet and doing Superman. I'm quite happy to carry on doing that. As long as you*

know, I feel fit. You know. You know if it's doing good, which I think it has done good.

(Participant: 004, 84y)

Additionally, there were demonstrations of retrospective acceptability, with participants reflecting positively on their experiences and expressing intentions to continue incorporating exercise into their daily lives. This intrinsic motivation, coupled with positive experiences and intentions for continued engagement, highlights the potential for long-term behaviour change and improved health outcomes. For example,

P: It [exercise] will be definitely something I carry on doing exercise until I physically, and I mean physically, can't do.

(Participant: 012, 54y)

8.2.1.2 Sub Theme Two: Emotional Engagement

Participants' emotional engagement with the intervention was influenced by various factors, including their initial decision to participate and their awareness of the intervention.

Participants' initial decision to participate in the intervention was often driven by personal motivations and perceptions of its relevance to their personal health goals. Those who perceived the intervention as personally relevant and aligned with their needs and interests were more likely to volunteer. Factors such as the perceived impact on health outcomes and alignment with personal goals played a key role in participants' decision-making process to participate:

R: How have you found the last few weeks using the ExerciseGuide? In terms of any thoughts that really come to mind.

P: I found absolutely fine. I have no problem doing it all.

(Participant: 009, 63y)

P: It didn't take a great deal of motivation or remembering. I just thought I've got to do that, and it was just straight on with the exercises.

(Participant: 017, 64y)

Additionally, external factors such as recommendations from healthcare providers or word-of-mouth referrals also influenced participants' decision to volunteer to participant. For example:

> *P: I think because it was the chance to do something positive. And something, you know, this [cancer] is something I'm not going to recover from. I think an exercise programme like this. I felt as if I was doing something positive. And this it's good for you mentally as well, isn't it?*
>
> *R: Yes. Yeah. You experienced both of them physical and those mental benefits as well?*
>
> *P: Yeah, yeah, because without. How I would have still continued with, you know. My normal activities but. But there was something missing still, and this [ExerciseGuide UK] has filled that really for me.*

(Participant: 002, 75y)

Furthermore, participants' awareness of the intervention and external factors such as promotional efforts and recommendations from healthcare providers played a role in their emotional engagement and decision to participate. Those who were well-informed about the intervention through promotional materials or personal recommendations were more likely to express interest and participate. For example:

> *R: What was it that got you into the study? What was your motivation?*
>
> *P: Simply you [doctoral student] asking me to…you asking me because, you know, you can have leaflets and things like that. But some people wouldn't even bother reading them, would they? But yeah, it was you saying, 'would you mind getting involved' and my main concern was the computer work. But no. But that's why I got*

> *involved with it because you mentioned it today. You said for research. Would you be prepared to do it? And I said, 'OK, yeah'.*

(Participant: 005, 77y)

Additionally, participants appreciated efforts to raise awareness about the intervention and its potential benefits, highlighting the importance of effective communication strategies in promoting engagement and participation. As demonstrated:

> *P: I think it's [ExerciseGuide UK] very, very good. And I think the main thing that you and your colleagues have got to possibly get through to people is to try and get them interested… It's about making people aware that there is this you can do, you know, don't just sit on the couch all day, have a go at this.*

(Participant: 005, 77y)

> *P:…I do think it's a pity that it couldn't be available to more people, but you know, some I know wouldn't be able to do it.*

(Participant: 006, 62y)

These findings underscore the need for tailored interventions that address individuals' needs and preferences and comprehensive communication plans to ensure that individuals are aware of the intervention and its potential impact on their health. By enhancing emotional engagement through personalised approaches and effective communication strategies, interventions can maximise participation rates and ultimately improve health outcomes.

8.2.1.3 Sub Theme Three: Website Evaluation

Participants' evaluation of the ExerciseGuide UK encompassed several aspects, including content utility, design appeal, delivery medium, and integration into existing healthcare pathways.

Participants appreciated the website's content when it was informative, relevant, and easy to navigate. Those who found the content useful were more satisfied with their overall experience. Additionally, participants valued design elements such as clear layouts, engaging visuals, and user-friendly interfaces, which contributed to their positive perception of the website's appeal.

> *P: Well, me personally, I just thought. I thought it was set out well. I thought there was lots of explanatory things.*
>
> *(Participant: 014, 71y)*

> *Yes, I like them [the animations]. They were clear. They were quite clear. I like the colours of them. Yeah, I wouldn't change them at all. They were great.*
>
> *(Participant: 012, 54y)*

> *P: But yeah, I thought it [ExerciseGuide UK] was good. It's very helpful. It's a go-to place.*
>
> *(Participant: 001, 64y)*

> *I found them [the modules] interesting and beneficial.*
>
> *(Participant: 005, 77y)*

However, concerns were raised about the exclusive digital delivery of the intervention. Some participants expressed apprehension, particularly for older users or those with limited digital literacy. Participants suggested the need for supplemental physical materials or integration into existing healthcare pathways to enhance accessibility and effectiveness. Participants believed that a combination of digital and physical resources would cater to diverse user populations and improve overall accessibility.

> *P:...I think the vast majority of, of people, of older people would work just as well with a printed booklet of exercises. You know, tailored too certain. Depending on people's physical capabilities at the time.*
>
> *(Participant: 002, 75y)*

> *P: Yes, I don't think the tracker was as important. I like to write things down. I know, I like to write the exercise and tick them off when I've done them and if I need to write notes I will.*

R: How do you feel about paper tracking log? Do you think that will be any use?

P: I think it will be.

(Participant: 005, 77y)

Furthermore, participants expressed intentions to continue using ExerciseGuide UK and recommended its integration it into cancer care pathways to ensure continuity of care and support. This integration would facilitate seamless access to intervention resources and promote ongoing engagement with the intervention.

P: To be honest, I thought it [ExerciseGuide UK] was very good. I'll keep it on my phone.

(Participant: 001, 64y)

R: So, what's your thoughts about this [ExerciseGuide UK] being a part of someone's cancer journey?

P: Absolutely. Absolutely.

(Participant: 009, 63y)

Overall, participants' feedback highlights the importance of user-centred design and integration into existing healthcare systems to maximise the effectiveness and accessibility of digital health interventions.

8.2.1.4 Summary

In summary, participants' affective attitudes towards the intervention were shaped by their experiences across three sub themes. Participants who gained enjoyment and enthusiasm from the prescribed exercises expressed higher levels of satisfaction with the intervention, demonstrating a positive exercise experience. These findings suggest a potential mediating role of enjoyment in adherence, where participants who found the exercises enjoyable were more likely to adhere to the intervention over time.

Emotional engagement was noted as an aspect of participation, underscoring its importance in influencing individuals' involvement, further highlighting its importance to ensure that the approach and intervention is personally relevant to participants, thus impacting their initial motivations for participation. Moreover, participants' emotional connection with the intervention may impact their perceptions of its effectiveness. Those who experience a deeper emotional connection may be more likely to perceive the intervention as more effective in achieving its intended outcomes.

When evaluating the website, participants valued the utility of intervention content and visual appeal, with certain design elements potentially being more effective in capturing attention and enhancing engagement. However, concerns were raised about the delivery being solely digital, particularly for elderly users, suggesting a need to explore generational differences in intervention preferences.

Lastly, participants' positive affective attitudes towards the intervention have a lasting impact on their behaviour beyond the duration of ExerciseGuide UK. Those reporting higher levels of enjoyment and satisfaction voiced they were more likely to continue engaging in health-promoting behaviours.

These insights underscore the importance of designing interventions that are enjoyable, accessible, and well-suited to participants' preferences and abilities to enhance overall satisfaction and engagement.

8.2.2 Theme Two: Burden

The second theme to be discussed is Burden. Per the TFA, burden can be defined:

> *"The perceived amount of effort that is required to participate in the intervention" (400)*

Burden is an important construct when discussing the acceptability of a web-based PA prescription platform (such as ExerciseGuide UK). Referring to the perceived amount of effort, inconvenience, or difficulty associated with engaging in a behaviour, for example, PA. Through understanding the possible burden (or lack thereof) may help future developments of the ExerciseGuide UK platform to be more acceptable and feasible for those LWBLC. However, burden can take place in varying forms, such as cancer, work, digital literacy, and physical capabilities. Considering such factors in relation to burden is vital to ensure both the platform and the physical activities are user-friendly and meets the needs of the users.

8.2.2.1 Sub-theme One: Physical and Cognitive Challenges

The physical and cognitive burdens of cancer and its treatments presented clear challenges for participants, affecting their ability to engage with the exercise programme and website effectively. For example, fatigue induced by chemotherapy, diminished eyesight, and cognitive fatigue were common concurrent barriers reported by participants:

> *R:…was there any times where you didn't really want to use the website or exercise?*
>
> *P: Yes. Particularly around three days after the chemo, you know? That really knocked me out for about three days…I just got knocked out.*

(Participant: 008, 74y)

> *P: So, one of the side effects for me of the medication, you know, it's an effect of my eyesight. So, you know, reading things has became a bit of a chore… I've struggled to concentrate on some of the writing.*

(Participant: 012, 54y)

Side effects from an individual's cancer and/or associated treatments highlight the importance of developing interventions that prioritise accessibility, usability, and personalisation to ensure diverse physical and cognitive abilities. By ensuring user-centred design is central to e-Health and m-Health and providing personalised support, interventions can ensure equitable access and empower all participants to engage effectively with the tools and exercise programmes.

8.2.2.2 Sub-theme Two: Digital Literacy and Perceived Complexity

Participants' perceptions of digital complexity and their level of digital literacy influenced their engagement with the website. Older adults, in particular, expressed concerns regard their concurrent navigation of ExerciseGuide UK independently:

> *P: Working with a package like that, I think they [older adults] would find that bit daunting. Especially people my age, younger people maybe would find that easier.*

(Participant: 002, 75y)

> *P: Like a lot of older people, I don't think. Would rather work from a booklet with those exercises in. And they would find it easier and more likely to make it a routine. Because they would possibly find. Going into the exercise guide on a PC, say, may be a little bit daunting.*

(Participant: 002, 75y)

While some participants found ExerciseGuide UK intuitive and user-friendly, others perceived it as overly complex and required assistance from family members for additional support.

> *P: I can get round it better. But that can be said for most websites. You know practice makes perfect. But no. I found it usable. You know, even when you're a bit of a dinosaur like myself. I did find it usable easy enough.*

(Participant: 017, 64y)

P: We [participant and wife] found it quite easy to use it. I'm lucky to have someone close to me to ask if I need to. But I thought it was quite easy.

(Participant: 004, 84y)

Addressing these concerns requires tailoring and designing digital interventions to meet users' diverse needs and preferences, promoting inclusivity and accessibility.

8.2.2.3 Sub-theme Three: Motivation, Resilience, and Empowerment

Those LWBLC may face a wide range of symptoms and side effects which impact one's motivation to engage in a website and/or exercise. However, participants demonstrated resilience and motivation to engage in the exercise programme within the ExerciseGuide UK study:

R: So maybe that diagnosis introduced a barrier for your exercise.

P: It did. But I physically couldn't do it [exercise] because, you know, I couldn't breathe properly. So that was true. I couldn't do it [exercise]. But I can do it now!

(Participant: 006, 62y)

The impact of treatment on the ability to complete the exercise was not the sole impact. It was noted some felt exercising at home was the only option for them:

P: Because of the restrictions on me, my exercises have to be done in the house, and I feel good about doing them.

(Participant: 017, 64y)

They viewed exercise as a source of empowerment and self-determination, with participants often highlighting optimism and a sense of achievement despite facing challenges. Tangible improvements in physical and emotional well-being promoted their continued commitment to ongoing participation, highlighting the impact and power of exercise in overcoming obstacles and fostering a sense of agency, promoting concurrent acceptability.

P: I wince, and I do them [the exercises]. It's not very enjoyable throughout, but you know, the result, you know. Seeing the improvements is what I enjoy, and I have improved a bit. I think if I hadn't done the exercises, I wouldn't be where I am today.

(Participant: 004, 84y)

P:…the floor exercises, the crunches, and you know, the heel touches. When I first did them, I thought this is a big mistake. I'm going to cause myself some mischief because I can see my blood pressure going through the roof or something. But I persevered. But now I can just get on the floor and do them…I was struggling to get off the floor and using the stick. And now I can just stand up.

(Participant: 011, 76y)

8.2.2.4 Sub-theme Four: User Experience and Navigation Ease

It was evident user experience was a critical factor in how participants engaged with ExerciseGuide UK. During the interviews, participants highlighted how ExerciseGuide UK's design and architecture facilitated a positive user experience. For example, straightforward navigation, intuitive design elements, and user-friendly interfaces promoted participants' sustained use and engagement of ExerciseGuide UK and enhanced their understanding of exercise instructions, thus promoting concurrent acceptability.

P: …funny enough, I wouldn't consider myself computer illiterate, but I found this very easy to use. I found no grave problems. And you know when it's set your lesson, you filled out, and then when it told you to "do this". You did that. It was easy to use.

(Participant: 005, 77y)

P: You know, because I'm a teacher, I'm always really aware of dyslexia and things like that. So yeah, I think it was really friendly colours.

(Participant: 003, 51y)

P: Yes, I thought it was quite good because. What sort of thing you go on to, things like this, there's loads of colours and loads of things going on. I like the fact that with this there was only a couple of colours in there, you know, with the things that you really need to stand out. So, like things that underlined in the pink. So yeah, I found it very easy to use.

(Participant: 003, 51y)

Visual aids, such as diagrams and animations, were crucial in clarifying complex concepts and promoting confidence in performing prescribed exercises.

R: did you find the instructions for the exercise is easy to understand?

P: Yes, yes. And the diagrams, yes…. Like I said, I've not found any difficulty with it at all.

(Participant: 014, 71y)

These conversations with participants from the ExerciseGuide UK study underscored the importance of user-centred design principles in optimising engagement and adherence. Considering the needs of the end-users is vital in developing online platforms, such as ExerciseGuide UK.

8.2.2.5 Sub-theme Five: Access to Supplementary Resources and Tracking

Within ExerciseGuide UK, there was an area of supplementary resources called "Extra Information." The purpose was to provide further, evidence-based information to participants while keeping the core modules concise to keep them manageable. However, participants recalled a need for more understanding and awareness of supplementary resources, reducing their concurrent acceptability.

R: So, there was a bunch of extra information on the website that I don't think you accessed, was the reason for that?

P: I probably didn't see it. If I saw something, I went through and had a look at it, so I probably didn't see it.

(Participant: 005, 77y)

R: So, you mentioned you didn't look at the actual information page. So, was there any particular reason for that?

P: …I don't think it was obvious.

(Participant: 008, 74y)

However, though some participants struggled to locate additional information, a subset found value in the further information and content provided once it was found.

R: And is that something that you think you would like to do or would have done?

P: Yes, yeah, I mean, knowing it's there is, this is the thing…

(Participant: 017, 64y)

Moreover, ExerciseGuide UK users recorded a lack of understanding for the tracking module embedded within the ExerciseGuide UK, highlighting a greater need for clarification, in addition to acknowledging the method (e.g., smartwatch or paper) by which they wanted to track.

R: There was a tracking module that you didn't really use. Was there any particular reason why you didn't engage with that module?

P: I don't really remember seeing it.

(Participant: 008, 74y)

R: Was there any reason that it [Tracking module] wasn't used, or did you have another way of tracking offline?

R: Initially, it wasn't clear…

(Participant: 017, 64y)

The underutilisation of tracking module suggested a need for greater integration with participants' existing tracking practices and preferences, such as paper-based methods or fitness trackers/wearable devices. Personalised guidance and support enhance participants' engagement with these features, promoting a sense of accountability and progress monitoring.

ExerciseGuide UK had a range of questions for varying purposes. Some were presented as Patient Reported Outcomes (PRO) questionnaires (e.g., HADS), while others were used for the *IF-THEN* logic, for internal algorithms to help the site provide personalised information and feedback. Participants had varying responses to the questions which they were asked on ExerciseGuide UK. Some found the number of questions frustrating:

> *R: How were the questions?*
>
> *P: They drove me mad at times…the amount. Yeah, the amount.*
>
> *(Participant: 006, 62y)*

While others found the questions to be repetitive:

> *P:…I used to think to myself, haven't already answered this, but in a different, in a slightly different way.*
>
> *(Participant: 012, 54y)*
>
> *P:…It kinda went on about the same thing, you know, more than once.*
>
> *(Participant: 011, 76y)*

On the other hand, some reported the number of questions was satisfactory and clear to understand:

> *R: How did you feel about the number of questions we asked you?*
>
> *P: I thought they were fair, you know, fair enough. There wasn't too much, and you did you did provide a progress bar for most of them, if not all of them. Which always does help. Because, you know, you think sometimes surveys are never-ending…On the whole, the phraseology of the questions, they were good.*
>
> *(Participant: 017, 64y)*

8.2.2.6 Sub-theme Six: Work Commitments and Time Management

Work commitments emerged as a significant barrier to engagement, highlighting the competing demands and responsibilities faced by participants. Balancing work obligations with exercise programmes posed challenges, mainly when fatigue or post-work exhaustion set in.

> *P: I do really struggle with the motivation because normally, when I'm in the work situation. I work 12-hour days. So, you know, I'm absolutely exhausted.*
>
> *(Participant: 003, 51y)*

Though work-related timings can be a burden, the exercises were thought to be manageable due to them taking a short time to do and increasing retrospective acceptability going forward:

> *P: I don't know how I would fit it in when I go back to work. You know, it's not motivation. But the exercises, they don't take hours out of your day, and that's the nice bit about it. They literally take, you know, maybe 15 minutes. So, I probably would keep them up.*
>
> *(Participant: 003, 51y)*

Participants emphasised the need for flexible scheduling options and personalised support to accommodate their diverse lifestyles and energy levels. Time management strategies and coping mechanisms were essential for optimising engagement and adherence in the face of competing priorities. Providing this flexible allowance may promote retrospective acceptability.

8.2.2.7 Summary

The exploration of the Burden theme within the ExerciseGuide UK intervention sheds light on the multifaceted challenges faced by participants as they engage with the online programme. Central to understanding these challenges is the recognition that participants often deal with significant physical limitations and cognitive burdens due to their health conditions. These issues can vary daily, influenced by factors such as their cancer and its associated treatments, which in turn may impact their interaction and engagement with ExerciseGuide UK and the exercise programmes.

Participants also described the struggle with technological barriers, particularly those from socio-economically deprived backgrounds or older individuals who may not have regular access to digital devices or are less familiar with the internet. The digital divide can exacerbate feelings of frustration and lead to decreased engagement with the overall intervention. For instance, although one participant managed to engage with and navigate ExerciseGuide UK without any issues, they expressed concern that others their age might find ExerciseGuide UK challenging, potentially deterring them from fully engaging with the essential components of the intervention.

Despite these challenges, the resilience and adaptability shown by participants were evident. Some adapted the exercise prescription provided by ExerciseGuide UK to better suit their energy levels and physical capabilities on any given day. Some participants mentioned modifying the exercises, breaking them down into more manageable parts, or spreading them out throughout the day to align with their varying energy levels.

The importance of support systems was apparent throughout the interviews with participants as a key sub-theme, with participants appreciating the intervention’s flexibility that allowed for caregiver or family involvement. This support not only helped participants overcome physical and technological hurdles but also provided motivational boosts necessary for sustained engagement. ExerciseGuide UK's design, which accommodated such flexibility, was crucial in ensuring that participants did not feel overwhelmed by the requirements, thus providing a sense of control and empowerment.

In essence, the Burden theme highlights a dynamic interaction between participant needs and ExerciseGuide UK’s design. It underscores the importance of interventions to be flexible and responsive to the varying daily realities of participants' lives. By incorporating adaptable strategies and providing support mechanisms, interventions can limit or mitigate the burdens faced by participants, thereby enhancing engagement and effectiveness. This approach ensures that interventions are not only usable but also genuinely supportive and empowering, helping participants to navigate their cancer diagnosis and beyond with confidence.

8.2.3 Theme Three: Ethicality

Ethicality is the third theme to be discussed. Ethicality can be defined:

> *"The extent to which the intervention has a good fit with an individual's value system" (400)*

In essence, Ethicality encompasses the alignment between the intervention and participants' value systems, reflecting the degree to which the intervention resonates with their intrinsic beliefs and priorities. Developing an intervention which is a good fit for an individual's value system is important for both initial and sustained engagement. Understanding the degree to which a user will perceive an intervention to align with their value system could promote acceptability for future intervention iterations. For instance, the importance of being active or engaging in exercise or exploring what the users actually want. As a result of considering these factors, ExerciseGuide UK could be redeveloped to maximise the ways in which it aligns with the user's personal values and beliefs to develop an effective and acceptable web-based PA prescription intervention.

8.2.3.1 Sub-theme One: Alignment with Personal Values and Goals

Within the interviews, participants explored the alignment between exercise promotion and their personal values and goals. Participants discussed their recognition of the importance of exercise not only for physical health but also for its broader benefits on their quality of life and well-being.

> *P: I always knew how important exercise is. You know, having the attitude that is important. And this has made me, this is made me actually involve myself and exercise*
>
> *(Participant: 003, 51y)*
>
> *P: I can't imagine life without exercise.*
>
> *(Participant: 009, 63y)*

With some illustrating they were even looking for this information already online, but could not find something right for them:

> *R: So, one of the things you mentioned there was before we kind of met was that you were getting frustrated with your lack of physical fitness.*
>
> *P: Yes, I actually been on Google and things like that, you know, trying to find exercises I could do. But all they said was do walking, but all they bloody doing is walking.*

(Participant: 013, 70y)

> *P: Even before you introduce me to the study, well into the study I had searched out various websites*

(Participant: 017, 64y)

Through the interviews, participants raised their underlying motivations and aspirations that drove them to prioritise exercise despite the challenges posed by cancer and its treatment.

> *R: Did you find it easy to start activity programme?*
>
> *P: Yes, yes, it was something I actually wanted to do. Because, you know, I was realizing I was hitting brick walls, getting out and doing things and hopefully improves me, and I was right. I did want to do some exercise, but I couldn't do the exercises that I used to do. You know whether it be getting back to playing table tennis or not.*

(Participant: 004, 84y)

The discussions with participants throughout these interviews provided rich insights into the ethical dimensions of intervention engagement, highlighting the impact of aligning health-promoting activities with personal values and aspirations.

8.2.3.2 Sub-theme Two: Desire for Improvement and Empowerment

Within this subtheme, participants reported a profound desire for personal improvement and empowerment through their participation in the ExerciseGuide UK study and via exercise. They expressed that exercise represented more than just physical activity; it served as a pathway to autonomy, agency, and self-determination throughout their cancer journey. Participants commented on their aims for enhanced well-being, functional capacity, and control over their health outcomes:

> *P: I knew I was getting worse, and I knew I would definitely have gotten worse if I didn't do some exercise. I know the benefits. And I do want to get better.*

(Participant: 004, 84y)

> *P: I wanted to carry on being active. And not being overwhelmed with the diagnosis…*

(Participant: 009, 63y)

By examining the ways in which exercise empowers individuals to reclaim agency over their lives, we gain deeper insights into the ethical imperative of supporting interventions that foster autonomy and self-efficacy. Through gaining this, participants demonstrated concurrent acceptability.

8.2.3.3 Summary

Ethicality in the context of the Theoretical Framework of Acceptability (TFA) refers to the extent to which the intervention aligns with the participants' value systems and is perceived as morally appropriate and beneficial. This theme explored how well ExerciseGuide UK resonated with participants' personal beliefs and their motivations for engaging with the programme.

Participants frequently highlighted the intrinsic importance of exercise, both for its physical benefits and its alignment with their personal values and health goals. Many expressed that maintaining an active lifestyle was an important aspect of their identity, regardless of their cancer diagnosis.

Additionally, ExerciseGuide UK's design appeared to resonate well with participants who were already motivated to stay active but needed guidance on how to do so post-diagnosis. Despite their diagnosis and other health concerns, participants appreciated the support in finding safe and effective ways to continue exercising. This alignment with their desire to remain active reinforced the intervention's ethicality, as it respected and supported their personal health goals.

Moreover, ExerciseGuide UK provided a sense of empowerment and control, which was particularly valuable for participants dealing with the uncertainty of cancer and its treatment. By engaging in the exercise programme, participants felt they were actively contributing to their well-being, which helped them take control of some aspects of their cancer journey. They expressed satisfaction in knowing they could still achieve physical achievements and maintain a level of independence in their health management.

The ethicality of ExerciseGuide UK was further reinforced by its tailored approach, which tailored the content to each participant's differences and needs. The ability to tailor exercise plans ensured that the material was not only effective but also respectful of each participant's unique health status at any given time. Participants appreciated this tailored approach, which they felt demonstrated respect for their individual circumstances and a commitment to their well-being.

In summary, the ethicality theme illustrated that ExerciseGuide UK's success is deeply tied to its alignment with participants' values and health goals. The intervention was perceived as ethically appropriate and beneficial by supporting their intrinsic motivation to stay active, offering tailored and respectful care, and empowering them to take control of their health. This alignment not only enhanced the acceptability of the intervention but also reinforced its effectiveness by fostering a strong, value-based connection between the participants and the programme.

8.2.4 Theme Four: Flexibility

Flexibility was highlighted as a theme from the data, highlighting participants' need for adaptable intervention component. Flexibility can be defined:

> *"The extent to which the intervention components can be used differently without changing the core effective ingredient"*

This theme captures how participants customised their use of, and their engagement with the digital exercise programme to fit their needs and technological capabilities better. Ensuring an intervention can be modified or adapted to meet the users' needs was considered an important component of concurrent acceptability. Users may have unique preferences and needs, which, if not met, may reduce their engagement in an intervention. The flexibility theme captures the participants engagement in varying methods, such as virtual engagement, printing physical copies of module content, or writing content out by hand. By considering the flexibility of ExerciseGuide UK, aspects such as user-friendliness and accessibility can be considered, regardless of the participant's preference to use digital technology.

8.2.4.1 Sub-theme One: Adaptability of Exercise Materials

Participants demonstrated a need for adaptable exercise materials due to varying preferences for digital versus physical formats. The website provided a digital platform, yet many participants expressed a preference for physical copies of exercise routines.

> *P: You know, [I] printed out the exercises. And the less than the days in the weeks, and I just followed that. To the letter, really. Which again has now got me into the routine were. I would find it difficult not to do the exercises. Because again, it's. It's a daily routine now, isn't it?*

(Participant: 002, 75y)

> *R: What did you find the benefit of having a physical copy of this instead of having it on your laptop?*
>
> *P: You know, having it just there in the spare room, just having it right next to me.*

(Participant: 009, 63y)

While a print function was available, not all had access to printing facilities. As alternatives, some participants chose to write out the exercises manually. This may negatively impact one's concurrent acceptability and lead to a lack of sustained or long-term engagement, which may reduce ExerciseGuide UK's retrospective acceptability.

8.2.4.2 Sub-Theme Two: Preferences for Tracking

An integrated module within the website facilitated the tracking of exercises and symptoms; however, this method did not align with everyone's preferences. During the post-study interviews with participants, it became apparent that they liked to track their progress, with some finding the ExerciseGuide UK approach cumbersome due to the need to log in repeatedly. Others preferred more traditional tracking methods, such as using paper or alternative apps:

> *P: I like to keep it [tracking] on paper. Just to be fair, I like to do it on paper.*
>
> *(Participant: 013, 70y)*
>
> *R: So, you took a more paper-based approach, then?*
>
> *P: Yes, yes, absolutely. It could be my age. I like things in paper. I like to see things written down.*
>
> *(Participant: 004, 84y)*
>
> *R: Was there any particular reason why you didn't use the online tracking module?*
>
> *P: Erm, not really, no. I had it printed out and made notes, so I didn't bother going online to do it.*
>
> *(Participant: 003, 51y)*

In comparison, alternative digital technology platforms were used to track which may be more convenient or personal to the users:

> *P: And I thought you know what? Me and him talk anyway, so I'll just tell him how well I'm doing. But yeah, my phone and watch. Have been my personal way of tracking, I suppose.*
>
> *(Participant: 012, 54y)*

These distinct preferences for how exercise materials are accessed and how progress is tracked underscore the importance of incorporating flexibility in the design of digital health interventions. By allowing participants to decide how they interact with various components of the intervention and what works best for them, programmes can enhance user engagement and ensure that the intervention remains effective across different user needs. By doing so, concurrent acceptability could be increased.

8.2.4.3 Summary

The Flexibility theme reflects how participants interact with and adapt the intervention components to suit their individual preferences and circumstances. This adaptability is crucial for ensuring ExerciseGuide UK resonates with its users' diverse needs. Participants valued the ability to modify the intervention, such as opting for printed materials instead of strictly digital content, which was particularly beneficial for those less comfortable with technology or those who preferred physical interaction with the programme content.

Many participants also appreciated the flexible tracking options that allowed them to monitor their progress in a manner that felt most natural to them. Whether through apps, paper logs, or the integrated tracking system, the choice to select a tracking method that best fits their lifestyle was crucial for maintaining engagement. However, it is important to note that the participants did not readily engage with the integrated tracking system. In fact, some did not know it was there. This flexibility not only enhanced usability but also empowered participants, giving them control over how they interacted with ExerciseGuide UK and building their acceptability with the platform.

The intervention's adaptability extended to the exercises themselves. Participants noted the value of being able to adjust exercise routines to fit their physical states and health on any given day. This aspect of the intervention was especially important for maintaining consistency in physical activity, even on days when participants felt less capable. By accommodating these variations, ExerciseGuide UK promoted a sense of personalisation and responsiveness that participants found both supportive and effective.

The Flexibility theme illustrated the importance of an intervention's ability to adapt to the changing needs and preferences of its users. This flexibility is not just a feature of the design; it's a fundamental aspect that can enhance the perceived relevance and effectiveness of the programme, ensuring sustained engagement and satisfaction and contributing to both concurrent and retrospective acceptability.

8.2.5 Theme Five: Intervention Coherence

Intervention Coherence is the fifth theme to be discussed. It can be defined as:

> *"The extent to which the participant understands the intervention and how it works" (400)*

The degree to which an intervention and its purpose is clear and understandable are important to the acceptability of an intervention, and in particular, a website. The primary themes of Intervention Coherence refer to the purpose of guiding participants via batch releasing information (a tunnelled architecture), components of behaviour change (e.g., goal setting), exercise benefits, and exercise prescription. Exploring those themes can allow exploration of participants acceptability, drawing on the clarity of instructions and guidance and what elements were useful or not. Gaining this insight into how coherent ExerciseGuide UK was, will provide an understanding whether the content and purpose of ExerciseGuide UK was clear, logical, and understandable by participants.

8.2.5.1 Sub-theme One: Goal Setting

ExerciseGuide UK had a dedicated module to help participants create a SMART goal (SMART being a mnemonic acronym: **S**pecific, **M**easurable, **A**chievable, **R**elevant, and **T**ime-Bound). Participants highly valued the goal-setting module on ExerciseGuide UK, which they highlighted empowered them to set personalised SMART goals. This feature was important for fostering a sense of autonomy and engagement. Participants explicitly noted the benefits of setting their own goals rather than having them imposed:

> *P: But I think if you don't have a goal, I mean, you want something to aim at. I want something to aim at so I can judge where I am. And if you don't have a goal, you will just tail it off...*

(Participant: 004, 84y)

P: But like I said at the beginning, I have found this training, you know, this exercise different from anything I've done before because one of the main things is you encouraged us to set our own targets. It made me feel more confident. Because I felt like I exceeded my own targets, and it makes you realise that you don't have to do a lot of exercise. You know, to achieve a good workout.

(Participant: 012, 54y)

This autonomy in goal setting not only encouraged continuous engagement but also reinforced participants' confidence, highlighting the intervention's adaptability to individual needs and preferences.

This sub-theme explores goal setting but extends to how the intervention facilitates the formation and maintenance of health-promoting habits. ExerciseGuide UK's design was key in supporting participants to develop routines that they could integrate into their daily lives, thereby turning sporadic actions into consistent behaviours:

P: I just followed that [exercise plan]. To the letter, really. Which again has now got me into the routine were. I would find it difficult not to do the exercises. Because again, it's. It's a daily routine now, isn't it?

(Participant: 002, 75y)

P: Once you've got it [exercise plan] into your head, you just go through them. Almost. You know, without thinking about it. And it becomes. More of a habit if you like. And I didn't mind that because it helped me to do it.

(Participant: 011, 76y)

8.2.5.2 Sub-Theme Two: Exercise Efficacy and Adaptation

This sub-theme addresses a few intersecting perceptions and experiences regarding the physical and psychological benefits of the tailored exercise programmes provided by ExerciseGuide UK. Participants often highlighted the tangible improvements in their health, which reinforced their belief in the efficacy of the exercise programmes.

Participants frequently commented on how the exercises helped maintain or even improve their physical health during their cancer journey. This was especially important given the context of their ongoing medical treatments, which could be physically and emotionally impactful:

> *P: I really did come to realise that every little does help. Every little is not little. Every little is something. And I've really came to realise that.*
>
> *R: And when you said every little, what is it? What is it you referring to?*
>
> *P: Exercise or just doing things in general.*

(Participant: 017, 64y)

> *P: …also, I've got cancer, you know, can I exercise? You're asking yourself that question when you're starting. Should I be exercising? Should I be rocking in a corner somewhere? So, you think to yourself, why bother? Why bother? What's it going to do? I'm dying. What's it going to benefit me? It's not just about the physical stuff. It's your brain, isn't it? It's those little things that we talked about them achievements, that sense of belonging. Putting yourself little targets in and achieving them…*

(Participant: 012, 54y)

These quotes from conversations with participants illustrate the common feeling among participants that exercise contributed positively to their overall well-being.

Furthermore, the nature of personalisation and tailoring of the exercise prescriptions meant that participants could see gradual improvements, which were important for maintaining their motivation and commitment. As exercises were adapted to fit their individual health statuses and capabilities, participants were able to progress at a pace that felt achievable and rewarding:

> *R: So how did you find the exercises? You know, the progression, the information, how do you find all that?*

P: Yeah, definitely good. Yeah, you know, it went up. They went up as the weeks went along, didn't it? You know, the amount of reps of the actual exercises went up, so I thought that was good.

(Participant: 003, 51y)

P: You know, I'm on week nine now. I'm hoping in a couple of weeks' time, instead of doing 12 repetitions, I'm hoping I can take up to 15. In that kind of things, and that's in the future, but I'm quite happy the way I am now. Things are going nicely for me. I'm doing the exercises fine now…

(Participant: 013, 70y)

Incorporating these perspectives not only highlights the physical benefits but also emphasises the psychological impact that participants experience through regular, personalised physical activity. The adaptability of the exercise prescriptions is key to participants' sustained engagement and concurrent acceptability. It ensures that participants continue to find the exercises relevant and beneficial to their evolving health and fitness needs.

8.2.5.3 Sub-Theme Three: Website Architecture

Adopting a tunnelled website architecture (e.g., participants are guided through short packages of information) vs a free choice architecture (e.g., all content releases at once) provided a useful strategy to hold participants back from going through all modules, all at once at the start of the website, which some suggested they would have done:

P: I think I would have done the lot [the modules] and gone to the end. And not done the build-up. I would have just wanted to achieve, maybe. And I like the fact that just held me back a little bit at work, personally for me.

(Participant: 012, 54y)

P: Yeah, I think it's better releasing them [modules] over the course of the weeks because, you know, if you do more, like. If they were all there with the start, I would have done all them at the start. And then

I probably would have forgot the stuff. So, you know, especially with chemo brain, it's nice that staggered.

(Participant: 003, 51y)

Moreover, offering participants that level of freedom to navigate through all modules upfront would lead to an entire dashboard from the start of the intervention. Having a dashboard with a full array of modules was thought to be daunting and overwhelming by the participants, especially with the amount of information they are provided during the early phase of their diagnosis:

R: Do you think that staggered approach was useful?

P: I do I do because…you can be swamped by it, you know. I'm not really a reader…If you were given access to everything. It could put a lot of people off. So, the way it's done. It's in small chunks, it guides you through.

(Participant: 001, 64y)

R: What your thoughts on that sort of staggered release versus

P: I think. Leave it like that, because if you give them something all at once, they get quite overwhelmed. It's a lot to digest. You know they've got enough going on as it is.

(Participant: 009, 63y)

It appeared the tunnelled architecture increased the concurrent acceptability of participants using ExerciseGuide UK.

8.2.5.4 Summary

Intervention Coherence concerns participants' understanding of the intervention, its components, and the logic behind its structure, reflecting how well it aligns with their expectations and perceived needs. This theme is important as it determines participants' initial and ongoing engagement with the intervention, influencing their overall acceptance and utilisation.

Participants often discussed the clarity and logical flow of the intervention, highlighting how well the components were integrated to form a cohesive programme. The structured progression of the modules, which gradually introduced new concepts and continuously modified exercise programmes, was particularly appreciated. This approach helped participants build their understanding and skills incrementally, which many found to be an effective method for approaching complex health behaviours without feeling overwhelmed.

The objectives of ExerciseGuide UK aligned with participants' personal health goals, which also played a crucial role in its coherence. Participants valued how the intervention aims resonated with their desires to improve their health, enhance physical functionality, and improve psychological strength. The clear delivery of these objectives at the outset of the study helped establish a sense of purpose and direction, which participants raised in the interviews as important for their sustained engagement.

Moreover, the use of clear, concise information throughout the intervention was noted as a key factor in maintaining coherence. Participants voiced that they appreciated the straightforward and understandable presentation of content, which facilitated easy comprehension and application of the information. This clarity in communication ensured that participants could effectively connect the activities and their intended outcomes within ExerciseGuide UK, reinforcing the programme's logic and relevance.

Feedback mechanisms and support provided through ExerciseGuide UK further reinforced its coherence. Regular interactions with the researcher (JC) and tailored feedback on progress made the programme's structure and purposes clearer, helping participants see the direct benefits of their involvement.

In summary, the Intervention Coherence theme encapsulates the participants' perceptions of the intervention's logical structure and its alignment with their health needs. It underscores the importance of clear objectives, logical progression, and effective communication in designing interventions that participants can easily understand, trust, and engage with fully. The intervention's coherence not only supports initial uptake but also fosters ongoing commitment, essential for achieving long-term health outcomes.

8.2.6 Theme Six: Perceived Effectiveness

Perceived Effectiveness can be defined:

> *"The extent to which the intervention is perceived as likely to achieve its purpose" (400)*

In order to determine if ExerciseGuide UK was acceptable, it is important to examine whether participants felt the site was able to achieve its purpose. Although ExerciseGuide UK's purpose was to provide those with a personalised PA programme with a focus on changing healthy lifestyle behaviour (e.g., PA and reducing sedentary time), the perceived purpose (and whether that was achieved) could be personal to and vary per participant. For example, if a participant solely wants to log into ExerciseGuide UK and look exclusively at the personalised PA programme, then the purpose has been fulfilled. Whereas, if a participant wishes to have a lot more information pertaining to healthy lifestyles and their cancer diagnosis, this difference in the participant's want from the site may lead to a difference in purpose being achieved. The main sub-themes within perceived effectiveness, which are discussed below, consist of website effectiveness and user engagement, tailoring, personalisation, check-ins, physical and psychological benefits, and managing breathlessness. Understanding the perceived effectiveness of ExerciseGuide UK and understanding how participants engaged with the site provided the opportunity to explore its acceptability. It is important to ensure the site meets the needs and achieved the desired purpose for the participant. Information and experiences gained add to the current understanding of the site's acceptability but provide scope for future iterations.

8.2.6.1 Sub-Theme One: Website Effectiveness and User Engagement

Participants noted that the website effectively facilitated habit formation by encouraging routines that integrate physical activity into daily life, such as taking stairs or doing exercises during routine home activities. These habits were supported by the website's structured approach to goal setting, which participants found motivating and essential for maintaining engagement.

P: But I think if you don't have a goal, I mean, you want something to aim at. I want something to aim at so I can judge where I am. And if you don't have a goal, you will just tail it off. I don't like giving up. I don't like failure. You know, if you don't have a goal, you will just think, why bother? You know you can go down a slippery slope if you don't have a goal.

(Participant: 004, 84y)

Participants further reflected on how physical activity and healthy activities have become part of their every day, building habitual patterns:

P: Whereas now. I would find it difficult not to do it if that would make sense…It [exercising] becomes very much part of your day. And your daily routine.

(Participant: 002, 75y)

P: I mean, today, for example, I was making a pie today, you know, I was in the kitchen, and in the kitchen is my two bottles of squash. And I use them for my arm exercises instead of the tins of beans used two bottles of squash. And while I was waiting, you know, doing little bits with the pie. I just noticed them, and I just. I think it just comes natural, I just grab hold of them and start doing, you know, a few bicep curls and this, that and the other.

(Participant: 013, 70y)

However, not all participants shared an experience of a change to their views or attitudes:

R: Was there any impact on views regarding healthy lifestyle choices or diet?

P: No, not really. I don't really do a healthy lifestyle.

(Participant: 008, 74y)

The website's design generally supported behaviour change through clear presentation and useful modules:

P: ...other places you could go for advice I didn't always go to. Those places that was suggested, but [I] did go to some. And I did find some of them useful, some in particular, yeah.

(Participant: 017, 64y)

R: In terms of the exercise, was the information clear enough?

P: Oh yes, that was very clear. Yes. I mean, to be honest, even while doing the exercises, I actually had the web page open. And went back to it to make sure I was doing it right, you know, that sort of thing. You know, like the arm stretch, just to see if I was doing it right. And yes, I saw was doing it right and there we go, question answered.

(Participant: 013, 70y)

R: Breathing exercises on the exercises as well. What are your thoughts on the instructions?

P: Oh, straightforward. straight forward. Yeah.

(Participant: 017, 64)

However, there were comments on the timing of releasing certain information, such as the breathlessness module. Participants felt that earlier access to this module could have been more beneficial, suggesting a need for optimisation in the sequence of content delivery.

P: With people like me. Like the breathing, you know. Because with lung cancer, it's gonna affect your breathing. So that could come up fairly early and signposted to it little bit more.

(Participant: 001, 64y)

When it came to the participants awareness and attitudes of healthy behaviours, it was highlighted through the interviews that participants felt ExerciseGuide UK had an impact on their attitude to being active and the impact over time small changes can make to quality of life:

R: Do you think there's been any impact towards your attitude towards exercise?

P: I think when I started on week four and week five. I actually realised how much, how much this is starting to do for me.

(Participant: 011, 76y)

R: And can you think of anything that you've learned off from the study or the website, any of the modules or any the exercises in general that have helped you build that confidence?

P: …I remember comparing it. I remember comparing it to Tesco's, that every little helps. That's basically summed it up. I really did come to realise that every little does help. Every little is not little. Every little is something. And I've really came to realise that.

R: And when you said every little, what is it? What is it you referring to?

P: Exercise or just doing things in general.

(Participant: 017, 64y)

8.2.6.2 Sub-Theme Two: Tailoring, Personalisation, and Check-Ins

The tailored exercise plans provided by ExerciseGuide UK were well received by participants, who appreciated that the exercises were adjusted to their personal health status and functional abilities. This personalisation not only made the exercises more appropriate but also enhanced participants' trust in the ExerciseGuide UK's safety and effectiveness.

R: Did the website tailor the exercise is enough to you, do you think?

P: Yes, yeah, yeah.

(Participant: 014, 71y)

P: I liked the way that when you put your details in it, it gave you exercises, right, that were applicable to you, because the exercises *you gave for my core stability and my hips. I've now incorporated that. And I will carry on having that in my workouts.*

(Participant: 001, 64y)

Regular interaction with an exercise professional (in this case the doctoral researcher, JC), either through check-ins or feedback mechanisms (e.g., emails or internal logging), further reinforced the tailoring process, making participants feel supported and understood:

R: What are your thoughts on the websites, tailoring ability and its ability to personalise it to your needs?

P: Yes, yes, I think it was very good. And I was amazed at the speed it did it with. You know. When we met as well when we spoke, you were very quick to change things which was great.

(Participant: 005, 77y)

P:…what the assessment does and what the, what the outcome of that assessment is, is basically what what the PT [personal trainer] first did for me when I walked into a gym. And that was huge. And I told him that all the problems I had. And they did draw me a plan up.

(Participant: 001, 64y)

As highlighted above, for some, the effectiveness of tailoring was sometimes perceived as dependent on professional oversight, with participants expressing a preference for more personalised contact to ensure the exercises were perfectly aligned with their needs.

R: I know we did talk about the website did tailor the exercises to you, but I [researcher] did do some extra tailoring.

P: Which is really helpful as you know what you're talking about.

(Participant: 013, 70y)

You know, when I first saw it. And I saw all the animations. You know, I thought that's not, that is really what I wanted is it's doing a whole body. You know my legs, my arms. I think I took a liking to it straight away, if you know what I mean. When I did the very first one, I thought oh, this isn't too bad. Well, I didn't say that. I actually thought this is good. I started off with some positive thinking. This will do me good as well. That was my first thoughts. When I very first did them, I was really pleased that someone came up with something tailored to me.

(Participant: 013, 70y)

In addition to tailoring and personalisation, participants mentioned that regular interactions with the exercise professional (JC) through scheduled check-ins enhanced the perceived effectiveness of the intervention. These check-ins served not only as motivational tools but also as accountability mechanisms.

Throughout the intervention, participants had two primary check-ins, which they felt was appropriate:

P: …I think that was about right [number of check-ins]. I don't want to see you every week. But yeah, I think it's about right.

(Participant: 004, 84y)

P: I think it [number of check-ins], it's probably, it’s been enough for me.

(Participant: 011, 76y)

Additionally, participants valued the personal connection with the exercise professional, stating that these interactions increased their commitment to the programme:

R: Would you have been less inclined [to do the exercises] if we didn't talk on the phone?

P: Only slightly [researchers name], only slightly, to be honest. But I would say talking with you it's motivated me a bit.

(Participant: 013, 70y)

R: Did meeting with me twice have any impact on your desire or willingness, or motivation to do exercise?

P: I think I can easily say yes. It had an impact on my motivation.

(Participant: 017, 64y)

These comments illustrate how these check-ins provided both motivational support and a sense of obligation that encouraged adherence, promoting the participant's concurrent acceptability of ExerciseGuide UK.

8.2.6.3 Sub-Theme Three: Physical and Psychological Benefits

Participants reported improvements in their overall confidence through their engagement with ExerciseGuide UK.

P: It [ExerciseGuide UK] boosted my confidence to no end, yeah.

(Participant: 013, 70y)

Moreover, participants discussed improvements in physical strength and ability to perform activities of daily living (ADLs), which they attributed to their consistent engagement with the prescribed exercises through ExerciseGuide UK:

P: It was quite difficult to even raise my arms a little bit at the beginning. But now I'm doing that with weight. So definitely improvement in strength there. But not only that, the leg ones are really helped as well.

(Participant: 003, 51y)

P: I've notice that these activities [activities of daily living] are a bit easier, so, you know, I've had trouble lifting things down from shelves before. And you know. Carrying things like water, but yeah, I've definitely, these are better. So now I just do these things, not even thinking about it, really.

(Participant: 003, 51y)

P: …there is a benefit, and it's the benefit you don't realise until the benefits there. For an example, bending. Bending to put your socks on. That used to be a bit of a problem for me. But now, after doing exercise, that isn't a problem.

(Participant: 005, 77y)

Additionally, psychological benefits such as increased confidence, satisfaction from exercise, and improved well-being were frequently mentioned, highlighting the dual benefits of exercise programme.

P: You know, I've just climbed them stairs. I didn't have to take a pause for breath. Mentally, that does you good.

(Participant: 004, 84y)

P: It's not just about the physical stuff. It's your brain, isn't it? It's those little things that we talked about them achievements, that sense of belonging. Putting yourself little targets in and achieving them.

(Participant: 012, 54y)

P: I think I always feel better mentally once I've exercised. You know, it does give you those endorphins, doesn't it?

(Participant: 003, 51y)

These outcomes fostered a positive attitude towards exercise and motivated continued participation, thus promoting concurrent and retrospective acceptability.

8.2.6.4 Sub-Theme Four: Managing Breathlessness

Breathlessness was a key concern for many participants, affecting their ability to engage in physical activity in this intervention.

R: So, managing your breathing better has allowed you to do more activity.

P: Yes, yeah, yeah.

(Participant: 014, 71y)

R: Did you have any barriers? To being active, to being physically active.

P: Mainly the breathing.

R: And has there been any changes with your breathing?

P: Yes, definitely. Definitely. Even with the walking about and things, you know, that's definitely helped me [breathing exercises].

(Participant: 014, 71y)

The intervention's resources and techniques for managing breathlessness not only improved participants' physical capability to exercise but also boosted their confidence in being active:

P: One of the biggest things I have learned from it now, and it's part of me now, is that I'm not afraid of being breathless. Right. I know if I do something, or if I've overdone it or something, and I'm really breathless, I sit down, and I do my breathing exercises through my diaphragm. And I'm relaxed. I know, I'm not gonna die. It's not gonna do anything. It's just going to go away in a couple minutes, and in a couple minutes I am back to normal. And that is the biggest, the biggest thing it taught me. I am not frightened of it.

(Participant: 013, 70y)

This empowerment was crucial in mitigating the psychological stress associated with breathlessness and enhancing overall engagement with the intervention.

8.2.6.5 Summary

The Perceived Effectiveness theme assesses how participants view the intervention's capability to meet its intended health outcomes. This perception is influenced by the tangible benefits participants experience throughout their engagement with ExerciseGuide UK. Participants frequently referenced improvements in both physical and psychological health as evidence of the intervention's effectiveness.

Physical benefits such as increased strength, greater flexibility, and improved endurance were commonly reported. These improvements often translated into better overall functionality, allowing participants to engage more fully in daily activities with less discomfort or fatigue. Psychological benefits were equally highlighted, with many participants noting enhanced well-being, reduced stress levels, and increased mental clarity.

The intervention's structured approach, which included tailored exercises, educational content, and regular support check-ins, was often credited for these improvements. Participants appreciated the comprehensive nature of ExerciseGuide UK, which not only addressed their physical health needs but also supported their psychological and emotional health. This holistic approach was crucial in reinforcing the intervention's effectiveness, as it aligned well with participants' overall health goals and expectations.

In essence, the Perceived Effectiveness theme reflects participants' acknowledgement of the intervention's impact on their health and well-being. The positive outcomes reported by participants underscore the importance of a well-rounded, responsive intervention design that addresses the multifaceted aspects of health improvement.

8.2.7 Theme Seven: Self-Efficacy

The final of the themes is Self-Efficacy. Self-efficacy is defined by the TFA as:

> *"The participants confidence that they can perform the behaviour(s) required to participate in the intervention" (400)*

For an intervention to be acceptable, users must feel confident in their ability to engage in it and the behaviours required to engage. If a user is not able to successfully carry out the required behaviours for engagement, such as using a website for PA prescription, then it may not elicit the desired or intended outcomes and, overall, not be acceptable.

Two primary behaviours are required to be involved in the ExerciseGuide UK study: a degree of engagement with digital technology and the performing PA. Both of these elements comprise two sub-themes within this theme and will be discussed in turn below.

8.2.7.1 Sub-Theme One: Digital Confidence

Participants, especially older ones from socioeconomically deprived areas, display varying levels of digital confidence. This variation often stems from limited prior exposure and experience to digital technology rather than geographic location per se. These participants sometimes felt overwhelmed by the rapid evolution of digital tools, which can be daunting for those not regularly engaged with modern technology. For example, one participant described themselves as a 'technophobe' and preferred to manually write down information as a way to interact with the intervention content more comfortably:

> *P: I'm a technophobe. I'm a technophobe. So, I wrote it down [exercise plan].*

(Participant: 013, 70y)

This behaviour underscores the importance of designing digital interventions that are accessible and user-friendly for all users, incorporating alternative methods of engagement to accommodate different levels of digital literacy and comfort. These methods are important for sustained use, which may increase the participants retrospective acceptability of ExerciseGuide UK.

8.2.7.2 Sub-Theme Two: Exercise Confidence

Individual health concerns such as breathlessness (also known as dyspnoea) and comorbidities may strongly influence an individual's confidence to engage in physical activities. Participants often hesitated to exercise due to fear of exacerbating symptoms like dyspnoea. However, personalised support and specific breathing techniques provided as part of the intervention alleviated these fears, enhancing participants' confidence to engage in physical activities. For instance, learning and applying these techniques allowed one participant to comfortably increase their activity levels, reflecting the positive impact of tailored health interventions on self-efficacy:

> *P: I'll be honest with you, because of the breathlessness. I, I was shying away from the cardio element because I wasn't comfortable. But now I found that I can get to a point where I can raise my heart rate for a prolonged period of time using the breathing.*

(Participant: 001, 64y)

Additionally, the intervention's thoughtful design to accommodate various health conditions reassured participants that they could safely engage in exercise, which was especially valued by those dealing with multiple health issues.

> *P: I am a little bit afraid that fact I've got osteoporosis as well, I won't say it has muddied the waters, as it hasn't, But it's a factor. You know, something you have to factor in yourself. On the results in that. Yes, it [ExerciseGuide UK] was specifically designed for lung cancer, and I realised that, but it's helped me overall, it has helped me overall.*

(Participant: 017, 64y)

This tailored approach not only alleviated initial fears but also reinforced their capacity to undertake physical activity despite their health challenges

8.2.7.3 Sub-Theme Three: Satisfaction from Exercise

Successfully completing exercise programmes provided participants with tangible evidence of their capabilities, which was particularly empowering following a cancer diagnosis and treatment, a time when many face a decline in self-belief. The act of completing physical exercises not only boosted their physical strength but also enhanced their mental resilience and satisfaction. Participants expressed a renewed sense of accomplishment and pride in their ability to maintain physical activity, which, in turn, further reinforced their overall self-efficacy:

> *P: I think satisfaction, yes, you know, knowing that you can still do these things [exercise] and knowing that help in your body.*

(Participant: 003, 51y)

8.2.7.4 Summary

Self-efficacy within the intervention context explored participants' confidence in their ability to engage with and benefit from ExerciseGuide UK. This theme is key as it directly influences participants' motivation to initiate and persist in health-promoting behaviours. Self-efficacy was noted not only in relation to physical activities but also in interaction with digital tools and navigating ExerciseGuide UK.

Participants expressed that their confidence increased as they became more familiar with the structure and content of ExerciseGuide UK. The tailored exercise programmes, which were tailored to match individual health conditions and capabilities, enhanced participants' self-efficacy. Knowing that the exercises were designed to accommodate their specific needs helped participants feel more capable and secure in their decision to engage.

Moreover, the clear instructions and supportive feedback mechanisms on ExerciseGuide UK contributed to a growing sense of competence among participants. Regular goal-setting and the ability to track progress reinforced this feeling, as participants could see tangible evidence of their achievements. However, it was noted that participants did not track using the integrated tracking system. This visibility of progress was important for maintaining motivation and belief in their ability to improve their health.

Overall, the self-efficacy theme highlights the crucial role of tailored support and clear, actionable feedback in fostering participants' confidence and engagement. By continuously addressing and supporting participants' confidence levels, the intervention not only aids in immediate behaviour change but also empowers participants to maintain these changes long-term.

8.3 Qualitative Learning

The qualitative interviews of this study aimed to explore the acceptability of the ExerciseGuide UK site using thematic analysis. The key learnings from these interviews provide valuable insights into the factors influencing acceptability at different stages of the intervention. The TFA, consisting of seven constructs, served as a guiding framework. Of the seven original constructs, Opportunity Cost was excluded, while a new construct called Flexibility was identified and incorporated into the analysis framework (see Figure 27). In line with the TFA, participants' perspectives on acceptability were explored across three-time points: Prospective Acceptability, Concurrent Acceptability, and Retrospective Acceptability.

Data pertaining to prospective acceptability highlighted that initial reluctance towards exercise shifted as participants discovered enjoyment in the activity. Actions such as face-to-face communication, recruitment from staff, and the opportunity to engage in something positive influenced participants' decisions to participate. One possible method to improve prospective acceptability of ExerciseGuide UK could be to increase the promotion and dissemination of the programme, ensuring that potential participants are aware of the benefits of PA and the programme itself. However, the ExerciseGuide UK study was carried out during the COVID-19 pandemic. The unprecedented impact on the NHS, the country, and the world, made it difficult to effectively disseminate and work within clinical settings as a non-clinical doctoral student.

Regarding concurrent acceptability, participants reported that starting the exercise programme was not too challenging; instead, it was perceived as reasonably straightforward. Nevertheless, challenges were encountered in locating the *Extra Information* section of the website. Not being able to identify the *Extra Information* section of the site would have negatively impacted concurrent acceptability, as participants could not easily find information that could have been of value to them. Participants' engagement may have been negatively impacted due to the requirement to log on to a website to track exercise and symptoms. Conversely, self-directed SMART goals received positive feedback regarding increasing concurrent acceptability by empowering participants to set personalised objectives.

Furthermore, participants expressed concurrent and retrospective acceptability of the programme's ability to tailor exercises to their needs and support long-term adoption. Retrospectively, participants expressed their intention to continue using ExerciseGuide UK, if available, and sustain their engagement in PA, with some suggesting they would keep active until physical limitations prevent them from doing so.

Chapter 9 Integration and Discussion

The overarching aim of this thesis is to investigate the feasibility and acceptability of ExerciseGuide UK. ExerciseGuide UK aims to provide tailored physical activity (PA) programmes to those living with and beyond lung cancer (LWBLC).

This chapter will provide an integration and synthesis of the collective quantitative and qualitative data from throughout this doctoral thesis to address the three questions put forward in Chapter 1 of this thesis, which are:

1. Is an online tailored physical activity platform feasible for those LWBLC?
2. Is an online tailored physical activity platform acceptable for those LWBLC?
3. What barriers exist for those LWBLC to engage in an online tailored physical activity platform?

To integrate and discuss the data throughout the thesis, the Pillar Integration Process (PIP), by Johnson et al., (2017) (380), will be adopted. The PIP is a technique for integrating quantitative and qualitative data in mixed methods research. It was chosen due to the transparent and rigorous methods which are underpinned by the same philosophical, methodological approaches described earlier in the thesis (pragmatism) with triangulation (see Chapter 3 (section 3.1.2.1))**.** The PIP consists of four key phases: 1) Listing, 2) Matching, 3) Checking, and 4) Pillar Building. The flow of the PIP is detailed in Figure 28.

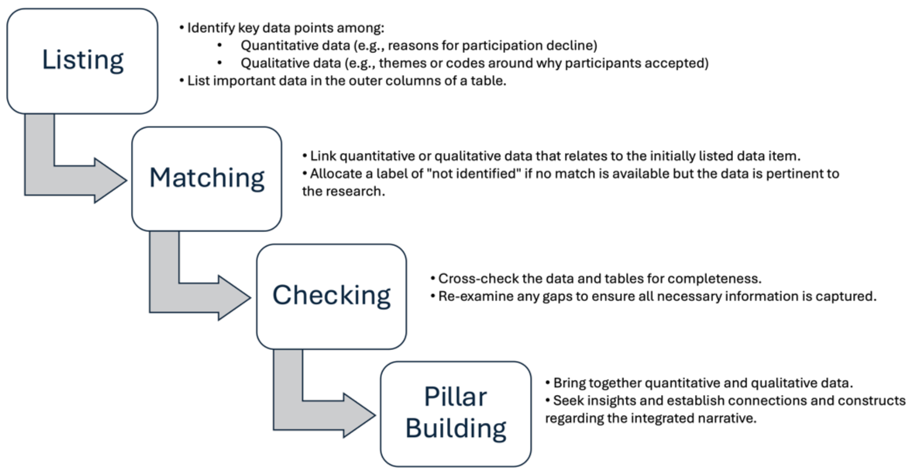


Figure 28: Pillar Integration Process Flow

The PIP has been applied to each question of this thesis. The following section will address each question, drawing on the pillars established in the PIP tables. All research questions have an accompanying PIP table, which can be found in Table 26, Table 27, and Table 28.

9.1 Question One: Is an online tailored physical activity platform feasible for those LWBLC?

Following the PIP, the data across the thesis were structured around two core dimensions: Feasibility Data and Participation Dynamics, evaluated against the pre-defined criteria, including a recruitment rate of at least 60%, a retention rate of no less than 85%, and a target participant range of 15 to 35, achieved within a five-month period ending May 30th, 2022.

The minimum recruitment target for ExerciseGuide UK was. However, the recruitment rate did not meet the pre-defined criteria. In fact, of the 59 eligible patients who were approached, 18 provided written informed consent, resulting in a 30.5% consent rate. The recruitment rate within this trial was approximately 50% lower than the mean recruitment rate from the systematic review evidence (62.85%) (3) and the predefined threshold for feasibility (≥ 60%) within this doctoral degree. Exploring the participation dynamics provided insight into the factors influencing participant engagement. The evidence collected illustrated that a large portion of potential participants, who are already actively involved in personal exercise routines, opted not to participate in the ExerciseGuide UK study. They perceived this exercise programme as an optional addition to their current exercise habits rather than a necessity. This decision was largely influenced by their satisfaction with their existing level of activity. These findings highlight a greater need to convey the importance of the unique advantages of educational resources and information throughout the treatment trajectory or beyond.

The dynamics of participation were largely shaped by participants' physical status and their digital literacy, particularly older adults. Often, patients declined to take part due to being weak and frail (21.95%). Moreover, not wanting to engage in a digital technology study was a common reason eligible participants gave for declining to participate in the ExerciseGuide UK study (19.51%). It was noted by an elderly participant (84y) that having someone who was more digitally literate helped them get used to ExerciseGuide UK. The ExerciseGuide UK findings indicate that enhanced support, such as involving family members during digital interventions, greatly improved engagement rates. This underscores the importance of future interventions to encourage and include support systems that cater to participants with varying degrees of digital literacy, ensuring inclusivity and sustained engagement. The ExerciseGuide UK study did not include the views or involvement of carers or participants' support networks, which would have provided a further lens to view how participants were able to engage with the platform. Evidence highlights older adults seem to be slower in learning how to use new technologies than their younger counterparts (446); they will learn and adopt them based on their perception of whether the technology holds value (447). Similar findings were noted in the doctoral systematic review, with two studies reporting the primary reasons for participant decline. Maguire et al. (2015) reported two primary reasons for participation decline were poor health status and being unfamiliar with technology (251). Moreover, Lafaro et al. (2019) echo the findings from ExerciseGuide UK that patients may decline due to being overwhelmed or having too much going currently going on (264), which was the third most common reason within the ExerciseGuide UK study.

Several external factors impeded participant eligibility and sustained involvement. Notably, clinician judgement regarding being too frail and/or weak to participate in a PA study (40.85%) and the absence of necessary technological tools emerged as primary barriers, excluding a significant portion of our intended demographic (25.35%). Wider research supports both participations decline or ineligibility of those living with and beyond cancer to digital exercise studies due to a lack of digital technology competency or lack of access (463, 468, 469). Within the doctoral systematic review by Curry et al., there were several concerns noted pertaining to the recruitment, including poor health status, lack of familiarity with digital technology and the internet, being overwhelmed, limited time, and no further supportive care was needed (3). Additionally, the economic implications of employing exercise professionals, which were not measured in the ExerciseGuide UK study, represent a notable oversight in the evaluation of the intervention’s overall economic feasibility.

The value of personal interaction in fostering participant engagement became clear throughout ExerciseGuide UK. Participants voiced a preference for direct interactions with researchers, which ultimately boosted their trust and compliance. Furthermore, given the substantial level of trust and confidence established through patient consultations with their primary oncologist, patients and their families are likely to be more receptive and responsive to research studies introduced and explained by their primary clinician (470). Although oncologists may have a favourable role in promoting recruitment (471), the researcher's presence can aid recruitment. The input from the oncologists for referrals highlighted the important role of integrating clinical support within the recruitment process, enhancing the credibility and appeal for study participation.

While the ExerciseGuide UK study achieved the minimum recruitment rate, it did fall short of meeting the pre-defined retention rate criterion of ≥ 85%. In fact, the recruitment rate was 66.67%. Further insight and context were highlighted when examining the retention rates across similar studies from the systematic review within this thesis. Across the eight studies in the systematic review, the mean retention rate was 84.77% (67–100%), meaning the retention rate did fall within the mean range of the studies. However, it is important to note there was an average sample size of 40.25 (± 31.65) within the systematic review and 18 in ExerciseGuide UK. Given the small sample size within ExerciseGuide UK, each individual's dropout or death largely affected the overall results and the percentage decrease in participation. In contrast, larger studies would likely see a diminished impact from similar occurrences due to their broader participant base. However, multiple factors can impact the retention rate of a study, not solely the sample size. For example, the reasons identified within the systematic review were postoperative complications, hospital transfer, pre-operative cancellation, emotional burden, and death.

In a recent review of exercise interventions for those diagnosed with cancer delivered via telehealth by Morrison et al., (2020), the retention rate ranged from 11% - 100% for website interventions (110). However, retention rates across different digital platforms yielded several key insights. Mobile and web-based interventions generally reported lower retention (below 70%) (110), aligning with broader digital health intervention research trends. The underrepresentation of lung cancer-focused studies within this data highlights a specific research gap, necessitating targeted investigations to understand better and address the unique engagement barriers faced within this subgroup.

Examining the recruitment outcomes relative to other studies identified within the doctoral review, particularly one conducted within the UK, demonstrated distinct successes and challenges. One study by Maguire and colleagues (2015) reported a recruitment target which was not met (target: 45, achieved: 16; response rate: 28.1%) (3, 270). Moreover, of the five studies which provided recruitment rate data, Maguire et al., (2015) yielded the lowest rate. However, there is little evidence suggesting the reason for a low recruitment rate and not achieving their sample size was due to being situated within the United Kingdom. However, the recruitment rate and target sample size of this one UK study most closely resemble ExerciseGuide UK.

The integration and engagement of online surveys within the ExerciseGuide UK study was successful and feasible, evidenced by substantial completion rates. All patients completed the baseline survey, and over 90% of participants engaged with the post-study surveys, affirming the practicality and effectiveness of digital surveys for continuous participant feedback and data collection within web-based research settings within this population.

9.1.1 Summary of Question One

The current study used the PIP to assess the viability of an online PA platform (ExerciseGuide UK) for LWBLC. Predefined Feasibility Outcomes and Participation were the two key pillars that were established.

The study explored at the participants' mean retention rate (66.67%) and average recruiting rate (30.5%) under the Predefined Feasibility Outcomes pillar. The ExerciseGuide UK website met some predetermined requirements, but it was nevertheless practical for some patients. Notably, the pandemic which took place during the study may have had an impact on the results and decreased feasibility when compared to earlier studies in the systematic review. It is necessary to look into potential variables causing these disparities further.

Due to the study's digital nature and the fact that many patients lacked access to technology, recruiting challenges were mainly attributed to this. In addition, the digital format discouraged many prospective participants from participating. However, the minimal recruitment goal was met in the prespecified time.

Due to the limitations of the pandemic, the feasibility exploration of healthcare professionals was not included in the study, highlighting the significance of integrating their viewpoints in future research. Even though the platform's recruitment rate was lower than that of the more extensive literature, which only covered a small portion of this topic, the reasonable retention rate (66.67%) indicated that most participants used the platform, suggesting it was moderately feasible.

Contextual factors, particularly the effects if the COVID-19 pandemic, were extremely important to the viability of the study. Social isolation and governmental constraints resulted in an increased technology dependence among older populations for daily tasks. For example, greater utilisation of digital technology to attend medical appointments or order in groceries. While digital technology provided a level of normalcy for most, the rapid shift of uptake and reliance likely was difficult for older people, especially those with limited past exposure of experience. Given the isolation restriction, individual may not have been able to gain help from their family and friends. However, in the case of ExerciseGuide UK, participants acclimated to the platform despite initial reservations, emphasising the importance of resolving perceived complexity in digital interventions.

To conclude question one, the practicality of ExerciseGuide UK can be rated as low to moderate based on achieving the minimum recruiting rate, a moderate retention rate and considering participant decline and grounds for ineligibility. The study offers insightful information about the viability of a tailored online PA platform for people with LWBLC, highlighting the significance of considering context when putting digital treatments into practice. The PIP table can be found below in Table 26.

Table 26: Pillar Integration Process Table discussing thesis question one: Is an online tailored physical activity platform feasible for those LWBLC?

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
Mean recruitment rate: (n=5): 62.83 ± 27.99% [a]	Systematic review data indicates online supportive care platforms appear to be feasible for those LWBLC [a]	Feasibility data: Recruitment, retention, sample size, data across the thesis for online supportive care platforms for those LWBLC.	Not Identified	
Mean retention rate (n=8): 84.77% (67–100%) [a]				
Sample Size Target: One study reported a recruitment target, which was not met (target: 45, achieved: 16; response rate: 28.1%) [a]				
Six studies were thought to be feasible. Two did not report on feasibility [a]				
Recruitment Rate: 30.5%[c]	Low-moderate feasibility for those LWBLC for ExerciseGuide UK [c]			
Retention Rate: 66.67%[c]				
Sample Size Target: 15 – 35[c] Actual Sample Size: 18[c]				
Achieved minimum sample size within pre-defined time frame (five months) [c]				
Patient reported outcome data was successfully collected [c]				

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
Patient reported no access to digital technology: n=18 (25.35%) [c]	Digital technology and recruitment for the ExerciseGuide UK study [c]	Participation	Concerns of age and digital technology engagement	Working with a package like that, I think they [older adults] would find that bit daunting. Especially people my age, younger people maybe would find that easier (002, 75y) [c]
Approx. 1/5th of patients declined to participate as they did not want to use digital technology [c]				
Top three patient given reasons for decline [c]: Did not wish to provide a reason (24.39%) Too weak and frail (21.95%) Did not want to use digital technology (19.51%)	Decision to not take part		Decision to take part	Yes, yes, you asking me because, you know, you can have leaflets and things like that. But some people wouldn't even bother reading them, would they? But yeah, it was you saying, 'would you mind getting involved (005) [c]
				I think because it was the chance to do something positive. And something, you know, this is something I'm not going to recover from. I think an exercise programme like this. I felt as if I was doing something positive. And this it's good for you mentally as well, isn't it? (002) [c]
Main reasons for participation decline for Maguire *et al.,* (2015)			Not Identified	

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
→			←	
included poor health status, patients feeling that they were being adequately managed by their clinical team and therefore perceived no need for additional supportive care interventions, and lack of familiarity with the use of technology [a]				
Reasons for declining from the study conducted by Lafaro *et al.,* (2019), included being no time (6), or being overwhelmed (5) [a]				
Maguire *et al.,* (2015) and Denis *et al.,* (2014), reported loss to follow up was due to death [a]	Loss to follow up		Not Identified	
Three participants lost was due to death [c]				

Note: QoL: Quality of Life; SUS: Systems Usability Score; PA: Physical Activity; PROs: Patient Reported Outcomes, LWBLC: Living with and Beyond Lung Cancer.

Study Type: Systematic Review: a; Think Aloud Usability Study: b; Feasibility and Acceptability Study: c.

P: Participant; R: Researcher.

9.2 Question Two: Is an online tailored physical activity platform acceptable for those LWBLC?

For the section question, there were four pillars identified (see Table 27), which were 1) Perceptions of the Digital Technology Design and Usability, 2) Impact on Physical Activity A and Behaviours, 3) Perceived Value for Cancer Care, and 4) Burden. Similar to the pillars in question one, the findings do share commonality, however, they have been presented in four discreet sections. Though, the qualitative and quantitative data and categories do span across the pillars and therefore may inform one another. Following the four pillars, a short reflective account of the doctoral student's acceptability will be provided. Including a reflective account aims to acknowledge the researcher as a part of the study. The Kolb Cycle will be used in section 9.2.6 to provide this reflective account for acceptability.

9.2.1 Pillar One: Perceptions of the Digital Technology Design and Usability

9.2.1.1 Content and Format

When assessing the acceptability of digital health interventions for individuals living with and beyond lung cancer (LWBLC), it is important to discuss the design and usability of the platforms, such as ExerciseGuide UK. The first pillar, regarding the acceptability of Exercise Guide UK, centres on user perceptions of digital technology design and usability. The focus is on the navigation, complexity, engagement, and developmental areas of ExerciseGuide UK, using previous research from this thesis and beyond.

ExerciseGuide UK offered a diverse range of health and behaviour content in multiple formats, including videos, text, animations, external sources (via hyperlinks), and infographics. This multifaceted approach aimed to accommodate varying user preferences and enhance comprehension and engagement. To measure acceptability, participants rated their agreement with various statements on a Likert scale from one (strongly disagree) to five (strongly agree). Post-study, participants were asked to rate their agreement on a Likert scale, from one (strongly disagree) to five (strongly agree), regarding whether the content on ExerciseGuide UK is easy to understand and whether the modules were useful. Participants reported a mean score of 4.38 (± 0.65) and 4.24 (± 0.73), respectively, reflecting a general satisfaction with the platform's design and content delivery. Reflecting back to the systematic review as part of this doctoral body of research, evidence affirms the importance of having user-friendly content to promote engagement, with online supportive care platforms being found to be user-friendly and easy to understand more successful (3).

In addition to the content being easy to understand and useful, participants voiced they liked ExerciseGuide UK's creation of a *go-to place* for information. This was because the modules did not disappear once revised. This consolidation was particularly appreciated, as it streamlined the process of accessing diverse health and behaviour resources.

When developing an online platform, it is important to consider its accessibility features. One way in which ExerciseGuide UK did this was by adhering to the Web Content Accessibility Guidelines (WCAG), ensuring strong readability through appropriate colour ratios and easily recognisable hyperlinks, underlined and coloured pink (vs standard text being black on a white background). These efforts were observed in the post-study questionnaire, where participants were asked if the content on ExerciseGuide UK was presented professionally with appropriate content, colours, and images on a five-point scale, providing a mean score of 4.15 (± 0.69). Furthermore, participants reported that the exercise animations and accompanying information were understandable and clear on ExerciseGuide UK were presented clearly.

Despite the efforts to maximise accessibility on the website version, users reported issues with mobile and tablet compatibility, as the content did not adjust well to smaller screens. This problem was a noted source of frustration and echoed concerns from a systematic review, suggesting that while the platform was adaptable to various devices, it required further optimisation for mobile use.

9.2.1.2 Complexity and Navigation

Participants generally found the site's complexity to be low, rating it 2.15 (± 1.14) out of 5. Navigation was rated higher at 4 (± 1.15) out of 5, indicating that users found ExerciseGuide UK relatively easy to navigate. While initial interactions were sometimes reported as complex, users typically adapted over time. An older participant emphasised the necessity of having a family member assist with navigation, highlighting the potential for perceived complexity among less tech-savvy individuals.

However, one participant did voice concern over an age-related perception of complexity. Having used the site, the participant stated they found no issues with engagement, though they thought adults their age (75y) would find it *a bit daunting*. Thus, the score provided may not have reflected their own experience but an assumption of others similar in age. Others found the site *straightforward* and *very easy to follow* (63y).

To explore age-related differences in perceived complexity, the data were divided into age tertiles: lower tertile (<64 years), middle tertile (64-73 years), and older tertile (>73 years). The middle tertile reported the lowest mean complexity score (1.5 ± 0.60), followed by the lower tertile (2 ± 1.41), with the older tertile finding the site most complex (2.8 ± 1.10). Although the sample size was small, these findings suggest an increase in perceived complexity with age. Additionally, one participant found the exercise prescription table overly complex, underscoring the need for simplifying certain elements for broader usability.

In an attempt to promote participant flow and ensure directed navigation, a tunnelled architecture was adopted for ExerciseGuide UK, rather than a free-choice model, which was well-received by participants. This approach helped prevent overwhelming choices and encouraged users to return back to the site. The nature of the website's architecture has been shown in other healthcare research interventions of digital tools to impact engagement. Evidence has illustrated that the tunnelled approach has led to greater engagement in areas such as module views and time spent on an application compared to free-choice access (472, 473, 474). Having a reduced level of continuous engagement with the site may have impacted the participant's behaviour change. A recent systematic review and meta-analysis support the notion of greater engagement with a digital health intervention and PA (475). However, the positive relationship reported across the 11 studies study was weak (0.08, 95% CI 0.01-0.14), with some inconsistent findings with varying study types that created large heterogeneity. Additionally, a systematic review of website architecture regarding web-based interventions, which aim to improve health outcomes, by Pugatch and colleagues (2018) reported (476) a tunnelled approach improved site engagement. The researcher team evaluated the level of behavioural knowledge in both the tunnelled and free-choice groups. Results indicated that participants in the tunnelled group exhibited significantly higher retention of information ($p<.001$). However, participants suggested a tunnelled approach was less efficient due to having less control. In the tunnel group, participants explored a greater number of pages (mean 11.4) compared to those in the freedom of choice condition (mean 7.4, $P<.001$). Additionally, users in the tunnel condition devoted more time to the site than freedom of choice users (3 minutes and 50 seconds compared to two minutes and 38 seconds; $F_{1,452}=6.32$, $P=.01$).

9.2.1.3 Extra Information

Lastly, ExerciseGuide UK participants were asked to rate their agreement post-study on how useful the *Extra Information* page was. The mean score reported was 3.77 (± 1.08). During the interviews, participants highlighted that they were unable to identify the Extra Information yet easily would have liked to explore the contents of this section. To promote the acceptability of ExerciseGuide UK, it is important to increase the visibility of this section, allowing effective engagement. Given an interest noted in the area, the location of the *Extra Information* section must be clearer to promote effective and appropriate engagement. There are multiple methods that could enable this to happen. Primarily, the *Extra Information* section could have been moved into the core module list on the dashboard. This would have provided a larger icon and made it more evident to the participants.

Overall, online supportive care platforms for those LWBLC have demonstrated good usability in the systematic review and Think Aloud interviews conducted as part of this doctoral research. Though, the impact of such platforms and their perceived effectiveness in relation to PA and healthy lifestyle behaviours are yet to be discussed.

Overall, online supportive care platforms for those LWBLC have demonstrated good usability in the systematic review and Think Aloud interviews conducted as part of this doctoral research. Though, the impact of such platforms and their perceived effectiveness in relation to PA and healthy lifestyle behaviours are yet to be discussed.

9.2.2 Pillar Two: Impact on Physical Activity Attitudes and Behaviours

The second pillar of acceptability examined the impact of ExerciseGuide UK on PA attitudes and health behaviours among individuals LWBLC. This focused on aspects such as confidence and motivation for both engagement with the ExerciseGuide UK platform and PA participation.

9.2.2.1 Influence on Confidence in Physical Activity

Participants rated the platform's ability to increase their confidence in engaging in PA on a Likert scale from one (strongly disagree) to five (strongly agree). The mean score was 4.08 (± 0.86). out of 5, indicating ExerciseGuide UK increased their self-efficacy towards being physically active. However, it is important to note that some participants had prior experience with regular activity and exercise, which may have contributed to their pre-existing confidence levels. Previous research has shown that self-efficacy can decrease at the initiation of web-based PA programs for individuals living with and beyond cancer (382, 477). For example, Forbes et al., (2017) suggest those living with and beyond cancer may overestimate their initial beliefs regarding their PA ability, and as they engage with a PA programme, their beliefs align more realistically with their current health, fitness, and contraindication status (477).

To address this, the website was designed to capture information about participants' beliefs, current health status, and PA experience, which may have supported the positive post-study scores. A more tailored list of questions could have further reinforced behaviour earlier within the ExerciseGuide UK platform, particularly for those with lower initial self-efficacy.

One key barrier to engaging in the exercise programme was breathlessness and breathing difficulties, with participants expressing being afraid or frightened about experiencing breathlessness during activity. However, some participants stated increased activity levels and exercise engagement following the incorporation of breathing exercises and the structured exercise programme provided via ExerciseGuide UK. One participant noted that their ability to push themselves harder and achieve more 'gains' was due to improved self-efficacy over time.

9.2.2.2 Evidence Supporting Digital Interventions for Breathlessness

The benefits of digitally delivered pulmonary rehabilitation have been illustrated for conditions such as asthma and chronic obstructive pulmonary disease (COPD) (478, 479). However, there is limited evidence specifically addressing breathlessness management in lung cancer. A literature review by Sereno et al. (2023) examined telemedicine for LWBLC, including two studies focused on improving breathlessness management. These studies, conducted in South Korea and the USA, reported positive outcomes in terms of breathlessness and user satisfaction (281) (480) (481). ExerciseGuide UK demonstrated similar benefits, with participants reporting relief from some of the physical and psychological impacts of breathlessness associated with malignant lung disease. Despite these positive outcomes, there remains an implementation gap in digital healthcare interventions for breathlessness management, highlighting the need for continued evaluation and adaptation of current delivery methods (482). One participant stated they are no longer frightened of it [breathlessness]. They stated they would be alright after doing some of the techniques taught via ExerciseGuide UK. Supportive services which focus on education and non-pharmacological approaches to chronic breathlessness management delivered face-to-face have are effective (483, 484). Nevertheless, an implementation gap remains. Despite the benefits acknowledged in the literature, the shift to digital healthcare interventions highlights the need to reevaluate current delivery methods (482).

Moreover, In March 2023, the SELF-BREATHE study, the first feasibility randomised controlled trial (RCT) of a digital, transdiagnostic, self-management breathlessness intervention, was conducted in the UK. The study showed that SELF-BREATHE was feasible and acceptable among participants, leading to improvements in both daily life and crisis management of breathlessness for individuals with advanced diseases, including lung cancer (482). While breathlessness is a significant symptom for LWBLC, it is one of many potential symptom burdens that need to be addressed.

9.2.2.3 Psychological and Physical Benefits of Participation

Participants also reported psychological benefits from participating in the study and being more physically active. Participants expressed a sense of achievement and a positive emotional response from exercising, feeling empowered by their ability to remain active despite their cancer diagnosis and the associated treatments. For example, in the interviews, participants noted the exercise's typical daily movements, such as lifting their arms above their head, lifting things down from shelves, and bending to put their socks on. These examples may increase an individual's quality of life. Throughout the PRO data collected pre- and post-study, both pain and fatigue demonstrate a suggestive decline (pain: -15.28 ± 32.14: P=0.178: CI: 34.71 – 0.00 and fatigue -6.48 ± 40.33; P=0.603, CI: -29.63 - 14.81, both post-pre-study). This aligns with the findings from the doctoral systematic review, which noted that participants who participated in an online education programme had a significant reduction ($P < 0.05$) in the top ten significant symptom distresses from baseline (282), and participants who performed PA displayed an improvement in their physical function (281). Therefore, participating in a PA web-based programme which is tailored to their specific needs may have led to an increase in their PA self-efficacy. However, ExerciseGuide UK implemented methods aimed at enhancing self-efficacy, such as goal setting.

9.2.2.4 Enhancing Self-Efficacy through Goal Setting

ExerciseGuide UK implemented methods to enhance self-efficacy, such as goal setting. Two modules were dedicated to setting goals and developing action plans. Participants rated the usefulness of these SMART goals and action-planning tools at 4.08 (± 0.64) out of 5. Feedback indicated that having specific goals to aim for increased their confidence and motivation. Participants within the study echoed the post-study questionnaire findings, highlighting they wanted something to aim at and setting their own goal made them feel confident. The importance of goal setting in eHealth PA interventions is widely supported in the literature, emphasising its role as an effective behaviour change technique (485, 486) (485, 487, 488).

In essence, the impact of the ExerciseGuide UK on PA attitudes and behaviours among LWBLC demonstrated acceptability within this pillar. ExerciseGuide UK successfully increased confidence in PA engagement, addressed barriers such as breathlessness, and provided psychological and physical benefits. The incorporation of goal-setting and action-planning modules further enhanced self-efficacy, supporting sustained PA engagement. Despite these positive outcomes, challenges such as initial complexity and the need for mobile compatibility remain

9.2.3 Pillar Three: Perceived Value for Cancer Care

The third pillar of acceptability focuses on ExerciseGuide UK's perceived value. This pillar examines how participants viewed ExerciseGuide UK's role in enhancing their cancer care experience, its alignment with their needs, and its overall impact on their health outcomes.

9.2.3.1 Perceived Value and Impact on Cancer Care

Participants rated ExerciseGuide UK highly during the post-study questionnaire for its value in their cancer care journey, with a mean score of 4.08 (± 0.86) out of 5. This rating indicates that most participants agreed that ExerciseGuide UK provided value during their treatment or survivorship, with some participants fully recommending the inclusion of ExerciseGuide UK in the cancer care pathway, underscoring its perceived importance.

Figure 29, illustrating the cancer continuum, shows where and how exercise can benefit patients from pre-treatment to survivorship and palliative care. ExerciseGuide UK could complement any one of these phases within the cancer care pathway. Moreover, shorter hospital stays and lower surgical complications are associated with higher cardiorespiratory fitness levels obtained through exercise. PA has been demonstrated to help maintain cardiovascular and muscular fitness and reduce cancer-related fatigue during treatment. Post-treatment benefits include improvements in body composition, well-being, cardiorespiratory fitness, muscular strength, and fatigue management. In palliative care, exercise helps maintain physical function, manage fatigue, and improve bone health.

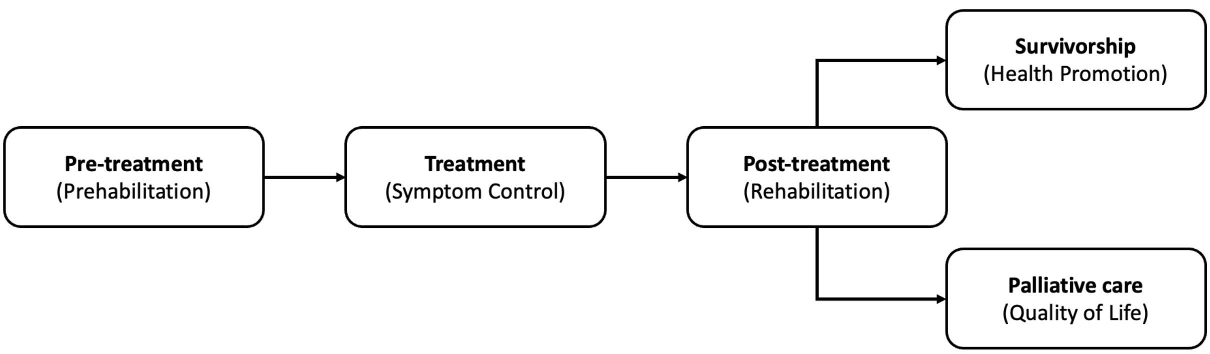


Figure 29: Key stages of the cancer care pathway where physical activity may provide potential benefit to the patient (adapted from MacMillan (489).

9.2.3.2 Exercise Across the Cancer Continuum

Exercise has been associated with increased survival and reduced risk of cancer progression or recurrence in survivors. Patients can benefit from exercise at every stage of the disease, from prehabilitation to palliative care, enhancing overall patient outcomes (489). Importantly, patients expressed a strong desire for PA as part of their oncology care, recognising its benefits and seeking more evidence-based information tailored to their needs.

9.2.3.3 Need for Evidence-Based and Tailored Information

Participants often struggle to find evidence-based information specific to their needs or interests. They voiced that available information is often generalised and not tailored to individual circumstances. ExerciseGuide UK addressed this gap by providing a consolidated site for personalised and evidence-based content in lay language, meeting the specific needs of patients.

9.2.3.4 Broader Impact Across Cancer Types

Literature from other cancer types shows enthusiasm for exercise advice and programs among patients with breast (490), prostate (490), non-Hodgkin's lymphoma (491), endometrial (492), bladder (493), and head and neck (494). However, less evidence exists for those LWBLC, making ExerciseGuide UK particularly valuable for this group.

9.2.3.5 Patient-Centred Approaches in Digital Health Interventions

Participants thought the site would be beneficial across the entire cancer pathway. This aligns with previous research on the acceptability of digital health interventions, emphasising the value of patient-centred approaches in oncology. Such approaches help manage and support physical and psychological needs in a tailored fashion, highlighting the positive outcomes of supportive care in lung cancer (495, 496). For individuals, LWBLC and, more broadly for those LWBLC, PA and exercise have been demonstrated to be quite effective within supportive care (115, 125, 127).

ExerciseGuide UK can offer affordable customised PA programmes and teaching materials. The results of the ExerciseGuide UK study thus show that digital technology can be a helpful and useful tool for people LWBLC, fulfilling their present health and activity demands and improving cancer care and services by relieving pressure and having a go-to information directory.

9.2.3.6 Role of the Researcher in Digital Interventions

One particular observation not captured in the quantitative data was the impact of the researcher themeselves. Post-study interviews revealed that the communication and check-ins with the doctoral researcher were an important part of the intervention. Literature suggests that digital or distance-based interventions without face-to-face support are viewed as less effective (497, 498). Face-to-face involvement (even through digital platforms) was crucial for participants beginning a PA eHealth programme, such as ExerciseGuide UK, as it increased motivation and accountability. Previous studies investigating digital technologies in cancer (488) and rheumatoid arthritis (499) have shown the significance of developing a relationship between the researcher, healthcare practitioner, and participants.

ExerciseGuide adopted a hybrid model to bridge the gap between exclusively digital and in-person intervention delivery. This included a minimum of a baseline introduction, a halfway review, and an optional close-out appointment with the researcher. Participants mentioned that these interactions were important for maintaining motivation and engagement. The hybrid approach addressed the need for human interaction within digital interventions, enhancing overall involvement and habit formation.

9.2.3.7 Supporting Evidence and Future Directions

The findings from ExerciseGuide UK support the value of integrating face-to-face support within digital health interventions. Suderman et al. (2022) illustrated similar results, highlighting the influence of virtual platforms on accountability dynamics (500). By understanding and addressing the need for human interaction, future studies can better suit the preferences and requirements of individuals living with and beyond cancer, potentially improving engagement and long-term adherence to healthy behaviours.

To close the perceived value for the cancer care pillar, the perceived value of ExerciseGuide UK was high, with participants recognising its strong benefits across their treatment and survivorship journey. ExerciseGuide UK's ability to provide personalised, evidence-based information in a user-friendly format was highly valued. The hybrid model, incorporating both digital and face-to-face interactions, proved effective in maintaining engagement and supporting behaviour change. These findings underscore the importance of integrating digital health interventions with personalised support to enhance patient outcomes in oncology care.

9.2.4 Pillar Four: Burden

The fourth and final pillar of acceptability explores the burden of engaging with ExerciseGuide UK. This pillar examines the frustrations, efforts, or limitations that participants experienced while engaging with ExerciseGuide UK.

9.2.4.1 Comorbidities and Exercise Engagement

Cancer patients frequently have comorbidities, which can complicate their ability to engage in physical activities. Evidence from Fowler et al. (2020) indicates that at diagnosis, a significant proportion of patients with colon, rectum, lung, or Hodgkin lymphoma have at least one long-term health condition, with many having multiple conditions (501). These comorbidities, combined with cancer, can pose substantial barriers to exercise engagement (502). Those LWBLC, in particular, experience more unmet and higher symptom burdens compared to other prevalent cancers, making exercise potentially even more challenging (502).

During the development of ExerciseGuide UK, reducing effort and promoting good usability were two of the key priorities. Data from ExerciseGuide UK emphasised the impact of comorbidities on some participants. For instance, a participant with osteoporosis expressed fear about starting an exercise programme, but ExerciseGuide was able to provide tailored support, that helped minimise these concerns. Participants reported a low mean score of 1.62 (± 0.65) out of five, indicating minimal perceived burden when asked if the intervention added an additional burden.

9.2.4.2 Impact of Treatment Side Effects

Although the score regarding perceived burden was generally low, minimising the burden further could enhance engagement and behaviour change, as even small burdens can deter participation or engagement in digital tools and/or exercise. Treatment side effects often present barriers to physical activity engagement (214, 503, 504), underscoring the need for personalisation based on individual health and fitness status (38). While some participants reported no change in their motivation or ability to engage while on treatment, others found that treatment side effects did impact their activity levels and their desire to engage with ExerciseGuide UK. The variability in treatment responses highlights the difficulty of tailoring interventions to individual needs. Elshahat et al. (2021) reported that cancer-related treatments were a significant barrier to physical activity (504), with 70-80% of mixed cancer cohorts reporting negative impacts on engagement due to treatment side effects (214, 505, 506, 507, 508)

9.2.4.3 Personalisation and Engagement

Evidence from the systematic review of this doctoral thesis supports the concept that personalised digital health resources can enhance self-learning and coping with cancer and its treatments (3). Tailored information yields greater engagement than generic messages (509, 510). However, text-heavy platforms often see reduced engagement and information retention as users tend to scan for keywords rather than read them thoroughly(511, 512). Through, incorporating pictures and videos could reduce this issue by decreasing cognitive effort and enhancing information processing (510, 513, 514, 515). While ExerciseGuide UK included integrated videos and pictures, participants noted that dense text segments were challenging and made reading feel burdensome.

9.2.4.4 Flexibility and Support

Participants experiencing more severe side effects benefited from the doctoral researcher’s assistance and opportunities for flexible engagement. The number of questions on the platform received mixed feedback. Some found the sheer number frustrating, while others suggested the number was appropriate. ExerciseGuide UK featured approximately in total 100 questions tailored to provide personalised information and exercise programming, excluding baseline, PRO, and review questionnaires. Answering a large number of questions is a known limitation of computer-tailored interventions (516). PROs included 85 questions; the baseline questionnaire had up to 34 questions (based on logic flow and skipping, and the post-study review also had 34 questions. The appropriate length for questionnaires varies, with no universal agreement on the optimal duration (517). A study by Millar et al. (2019) found that web-based surveys are feasible for cancer patients but suggested providing paper-based options for older adults (518).

Self-Monitoring and Tracking

Self-monitoring has been shown to be important and effective for behaviour change and promoting physical activity (519). However, engagement with the tracking module within ExerciseGuide UK decreased over time. Participants demonstrated a preference for paper-based tracking over digital methods. Similar findings were reported by Evans et al. (382, 390), where engagement with a tracking module in a supportive care tool for metastatic prostate cancer decreased significantly over time. In the ExerciseGuide UK study, 66.67% of participants started the tracking module but only completed it once within the first three weeks. No participants completed the module more than once. Many opted to track their progress with pen and paper instead.

9.2.5 Pillar Conclusion

ExerciseGuide UK supports the viability of online cancer care platforms. Acceptance centres on reducing burden through patient-centred design and flexibility. Features such as graphical and video integration, customised complexity levels, flexible tracking options, and researcher support can help overcome barriers like treatment side effects, comorbidities and motivation. Proper implementation can make digitally enabled personalised care widely accessible.

The four pillars discussed summarise the key findings of acceptability for the participants. However, the acceptability of the doctoral researcher remains to be discussed. Researchers often impact the studies they conduct, and it is important to reflect on this influence. The next section will provide a reflective account of the doctoral student's acceptability experience.

9.2.6 Doctoral Student Reflexive Summary of Acceptability

The following reflexive account will use a first-person narrative. I will use the Kolb cycle for experiential learning and reflective practice (520). The process was developed by an American educational theorist, David A. Kolb. The Kolb Cycle provides a structured framework for understanding the learning process and engaging in reflective thinking. There are four phases within this cycle: concrete experience, reflective observation, abstract conceptualisation, and active experimentation. Figure 30 demonstrates the Kolb cycle.

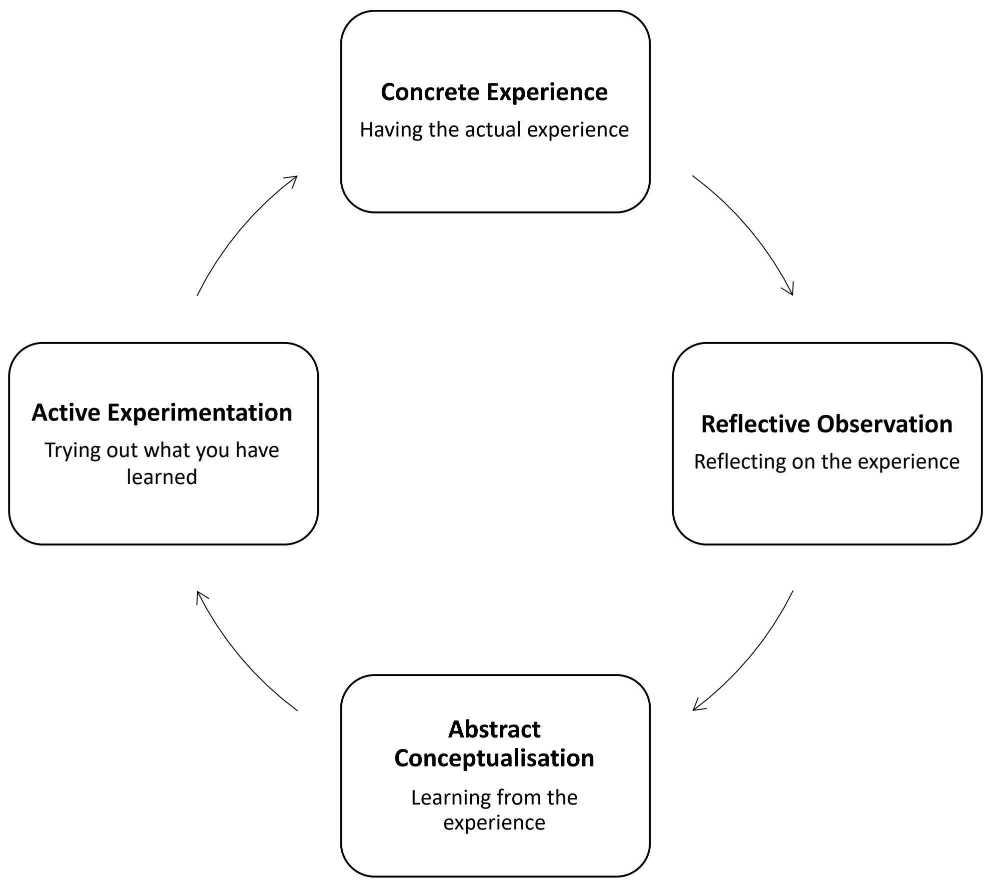


Figure 30: Example of the Kolb Reflective Cycle

In order to explore the acceptability of ExerciseGuide UK, we explored quantitative and qualitative information gathered from the study participants. However, exploring my own perceptions, actions, and overall experiences as the researcher delivering the study is important. It may be beneficial for acceptability to examine my actions, as the doctoral researcher delivering this study may have shaped or influenced the research.

I will now apply each of the four phases to my reflection on the acceptability of ExerciseGuide UK.

9.2.6.1.1 Concrete Experience

As the primary researcher delivering this research study, I had the opportunity to engage with participants at varying stages of the study. I was able to engage with some patients at the point of first approach/recruitment within the clinical setting. I was able to engage and communicate with all participants through scheduled conversations at baseline and midpoint to gather feedback, review behaviour change techniques (e.g., goal setting), observe their engagement in the exercise programme, and engage in post-study interviews. Through interaction with potential participants and active participants, I was able to gain first-hand experience of the acceptability of ExerciseGuide UK. Both verbal and non-verbal cues, engagement, interest, and any barriers and challenges present from the participants' perspective were highly important in understanding the user's acceptability throughout the study, from first contact to post-study interview.

However, it should be noted that due to the restrictions enforced due to the COVID-19 pandemic, at the beginning of the ExerciseGuide UK study, I could not recruit in person within the clinic. At this point in time, recruitment was conducted by clinical members of staff (e.g., Cancer Nurse Specialists and Medical Oncologists). Due to not being in the clinic myself, it was challenging to acknowledge and explore the potential participant's barriers and facilitators to engagement.

9.2.6.1.2 Reflective Observation

Following the process of analysing the data collected, it was important for me, as the primary researcher delivering the ExerciseGuide UK intervention, to critically reflect on components of acceptability. In the earlier methodology chapter (**Error! Reference source not found.**), I examined my epistemology and ontology, laying out my possible biases, assumptions, and preconceptions that may have influenced the study. Through this process of introspection, my biases may have affected how the participants engaged and their perception of intervention acceptability.

9.2.6.1.3 Abstract Conceptualisation

Exploring the acceptability of the participants, I used the Theoretical Framework of Acceptability (TFA). The TFA guided my thematic analysis of ExerciseGuide UK's acceptability from the patient's perspective. However, I did not apply such a framework to my own reflective understanding of my acceptability. For example, it may have been useful to examine how my personal beliefs, values, and possible biases may have influenced the design and delivery of the intervention. Following my time spent within the health and fitness industry, I have developed strong feelings that PA and exercises are vital elements of an overall healthy lifestyle. Though I did consult the PPI group, my beliefs may have led to me suggesting and developing modules pertaining to health lifestyle factors I feel personally important, such as summary diet, sleep, and mental health modules. It is possible this rounded approach aligned with my personal beliefs and thus improved the acceptability of ExerciseGuide UK.

9.2.6.1.4 Active Experimentation

Though I did not apply a dedicated framework to examine my acceptability, I did have two strategies to challenge my choices to promote higher levels of acceptability. The first strategy was seeking continuous feedback from my supervisory team. I held monthly meetings with my academic supervisors, who often challenged me to consider not only my underpinning philosophy, but the behaviour change techniques adopted and the selection and method of the exercises which are being prescribed. Thinking through my justifications for my decisions may have increased the acceptability of ExerciseGuide UK by mitigating the interference of my personal beliefs and biases. Moreover, I actively experimented with various approaches to enhance the usability and acceptability of ExerciseGuide UK. I conducted iterative PPI with a sustained PPI group to aid the redevelopment and adaptation of ExerciseGuide UK.

Additionally, I conducted Think Aloud interviews with those LWBLC via Zoom. Following the Think Aloud data analysis, I presented suggested revisions and anonymised data outputs. Following this process allowed a collaborative iteration process to ensure the site content was relevant and appropriate for those LWBLC.

9.2.6.2 Summary of Question Two

Personalised PA websites, such as ExerciseGuide UK, appear to be moderately acceptable for those LWBLC across the care continuum, according to the integration of findings across this thesis and wider literature. Quantitative evidence showed simplicity of use, minimal burden, and favourable effects on attitudes and confidence. Qualitative study results highlighted desired characteristics including customised information, hybrid human-digital interaction delivery, and valued researcher rapport. Although ExerciseGuide UK has some drawbacks, such as the inability to assess complex participants and digital accessibility, its general viability and appreciation demonstrate the potential of collaboratively developed, patient-centred online tools in oncology care. Participants defined the need for customised resources that ExerciseGuide UK clearly delivers. Standard services could incorporate adaptable, personalised platforms to enhance outcomes and quality of life.

Table 27: Pillar Integration Process Table discussing thesis question two: Is an online tailored physical activity platform acceptable for those LWBLC?

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
ExerciseGuide UK content was easy to understand: 4.38 (± 0.65) [c, *]	Positive Usability	Perceptions of the Digital Technology Design and Usability	Complexity	I think the vast majority of, of people of older people would work just as well with a printed booklet of exercises. You know, tailored too certain (P: 002, 75y) [c]
ExerciseGuide UK was presented professionally with appropriate content, colours, and images on a five-point scale. The outcome was a mean score of 4.15 (± 0.69) [c, *]				“R: How important was it for you to have her [wife] there to help you with the website? P: To start with, very important because I wasn't sure whether I was doing it correctly to start with, but you know, I think I would have got through it" (P: 004, 84y) [c]
How easy they thought ExerciseGuide UK was to navigate. A mean score of 4 (± 1.15) [c, *]				P: Working with a package like that, I think they would find that bit daunting. Especially people my age,

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
				younger people maybe would find that easier. (P: 002, 75y)
ExerciseGuide UK was easy to use and navigate: 4 (± 1.15) [c, *]			Website Architecture	P: I think I would have done the lot and gone to the end. And not done the build-up. I would have just wanted to achieve, maybe. And I like the fact that just held me back a little bit at work, personally for me. (P: 012, 54y) [c]
One study reported that majority of participants felt reassured and the advice from the intervention was user friendly and easy to understand [a]				Yeah, I think it's better releasing them [modules] over the course of the weeks because, you know, if you do more, like. If they were all there with the start, I would have done all them at the start. And then I probably would have forgot the stuff. So, you know, especially with chemo brain,
5/8 studies reported one or more measures of satisfaction, with majority reporting they were highly satisfied with the interventions [a]	Review satisfaction/dissatisfaction reasons			

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
→	→		←	←
Reasons reported for dissatisfaction with online tools were lack of interaction with health care professional, insufficient tailoring of exercises, inadequate insight into progression, and difficulty accessing via mobile phone. Moreover, the occurrence of system errors and difficulty in handling the application [a]				it's nice that staggered. (P: 003, 51y) [c]
SUS Score (n=7): 72 (± 25) [b]	SUS Score			
SUS score (n=13): 72.12 (± 14.15) out of 100 [c]				
Did ExerciseGuide UK increased confidence to participate in PA: 4.08 (± 0.86) [c, *]	ExerciseGuide UK Personally Beneficial	Impact on Physical Activity Attitudes, and Behaviours	Breathing and Breathlessness	R: Did you have any barriers? To being active, to being physically active. P: Mainly the breathing. R: And has there been any changes with your breathing?

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
				P: Yes, definitely. Definitely. Even with the walking about and things, you know, that's definitely helped me. (014, 71y) [c]
				R: So, managing your breathing better has allowed you to do more activity. P: Yes, yeah, yeah. (014, 71y) [c]
Did would ExerciseGuide UK change your attitude toward participating in PA: 3.77 (±0.93) [c, *]			Goal Setting	P:…you know, this exercise different from anything I've done before because one of the main things is you encouraged us to set our own targets. It made me feel more confident. Because I felt like I exceeded my own targets, and it makes you realise that you don't have to do a lot of exercise. (P: 012, 54y) [c]

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
→			←	
Were ExerciseGuide UK modules useful: 4.23 (± 0.73) [c, *]			Increased strength for Activities of Daily Living	P: It was quite difficult to even raise my arms a little bit at the beginning. But now I'm doing that with weight. So definitely improvement in strength there. But not only that, the leg ones are really helped as well (P: 003, 51y) [c]
Participants who participated in an online-based health education program had a significant increase in global QoL in comparison to a control group (Huang et al., 2019) [a]	QoL			P: I've notice that these activities [activities of daily living] are a bit easier, so, you know, I've had trouble lifting things down from shells before. And you know. Carrying things like water, but yeah, I've definitely these are better that way. So now we just do these things, not even thinking about it, really. (P: 003, 51y) [c]
All participants who participated in a mobile-based pulmonary rehabilitation platform exhibited an overall significant increase in QoL (Ji et al., 2019) [a]				

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
Participants who performed physical activity displayed an improvement in their physical function (Ji et al., 2019) [a]	Physical functioning and Symptom Distress			P: …there is a benefit, and it's the benefit you don't realise until the benefits there. For an example, bending. Bending to put your socks on. That used to be a bit of a problem for me. But now, after doing exercise, that isn't a problem (P: 005, 77y) [c]
Participants who participated in an online education programme had a significant reduction ($P < 0.05$) in the top ten significant symptom distresses from baseline (Huang et al., 2019) [a]				
Would ExerciseGuide UK add value to your cancer and service while receiving treatment or during survivorship, participants reported a mean score of 4.08 (± 0.86) [c, *]	Integration into care	Perceived Value for Cancer Care	Something Wanted	R: Did you find it easy to start activity programme? P: Yes, yes, it was something I actually wanted (004, 84y). [c]
				P: Yes, I actually been on Google and things like that, you know, trying to find exercises I could do. But all they said was do walking, but all they bloody doing is walking. (013, 70y) [c]

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
→	→		←	←
ExerciseGuide UK is something I would like to continue to use on a regular basis: 3.54 (± 1.33) [c, *]			Communication	P: I've loved the one-to-ones because it's made me feel special. It made me feel that I was important (P 012, 54y) [c]
				R: Did meeting with me twice have any impact on your desire or willingness, or motivation to do exercise? P: I think I can easily say yes. It had an impact on my motivation. (P: 017, 64y) [c]
None applicable	None applicable			P: I think it [number of check-ins], it's probably, it's been enough for me. (P: 004, 84y) [c]
				P: No, no, I think that was about right [number of check-ins]. I don't want to see you every week. But yeah, I think it's about right. (P: 011, 76y) [c]

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
→	→		←	←
			Feeling Valued	. There's a lot of people out there with cancer and the services, you know, it works as hard as it can, and you are just a number, and you are just a face. So, it's been really nice (012, 54) [c]
Did ExerciseGuide UK add an additional burden to them personally, with participants reporting a mean score of 1.62 (± 0.65) [c, *]	Added burden	Burden	Questions	R: How were the questions? P: They drove me mad at times…the amount. Yeah, the amount. (006, 62y) [c]
				P:…It kinda went on about the same thing, you know, more than once. (P: 011, 76y) [c]
				R: How did you feel about the number of questions we asked you? P: I thought they were fair, you know, fair enough. There wasn't too much, and you did you did provide a progress bar for most of them, if not all of them.

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
→			←	
				Which always does help (017, 64y) [c]
			Treatment side effects	I am a little bit afraid that fact I've got osteoporosis as well, I won't say it has muddied the waters, as it hasn't, But it's a factor. You know, something you have to factor in yourself. On the results in that. Yes, it was specifically designed for lung cancer, and I realised that, but it's helped me overall, it has helped me overall (P: 017, 64y). [c]
				"One of the side effects for me of the medication, you know, it's an effect of my eyesight. So, you know, reading things has became a bit of a chore… I've struggled to concentrate on some of the writing" (P: 012, 54y) [c]

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
			Preference for paper-based intervention rather than online	R: How do you feel about paper tracking log? Do you think that will be any use? P: I think it will be. (006, 77y) [c]
				The floor exercises, and then read it back to myself again. I was going to clicking back into the forwards. So maybe a bit of a printout? So, you know, if you are on the floor, you got the piece of paper there (012, 54y) [c]
				R: So, you took a more paper-based approach, then? P: Yes, yes, absolutely. (004, 84y) [c]
			Mitigate burden for more complex patients	P:…what the assessment does and what the, what the outcome of that assessment is, is basically what what the PT [personal trainer] first did for me when I walked into a gym. And that was

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
				huge. And I told him that all the problems I had. And they did draw me a plan up (P: 001, 64y) [c]
				R: What are your thoughts on the websites, tailoring ability and its ability to personalise it to your needs? P: Yes, yes, I think it was very good. And I was amazed at the speed it did it with. You know. When we met as well when we spoke, you were very quick to change things which was great. (005, 77y) [c]

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
				"Because of the restrictions on me, my exercises have to be done in the house, and I feel good about doing them." (P: 017, 64y) [c]

Note: QoL: Quality of Life; SUS: Systems Usability Score; PA: Physical Activity; PROs: Patient Reported Outcomes;

Study Type: Systematic Review: a; Think Aloud Usability Study: b; Feasibility and Acceptability Study: c.

**N=13 and reported a five-point Likert scale (one strongly disagree and five strongly agree).*

R: Researcher; P: Participant

9.3 Question Three: What barriers exists for those LWBLC to engage in an online tailored physical activity platform?

The third and final question of this thesis to address is the barriers faced by those LWBLCs when engaging with an online supportive care platform, particularly ExerciseGuide UK. Four key pillars were identified to understand this question: digital accessibility and concerns, digital complexity and learning, health-related outcomes, and timing.

9.3.1 Digital Accessibility and Concerns

Accessibility of digital technology emerged as a substantial barrier for those LWBLC. Within the ExerciseGuide UK study, 25% of individuals approached were excluded because they lacked access to digital technology. Additionally, approximately 20% of eligible patients declined to participate due to reluctance to engage with digital technology. This aligns with wider evidence from our systematic review, such as Maguire et al. (2015), which found that a primary reason for declining participation was unfamiliarity with digital technology among UK patients. Though it can be argued digital technology, if engaged with it, can be beneficial for patients, does solely relying on such mediums potentially increase inequalities?

During the COVID-19 pandemic, there was an increased reliance on the internet for everyday activities. However, Kung and Steptoe (2023) reported that daily internet engagement among individuals aged 50y and older did not increase from pre- to post-pandemic levels despite the rapid shift to online reliance. This study also highlighted that older age, lower socioeconomic status, and loneliness negatively affected internet engagement (521). These findings suggest that the poor participation and engagement observed in our study may be due to similar factors, where older and less affluent participants faced challenges due to lack of access or digital literacy (521)

Future research should consider these challenges by improving technology access, providing training, and incorporating user-centred design to enhance engagement with digital health interventions. Essentially, if we design these platforms and those who need them cannot access them, we have a larger concern on our hands.

9.3.2 Digital Complexity and Learning

Despite initial concerns about digital literacy, participants found our platform to be approachable and simple. Think Aloud interviewees reported that the website was easy to use and engage with, with most being able to navigate it effectively from the start. While digital technology posed a barrier initially, the platform's simplicity helped overcome these concerns, leading to increased user confidence and engagement. However, some perceived others would have trouble engaging with ExerciseGuide UK, even though they themselves did not.

9.3.3 Health-Related Outcomes

Health-related outcomes, particularly breathlessness, can be considerable barriers to engagement (125). According to Cancer Research UK, 60% to 90% of lung cancer patients experience breathlessness, which can deter physical activity and exercise (522). Participants in the ExerciseGuide UK study echoed these views, with severe breathlessness being a primary barrier to engaging in the PA programme. However, those who practised prescribed breathing exercises before progressing to more intense activities found these preliminary exercises beneficial, reducing their fear of breathlessness during physical activity.

Comorbidities also had an impact and often restricted participants' ability to engage in physical activities. Literature suggests that comorbidities can present extensive barriers to PA engagement, and the participants within ExerciseGuide UK reflected this, stating that physical limitations and fear hindered their activity levels (214, 503, 504). Nonetheless, the tailored support provided by our platform helped lessen these concerns. Moreover, patients who experience one of more commodities comorbidities may not only have physical limitations, but a complex interplay between psychophysiological limitations (523). It is important to build up self-efficacy to ensure confidence when engaging in PA (524). A tailored approach to PA advice and information is vital for individuals with multiple health conditions, as it builds self-efficacy and confidence in their ability to engage in PA. Participants reported a mean confidence score of 4.08 (± 0.86 SD) out of five, regarding their ability to participate in PA post-intervention, indicating the platform's positive impact on their self-efficacy.

Cancer treatments further influenced participants' engagement with the ExerciseGuide UK platform and PA programme. Treatment side effects, such as fatigue and breathlessness, posed barriers, with some participants unable to be active during treatment cycles. As 008 stated, "*around three days after the chemo, you know? That really knocked me out for about three days…I just got knocked out*". Real-time patient input, like ecological momentary assessments, could help tailor interventions to individual needs during and after treatment. For instance, ocular damage from treatments made it difficult for some participants to read lengthy text, highlighting the need for flexible and accessible design features such as text-to-speech and scalable font sizes.

9.3.4 Timing

Timing and making time for the exercise or using ExerciseGuide UK were also barriers. Participants rated their desire to continue using the programme regularly at an average of 3.45 out of 5, indicating moderate interest in sustained use. The doctoral systematic review reported that "not enough time" was a key reason for decreased participation, a feeling shared by participants who highlighted work schedules and fatigue as key barriers (3). Allowing flexibility in the timing and frequency of website engagement based on participants' schedules and energy levels could enhance sustained use. Features such as goal setting, reminders, and tracking can help integrate the intervention into daily routines, making it easier for participants to maintain engagement.

9.3.5 Summary of Question Three

The question explored the barriers faced by LWBLC participants in a digital health intervention designed to encourage PA and provide information on healthy lifestyles. The intervention's four primary pillars are outlined.

First, the Digital Accessibility and Concerns pillar emphasises that an approximately one-quarter of patients had no access to the internet and that ~25% chose not to participate owing to tech-related concerns. This is consistent with research suggesting that a barrier to involvement is a lack of familiarity with technology.

Second, the Digital Complexity and Learning pillar demonstrates that after some initial learning, users regarded the website to be generally straightforward to use. However, some thought that there was a lack of computer literacy, so they wrote out content. It is emphasised that informal care givers can offer older individuals specialised information and help with their initial learning.

Third, the Health-related Outcomes pillar demonstrates that the intervention helped patients overcome barriers to breathlessness and improved confidence in PA. It was advantageous to enable at-home exercising and to adjust for comorbidities. Findings suggest that capability is impacted by treatment status. Post-treatment visual restrictions highlight the demand for multimedia material.

Lastly, the Timings pillar indicates that engagement was variable but may have been due to learning saturation. Lack of time and tiredness from work were frequent obstacles to participation. However, participants did not have any trouble incorporating it into their days.

In conclusion, despite the fact that there are still some digital barriers, this personalised digital intervention promoted learning, increased confidence in PA, and got around some treatment-related obstacles. Digital literacy, multimedia knowledge, and timing after work are important factors for optimisation.

Table 28: Pillar Integration Process Table discussing thesis question three: What barriers exist for those LWBLC to engage in an online tailored physical activity platform?

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
Patient reported no access to digital technology: n=18 (25.35%) [c]	Digital exclusion within ExerciseGuide UK study	Digital Accessibility and Concerns	Not Identified	
Patients decline to participant because they did not want to use digital technology: n=8 (19.51%). [c]	Decline in participation due to digital technology			
Reasons for decline [a]: Maguire *et al.,* (2015): lack of familiarity with the use of technology				
The ExerciseGuide.org.uk website was unnecessarily complex: Mean (SD): 2.15 (± 1.14) [*, c]	Complexity for engagement	Digital Complexity and Learning	Fear of digital technology	"I'm a technophobe. I'm a technophobe. So, I wrote it down" (013, 70y) [c]
5//7 found the website unnecessarily complex [b]				P: Like a lot of older people, I don't think. Would rather work from a booklet with those exercises in. And they would find it easier and more likely to make it a routine. Because they would possibly find. Going into the exercise guide on a

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
→			←	
				PC, say, may be a little bit daunting (002, 75y) [c]
6/7 suggest they imagine that most people would learn to use this website very quickly [b]	Learning		Digital Learning	R: How important was it for you to have her there to help you with the website? P: To start with, very important because I wasn't sure whether I was doing it correctly to start with, but you know, I think I would have got through it (004, 84y) [c]
5/7 suggest they imagine I felt very confident using this website [b]				P: Working with a package like that, I think they would find that bit daunting. Especially people my age, younger people maybe would find that easier. (002, 75y) [c]
The ExerciseGuide.org.uk website has increased my confidence to participate in physical activity. [c] Mean (SD): 4.08 (± 0.86) *, [c]		Health-related outcomes	Breathlessness	"I'll be honest with you, because of the breathlessness. I, I was shying away from the cardio element because I wasn't comfortable. But now I found that I can get to a point where I can raise my heart rate for a prolonged period of time using the breathing" (001, 64y) [c]
				R: In terms of the exercises, you know the physical activities and the breathing

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
				exercises. How easy did you find it to start doing them? P: Very easy, very easy. You know it's no problem. It's part of your day, isn't it?... (018, 73y) [c]
				"R: Did you have any barriers? To being active, to being physically active. P: Mainly the breathing." (014, 71y) [c]
				"P: One of the biggest things I have learned from it now, and it's part of me now, is that I'm not afraid of being breathless. Right. I know if I do something, or if I've overdone it or something, and I'm really breathless, I sit down, and I do my breathing exercises through my diaphragm. And I'm relaxed. I know, I'm not gonna die. It's not gonna do anything. It's just going to go away in a couple minutes, and in a couple minutes I am back to normal. And that is the biggest, the biggest thing it taught me. I am not frightened of it." (013, 70y) [c]

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
			Comorbidities	"I am a little bit afraid that fact I've got osteoporosis as well, I won't say it has muddied the waters, as it hasn't, But it's a factor. You know, something you have to factor in yourself" (017, 64y) [c]
				P: Because of the restrictions on me, my exercises have to be done in the house, and I feel good about doing them. (017, 64y) [c]
			Cancer Treatment	R:…was there any times where you didn't really want to use the website or exercise? P: Yes. Particularly around three days after the chemo, you know? That really knocked me out for about three days…I just got knocked out. (008, 74y) [c]
				P: Nope, nope. The treatment has not stopped me doing anything. (006, 62y) [c]
				R: So maybe that diagnosis introduced a barrier for your exercise. P: It did. But I physically couldn't do it [exercise] because, you know, I couldn't breathe properly. So that was true. I

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings
				couldn't do it [exercise]. But I can do it now! (006, 62y) [c]
				P: So, one of the side effects for me of the medication, you know, it's an effect of my eyesight. So, you know, reading things has became a bit of a chore… I've struggled to concentrate on some of the writing (012, 54y) [c]
The ExerciseGuide.org.uk website is something I would like to continue to use on a regular basis: Mean (SD): 3.54 (± 1.33)[*, c]	Regular Engagement	Timing	Work	P: I do really struggle with the motivation because normally, when I'm in the work situation. I work 12-hour days. So, you know, I'm absolutely exhausted. (003, 51y) [c]
Reasons for decline: Lafaro *et al.*, (2019) reported common reason was patients having no time [a]	Timing for participation in study		Timing for completion of exercises	P: I think the only restraint was, you know. The time the timing of it. Making sure I allowed the time. You know. If I got up late and I thought, come on. I've gotta get my exercise in. But you fit them in somewhere. But yeah, there was no real problem. (002, 75y) [c]

Note: QoL: Quality of Life; SUS: Systems Usability Score; PA: Physical Activity; PROs: Patient Reported Outcomes;

Quantitative Findings	Quantitative Categories	Pillar Building Themes	Qualitative Categories	Qualitative Findings

Study Type: Systematic Review: a; Think Aloud Usability Study: b; Feasibility and Acceptability Study: c.

** One (strongly disagree) to five (strongly agree). P: Participant; R: Researcher.*

9.3.6 Reflexive Account

Undertaking a PhD journey is a multifaceted experience marked by moments of clarity, challenges, and personal growth. My decision to pursue doctoral research was rooted in a convergence of personal experiences and academic interests, brought together by a strong belief in the potential of physical activity and digital technology to transform health and wellbeing outcomes, particularly for individuals living with and beyond non-communicable diseases (NCDs), such as cancer.

My journey into academia was shaped by hands-on experiences working with diverse communities in both the United Kingdom and the United States of America. While working in the USA, I had the opportunity to engage with children and adults from various backgrounds. Here, I first recognised the potential of technology in health promotion and education. Integrating technology into our activities sparked enthusiasm and engagement among younger children and adults. However, I noticed a disparity in its utilisation across age groups. While younger participants readily embraced technological tools, the same wasn't true for older adults. This observation left me questioning why such valuable resources weren't automatically integrated into programmes focusing on older demographics.

Motivated by this curiosity, I embarked on a journey to understand the factors contributing to this digital divide. This intrinsic motivation, combined with a genuine desire to bridge the gap and address the needs of underserved populations, laid the foundation for my doctoral research. Exploring the intersection of health, exercise, and digital technology, particularly in leveraging technology to improve health outcomes for older adults, became the focal point of my academic pursuit.

As I delved deeper into the world of academia, my research interests underwent a process of evolution and refinement. While my initial inclination leaned towards breast cancer research, an early exploration of existing literature revealed gaps in our understanding of digital interventions for lung cancer, a demographic often not given as much attention in supportive care research. This pivot underscored the importance of adaptability and open-mindedness in my research and laid the groundwork for a more inclusive and nuanced approach.

Central to my doctoral process was embracing patient and public involvement (PPI) as a guiding principle in research methodology. Collaborating closely with individuals from diverse backgrounds, patients, and caregivers proved to be a transformative experience, enriching my research process and fostering a deeper understanding of the lived experiences of those affected by cancer. From adopting a user-centred design, to shaping research methodologies, their invaluable insights guided the trajectory of my doctoral research.

However, the doctoral process was not without its share of challenges. The unprecedented onset of the COVID-19 pandemic disrupted research protocols, necessitating a rapid shift towards virtual platforms for PPI engagement. Although the rapid shift was necessary, it came with its own set of considerations. I realised that by transitioning solely to virtual engagement, I might miss out on a potential portion of users who do not engage in digital technologies. Those individuals could have provided valuable insights into the barriers to digital engagement. Despite these unforeseen obstacles, the resilience and adaptability of the research community prevailed, paving the way for innovative solutions and novel approaches to collaborative inquiry. On a personal level, the doctoral journey has been a period of profound growth and self-discovery. From refining presentation skills to embracing qualitative methodologies, each milestone and setback served as a foundation for personal and professional development. Engaging with PPI members, navigating moments of grief and isolation amidst participant deaths, and grappling with the inherent uncertainties of doctoral research all contributed to a handful of low moments throughout this doctoral journey. However, I sought the advice of my supervisors and peers to help me get through this. I scheduled regular standing meetings with supervisors, mentors, and peers to provide a sense of community to share the highs and lows of the week, seek advice, and generally talk.

My contributions to the academic community, spanning publications, presentations, and mentorship initiatives reflect a commitment to knowledge dissemination and collaborative learning. Yet, the tangible impact on healthcare practices resonates most deeply.

As I stand on the brink of the next phase in my academic journey, I am filled with sincere gratitude for the many lessons learned, the invaluable relationships developed, the mentorship from my supervisors, and the numerous opportunities that await. Reflecting on the path behind me, I am humbled by the growth I experienced, both personally and professionally, and excited by the possibilities that lie ahead.

9.4 Concluding Strengths and Limitations of Doctoral Research

One of the primary strengths of this doctoral research lies in its methodology, which prioritises active engagement with end-users throughout the research process. The user-centred design process, involving a diverse Patient and Public Involvement (PPI) group, of those who have cared for or are those LWBLC, ensures that the ExerciseGuide UK's development remained responsive to the evolving needs and preferences of its intended users. This participatory ethos and approach capture a true sense of ownership and collaboration among PPI members, ultimately resulting in an intervention that is more appropriate and relevant to its target audience.

Secondly, the early incorporation of a usability study, conducted through Think Aloud interviews, served as a crucial method of identifying the barriers to successful engagement. By identifying usability issues and bugs prior to the feasibility study, I was able to address issues proactively, thereby enhancing the overall user experience of ExerciseGuide UK. The transparent and iterative nature of this process, involving summarising and presenting findings back to the PPI group for collective decision-making, further underscoring the participatory approach of the research endeavour.

Thirdly, the dissemination of multiple academic outputs stemming from this doctoral research, including a systematic review, a protocol paper, and a commentary co-authored with PPI members, embodies the academic rigour and impact of the research. These publications contribute valuable insights to the existing literature and highlight the collaborative and inclusive nature of this body of work, wherein the voices and perspectives of end-users are given due recognition.

Fourthly, the systematic review conducted prior to the redesign phase provides a comprehensive synthesis of existing evidence, informing the research question and framing the study within the broader context of existing knowledge and research gaps. This methodological rigour ensures that the study is built upon a solid theoretical foundation, enhancing its credibility and relevance within the academic community.

Lastly, the integration of both quantitative and qualitative methods in the study design allows for a nuanced and holistic understanding of feasibility and acceptability. Triangulating data from multiple sources enabled me to capture the intricacies and nuances of user experiences, preferences, and perceptions, providing an overall analysis and interpretation of findings.

Despite the strengths of this study, several inherent limitations warrant consideration. Firstly, the restriction to virtual PPI sessions, due to the COVID-19 pandemic and the national social engagement restrictions put into place. While virtual engagement enabled continued collaboration with PPI members during challenging and isolating times, it may have presented barriers for individuals with limited digital literacy. The reliance on digital platforms for PPI may have inadvertently excluded voices and perspectives from those who are less comfortable or digitally competent with technology. This limitation is particularly salient in the context of healthcare research, where ensuring diverse representation is crucial for designing interventions that are accessible and relevant to all end-users.

Secondly, the inability to include healthcare professionals in the design process and post-study interviews due to pandemic-related pressures represented a significant missed opportunity. The insights and expertise of healthcare professionals would have been invaluable for understanding the practical implications and feasibility of implementing interventions within clinical settings. By not incorporating their perspectives, the study may have overlooked important considerations that could impact the intervention's adoption and effectiveness in real-world contexts.

Thirdly, the virtual delivery of all Think Aloud interviews conducted during the usability study. While virtual interviews offered convenience and flexibility, they may have introduced biases in the assessment of website usability. Individuals with higher digital competence or familiarity with telecommunication technologies (e.g. Zoom) may have been more comfortable navigating the website, potentially skewing the study's findings towards a more positive evaluation of usability. In contrast, those who are less digitally literate may have encountered greater challenges or frustrations that were not adequately captured in the virtual setting.

Fourthly, the lack of formal exploration of participant compliance with exercises and revisions based on patient needs represents a gap in the study's methodology. While qualitative interviews provided insight into the participants' experiences and preferences, especially around the need for further tailoring from the researcher, the absence of data collection on exercise adherence and adaptation from the participants within ExerciseGuide UK limits the ability to assess intervention fidelity and effectiveness. Without robust documentation of participants' engagement with the intervention and any modifications made in response to their feedback, it is challenging to provide summaries or conclusions about the intervention's impact or scalability.

Fifthly, a limitation of this review is that while it included various forms of supportive care, the specificity of exercise interventions was not thoroughly distinguished from other supportive care elements, potentially overlooking the unique challenges and benefits associated with online exercise support for lung cancer patients.

Lastly, regarding the systematic review search strategy employed in the systematic review chapter, it's important to address the decision to limit the search to lung-related literature. The decision to focus exclusively on lung cancer was deliberate and aimed at ensuring relevance and specificity to the research question at hand. By narrowing the scope of the search to lung cancer, the study aimed to consolidate evidence pertinent to the population of interest, thereby facilitating a targeted analysis of the existing literature.

However, it's acknowledged that this approach may have inadvertently overlooked valuable insights from research conducted in other disease contexts, such as diabetes, cardiovascular disease (CVD), or other cancers. These areas may offer relevant perspectives and interventions applicable to the broader context of exercise support in cancer care. Additionally, considerations regarding the specificity of exercise-related literature versus broader 'cancer support' literature are noted, particularly in the context of delivering exercise interventions online.

Moving forward, there is recognition of the need to critically evaluate and in a future review expand the search strategy to encompass a broader spectrum of diseases and interventions relevant to exercise support in cancer care. By doing so, a new review could further supplement its analysis and provide a more comprehensive understanding of the wider literature of exercise interventions in oncology.

Overall, while this study offers valuable insights into the feasibility and acceptability of the intervention, these limitations underscore the need for continued refinement and methodological rigour in future research endeavours. Addressing these limitations through more inclusive engagement strategies, methodological enhancements, and interdisciplinary collaborations will be essential for advancing knowledge and improving outcomes in the field of healthcare and digital health research.

9.5 Future Updates, Changes, and Use of ExerciseGuide UK

ExerciseGuide UK aimed to provide tailored exercise information and educational resources for individuals LWBLC. The platform aimed to continuously update and enhance its content, incorporating the latest oncology research. Moreover, ExerciseGuide UK served as the foundation for a new intervention site, CANFit. Developed by the doctoral researcher (JC) and the web developed from ExerciseGuide UK, CANFit represented a large upgrade from ExerciseGuide UK, introducing more personalised features, enhanced tracking capabilities, and an expanded 'Extra Resources' section.

However, the unforeseen death of the web developer resulted in a substantial loss, as access to the original coding and infrastructure was lost. Consequently, it became necessary to decommission all ExerciseGuide platforms, including both ExerciseGuide UK and the CANFit site.

Looking forward, there is a commitment to develop a new platform that will serve as a comprehensive 'one-stop-shop' for individuals living with and beyond cancer. This future site is planned to provide a user-friendly interface where minimal input from the user will generate a curated list of evidence-based resources specifically tailored to the user's cancer type, associated symptoms, treatments, and burdens. This new initiative aims to build on the lessons learned from ExerciseGuide UK to enhance the quality of life and accessibility of information for those living with and beyond cancer and their families and carers.

9.6 Summary of Chapter Nine

Integrating the findings throughout this chapter, online supportive care interventions for those LWBLC appear to be feasible and acceptable, within this research significantly advancing an under-research area of a rapidly developing field of digital health in oncology care.

The study generated compelling quantitative and qualitative evidence that ExerciseGuide UK was highly usable, valued, and beneficial for supporting confidence and motivation to exercise throughout the cancer care continuum. Participants were able to articulate the need that this tool satisfies by offering individualised activity recommendations and information.

Engagement was increased in ExerciseGuide UK by including human interaction, emphasising the value of using hybrid care approaches in digital supportive care platforms, which aligns with previous research. However, adherence issues including diminishing tracking engagement point to the need for more behaviour modification strategies or flexibility in intervention usability (e.g., optional paper-based methods).

Comorbidities and side effects from treatment have also come to light as significant barriers needing more precise tailoring and flexibility, highlighting the need for human interaction. Online platforms can give personalised supportive cancer care if they are thoughtfully designed with the patient and user preferences in mind.

This effort represents a significant advancement in the expansion of technology-enabled access to personalised services. It defines the viability, acceptability, and directions for optimisation as the first stage of a larger research programme.

To promote practical application and long-lasting influence, the following phase ought to expand on these discoveries. In order to engage persons with comorbidities, integrate hybrid models, and overcome barriers to increase adherence, more research is required.

Current cancer care delivery can be supported by digital innovation if user needs are carefully considered. This work offers foundational initial evidence to move the field in the direction of integrating online supportive care int he cancer continuum for those LWBLC

Chapter 10 Thesis Conclusion

This doctoral thesis explored the feasibility, acceptability, and barriers to a web-based physical activity (PA) and lifestyle intervention (ExerciseGuide UK) for those LWBLC in the UK. The main findings demonstrated that ExerciseGuide UK appears feasible for a subset of lung cancer patients, however, it is important to focus on improving accessibility for those lacking digital accessibility. Overall, ExerciseGuide UK was well received, and participants regarded it as a useful supplement to current cancer treatment. An important outcome highlighted within this work was breathlessness, which had a severe impact on quality of life and could benefit from the provision of tailored advice and support.

The strong patient and public involvement (PPI) throughout ExerciseGuide UK's development was an important novel feature. Those LWBLC participated in think-aloud interviews and a PPI group worked closely with the research team to refine the platform took an active role in the design of the project. This gave important information that helped create a platform that was more patient-focused and individualised. For both exercise prescription and healthy living information, the use of algorithms and customised content was unique and allowed for individualised support. Additionally, virtual meetings showed that when combined with checks-ins (promoting accountability), safe exercise provision is possible remotely without adverse effects.

This research addressed an understudied population in comparison to other prevalent cancer groups. Despite stigma around digital literacy in this population, findings showed the majority of participants actively engaged with and gain benefits from ExerciseGuide UK. This demonstrated eHealth solutions should not be readily dismissed in this population and supports further exploration of similar platforms. This research filled a knowledge gap around digital health interventions for UK lung cancer patients, going beyond feasibility to examine real-world integration into the cancer pathway.

A key barrier revealed was the inequity of digital accessibility, resulting in the exclusion of certain patients from the study. This finding highlights the need to prioritise designs that mitigate this through careful consideration of how to best support mass engagement, for example offline access options. Wider initiatives to improve digital inclusion for lung cancer patients should also be considered by healthcare providers and researchers. Lack of accessibility perpetuates the digital divide, preventing patients from utilising helpful resources.

Given feasibility concerns for some, larger scale studies are required to definitively examine feasibility, acceptability and efficacy of these interventions for health outcomes. Comparisons between digital platforms and standard care could illustrate such benefits. Breathlessness and related psychosocial impacts should be included as key targets, considering the high symptom burden revealed and impact of simplified information. Future research must take an inclusive approach, exploring steps to ensure equity for disadvantaged groups.

ExerciseGuide UK showed how, with thoughtful planning and implementation, eHealth has the ability to complement standard cancer services. This provides an opportunity for optimising such interventions alongside evaluating their real-world impact across the cancer care pathway.

To summarise, the key recommendations stemming from this research are:

1. Policy makers and healthcare care boards should consider integrating tailored eHealth tools like ExerciseGuide UK to extend their supportive care services in an accessible, equitable manner.
2. Further resources and research are needed to address the unmet needs of lung cancer patients experiencing severe breathlessness and related psychosocial impacts.
3. Equity of access must be centred in the design and delivery of eHealth interventions to ensure patients facing disadvantage can still benefit.
4. Ongoing PPI throughout development of eHealth advances leads to more patient-oriented, usable, and relevant platforms.
5. Large-scale studies should examine efficacy of web-based physical activity and lifestyle interventions for lung cancer patients.

In conclusion, this thesis makes valuable contributions both academically and practically. It addressed significant knowledge gaps about digital health treatments for those LWBLC and demonstrated that, in spite of stereotypes, they might be practical, agreeable, and helpful. It was important in that it emphasised digital exclusion as a pressing issue. Collaboration with patients contributed insights that were crucial to the study. The key next stages will be to maximise equitable access, increase assistance for people who experience breathlessness and continue evaluations through larger trials. The foundation for incorporating digitally delivered, personalised supportive care into lung cancer routes has been set forth in this thesis.

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Chapter 12 List of Abbreviations

Abbreviation	Term in full
LWBLC	Living with and beyond lung cancer
ADLs	Activities of daily living
PPI	Patient and Public Involvement
PA	Physical activity
RCT	Randomised controlled trail
COVID-19	Coronavirus-19. This is a new (2020) form of the Coronavirus known as Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2)
PBA	Person based approach
eHealth	Electronic health
mHealth	Mobile health
NSCLC	Non-small cell lung cancer
SCLC	Small cell lung cancer
PM	Pleural Mesothelioma
QoL	Quality of Life
HRQoL	Health related quality of life
NICE	National Institute for Health and Care Excellence
NHS	National Health Service
WHO	World Health Organization
NCD	Non-communicable disease
CVD	Cardiovascular disease
CRD	Cardiorespiratory disease
COPD	Coronary obstructive pulmonary disorder
CRF	Cancer related fatigue
ACSM	American College of Sport Medicine
HYMS	Hull York Medical School
UI	User Interface

MeSH	Medical Subject Headings
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
AMSTAR	Assessment of multiple systematic reviews
S&PAM	Ambulant symptom and physical activity monitoring
WEP	Web-accessible home-based exercise program
P.R.	Pulmonary Rehabilitation
CCM	Chronic Care Self-Management Model
SMT	Symptom Management theory
MRC	Medical Research Council
PHP	Recursive acronym for PHP: Hypertext Preprocessor
SES	Socio-economic status
LTP	Long Term Plan
SUS	Systems Usability Scale
HADS	Hospital Anxiety Depression Scale
CHAMPS	Community Health Activities Model Program for Seniors
EORTC-QLQ-30	European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire
MoA	Mechanisms of Action
HRA	Health Research Authority
HCRW	Health and Care Research Wales
SPIRIT	Standard Protocol Items: Recommendations for Interventional Trials
RPE	Rate of Perceived Exertion
SMART	Specific, Measurable, Achievable, Realistic and Time-Bound
FITT	Frequency, Intensity, Time, and Type
HTTPS	Hypertext Transfer Protocol Secure
TLS	Transport Layer Security
ASA	American Society of Anaesthesiology
HCPs	Healthcare Professionals

PIS	Participant Information Sheet
SQUASH	Short QUestionnaire to ASsess Health enhancing physical activity
CTA	Concurrent Think-Aloud
RTA	Retrospective Think-Aloud
GRIPP	Guidance for Reporting Involvement of Patients and the Public
GRIPP-SF	Guidance for Reporting Involvement of Patients and the Public – Short Form
GRIPP-LF	Guidance for Reporting Involvement of Patients and the Public – Long Form
HUTH	Hull University Teaching Hospital
OA	Open Access
ASA	American Society of Anaesthesiology
UK	United Kingdom
USA	United States of America
PIP	Pillar Integration Process
SRQR	Standards for Reporting Qualitative Research

Chapter 13 Appendices

13.1 Appendix One: List of all modules on ExerciseGuide UK.

Table 29: List of modules on ExerciseGuide UK.

Module Name	Release Timings (weeks)	Tunnelled/Hybrid; Module Dependency	Temporary or Permanent
Baseline Questionnaire	1	Tunnelled; Sign up	Temporary
EORCT	1	Tunnelled; Baseline Questionnaire	Temporary
HADS	1	Tunnelled; EORCT	Temporary
CHAMPS	1	Tunnelled; HADS	Temporary
Introductory Module	1	Hybrid	Permanent
Physical Activity Safety	1	Hybrid	Permanent (for three weeks)
Exercise Prescription (weeks 1 – 3)	1	Tunnelled; Physical Activity Safety	Permanent
Goal Setting	1	Hybrid	Permanent
Action Plan	1	Tunnelled; Goal Setting	Permanent
Breathlessness	1	Hybrid	Permanent
Physical Activity Benefits	2	Hybrid	Permanent
Other Activities	2	Hybrid	Permanent
Healthy Lifestyle	3	Hybrid	Permanent
Mental Health	3	Hybrid	Permanent
Tracking	Weekly	Hybrid; weekly release	Permanent (resets every seven days)
Exercise Plan (weeks 4 – 8)	3	Tunnelled; delay of four weeks	Temporary (release at four weeks)
Platform Review	8	Tunnelled; delay of eight weeks	Temporary

Note: this table shows each module and their release timing, whether they are dependent on any other modules (e.g., tunnelled), and whether they are a temporary or permanent fixture (temporary being disappears after use and permanent being it remains for the duration of the intervention). The hybrid dependency demonstrated modules were released in small batches however once released did not follow a tunnelled approach.

13.2 Appendix Two: Table of Change

Table 30: Table of Change from the Think Aloud interviews with proposed change, reason for change (if any), agreed change, and MoSCoW criteria.

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
Signup Page and Getting started page					
	"I think it's [the sign up/sign up page] really quite clear. Yeah, it gives me an option to get started now. Or, if I'm already registered. I can log straight in. I'm totally drawn to the it's free. In that. So yeah." – P005	N/A	N/A	N/A	N/A
"You going straight into the getting started and you had that presumption that. Everyone has come to this resource. Specifically for the exercise. Not that they're just a little curious. So why didn't you know, sell it with the benefits at the start" – P001 "Improved well being. I haven't seen much of that being mentioned at the beginning, I think. Maybe do a bit of selling at the start the front end, but yes, that is a nice idea" – P003		Add some information regarding benefits of physical activity to the introductory page	EAS, REP, EXP (via PPI)	Add in some general and lung cancer specific benefits to the introduction module.	MUST
"And I can't see finish" – P001 "Do you want me to click on action plan?" – P003 "So. It says please click finish in your bottom right to continue. I can't see that.. it's got action plan there in the		Change the button which says "Action Plan" to "Finish"	REP, EAS	Change the button which says "Action Plan" to "Finish"	MUST

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
bottom right. So is that where I'm going?" – P005					
	"Yeah, I do think it's quite a good idea. Just in case people aren't, you know, would rather do visual than reading." – P005 "Yeah, I like the idea videos coz I like. I think yeah. By seeing. Like a visual learner, I think I'm all. Yeah I like to see what someone is doing rather than just read. What I'm meant to do? If you can see the video, it's easier to know we supposed to be doing. And you last likely to make mistakes." – P007	N/A	N/A	N/A	N/A
"It looks inviting, yeah. It looks inviting it doesn't. It doesn't look specific to lung cancer, so I might be thinking, Oh my gosh is it people like? Is it doing during a triathlon? Who are signing up for it? Do you know what I mean? And would that be way out of my league?" – P007		Add the phrase 'living with and beyond lung cancer' onto the sign-up page	EAS, EXP (via PPI)	Added the phrase 'who have had a lung cancer diagnosis'	SHOULD
"I'm having to lean forward and struggling to read it [the dashboard image]." – P003 "Yes, it's a little small. So yeah. So the screen I'm looking at. It seems to be yeah, quite small and difficult to read." – P004		Make image larger	EAS	Increased the size of the images on this module.	MUST
	"yeah, that's nice, so description. Think it is a compass …yeah, so	N/A	N/A	N/A	N/A

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
	this is a type of thing. That when I was diagnosed I would have quite liked. You know, cause I did ask a lot of questions. And they were not really met very clearly. Or with a lot of sort of confusion" – P004				
	"I think. Yeah. It's it's easy to read, it's nice. It's a nice size font and text. Yeah." [getting started module] – P005	N/A	N/A	N/A	N/A
	"Ohh, I love videos. That's great. Really relieved, now. I've got to here [Participant is referring to the video in the getting starterd module.] because I'm thinking. Information, information information. Will I remember this? Did I need it? But now I've seen this and that's wow that's great." – P006	N/A	N/A	N/A	N/A
"Maybe for someone like me it might be helpful. So my up here. You we have got videos to support you. Because I might have stopped scrolling down to be honest and gone into one of these things before I realised there was a video. I think it's quite important" – P006		Let people know there are videos further down?	NC, EXP (via PPI)	The detail regarding videos below was not provided earlier.	N/A
Physical Activities and Exercise					
	"I think this is a really good without even reading the questions. The bullet you can click on. When	N/A	N/A	N/A	N/A

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
	someone's looking at that, they can rattle through there very quick. And see what they're doing sort of thing" – P002				
	"I mean, the visuals are good, they're very clear in terms of what you need to do" – P002 "And the animations good. It's a good size." – P005 "You know what I like? The animation is very simple. There is sometimes you look at YouTube for example. They talk about the call and they give you far too much information. Well, that's really, really simple. Which is good. I'm not being blinded by science here"	N/A	N/A	N/A	N/A
"Again, I think that could be, I think that could be a bit bigger" [aerobic walking advice] – P005		Increase the size of the aerobic advice	EAS	Increased the size of the table	MUST
"We ask a couple of questions. Are there any limitations which you may have? So we ask a couple of quick questions. Please answer the following eight questions. Well, are there two questions or eight?" – P007		Change "couple of quick questions" to "some quick questions"	EAS	Changed "couple of quick questions" to "some quick questions"	SHOULD
"I am not sure, or understanding what it is you're asking, I am guessing, you are asking what I do at the moment or are you asking what experience I have had in the past" – P001		Revise question to include the terms "past and present". Additionally, add an example.	EAS, EXP (via PPI)	Revised to state "How would you rate your current physical activity and exercise ability?" and added an example.	MUST

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
"How would you rate? Erm. I don't know with how would you rate your exercise experience. Erm. What does that I mean? I'm not, yeah, I'm not understanding that really. As in my experience with equipment in the gym. I don't know" – P005					
"I guess that is now and erm, probably needs some more clarification, as in do we class walking as exercise, or do we class erm, more than walking, like in a gym or doing yoga or something" – P001		Add in some examples	EAS, EXP (via PPI)	Added in a range of examples, including lighter activities.	SHOULD
"Another thing that's missing here is what's the benefit? If I was someone who picked this up and was told to do a standing dumbbell row, what am I getting out of it" – P002		Add in per exercise what is the benefit	NC, EXP (via PPI)	No change. PPI group voiced concerns this may over complicate the currently clear information.	N/A
"And then the same again. I guess. There's no instructions on this one." – P002 "Oh, this button doesn't seem to be. Is it coming up?" [referring to the Triceps kickback] – P003 "I'm doing the. Show instructions but they're not coming up." – P005		Remove bug preventing show instructions not working on multiple exercises.	EAS	Removed bug, show instructions now work for all exercises.	MUST
	"Yeah, I like that building up as you go through" – P003	N/A	N/A	N/A	N/A
"So along the scale it hasn't got a number, so it's difficult to use" – P004		Provide numbers along the bottom	EXP (via PPI)	Provided numbers along the scale	COULD

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
"maybe it should be a little larger" – P004 "The actual button you can click on could be a bit bigger or maybe." – P005		Increase the size of the show instructions button	EXP (via PPI)	Increased the size of all show instructions for resistance exercises and changed colour to pink to increase awareness	SHOULD
	"There's a good range of exercises. Yes, fairly clear and straight forward" – P004 "I think the instructions are really clear. Erm, I like, I like how it's out there with the instructions and then the key points is really good." – P005 "Yep, that's good and clear" – P006	N/A	N/A	N/A	N/A
SMART Goals and Action Planning					
	"Right so yeah. I mean, yeah, it's easy to understand. And yeah. I can press finish." – P001 "Yeah. Yep. Yeah, quite like that, it's quite nice" – P003 "Well, I say. Okay. Okay, that's quite clear, yeah. Okay, yeah… Yes, it's clear, Yep." – P004 "yeah, but I like the. The responses my responses are in bold. That makes it quite clear… Or print this out, so that's good." – P005	N/A	N/A	N/A	N/A
"The only thing I would say you know. Having a calorie restriction as a risk. I don't know if it's not day and age, is that considered to be healthy or not?" – P002		Replace calorie specific goal example with another healthy	EXP (via PPI)	Reinforced the physical activity theme with another physical activity SMART goal example.	

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
		lifestyle focused goal			
"That's a strange way of saying, isn't it about your goal setting habits… Would it be simpler, are now going to ask you too. Going to ask you a few questions. To help you set your goals." – P003		Revise question to "we are now going to ask you about your goal setting experience"	EXP (via PPI)	Revised to " We are now going to ask you a few questions about setting goals in relation to exercise."	SHOULD
"Yes, that [Q1] shouldn't be yes or no, should it?" – P003		Change to Yes, sometimes, no?	NC, EXP (via PPI)	No change based on discussion with PPI members.	N/A
"So for your overall goal, I would think your overall goal was I would like to be eating 2200 calories per day and two pieces of fruit and veggies snacks regularly by the 15th by the 15th of June. So I would say that the overall goal" – P007		Identify which goal is the generic non-SMART goal and the SMART goal below.	EAS, EXP (via PPI)	Labelled the generic non-SMART goal and the SMART goal for clarity and readability.	MUST
"I'm not really sure about this box to be honest" [the types of exercises question] – P003		Add extra information tab detailing examples of activities	EAS, EXP (via PPI)	Added extra information tab detailing examples of activities discussed with the PPI group	MUST
"Is it the show extra help? Boxes, are they dynamic or are they static? …Yeah, I mean I said. If I've said I want to increase my body strength. Walking is not necessarily going to do. It's probably not the best. I need to do sort of weight and resistance and stuff" – P003		The extra information boxes change based on the information provided by the participant throughout the website.	NC	Not currently feasible.	N/A
"So you have a box that's not clear. For this module you are aiming.		Create a placeholder to guide participants	EAS, EXP (via PPI)	Created a placeholder to guide participants and	SHOULD

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
Okay. Maybe another prompt to say where you put your goal in" [the box to write your goal in] – P004		and created a darker and thicker boarder.		created a darker and thicker boarder.	
"it says we mentioned a specific method, where was that mentioned or have I missed it?" – P005		Remove the statement detailing prior mentioned goal setting content.	EAS	Removed the statement detailing prior mentioned goal setting content.	MUST
	"Yes, it's quite nice [SMART goals infographic], different colours. Sort of stand out a little" – P004 "Okay. Er. Like the colours on that, it's nice [SMART goal infographic]." – P005	N/A	N/A	N/A	N/A
	"that's good -extra help button on action plan], yeah. Because I wouldn't over remembered" – P005	N/A	N/A	N/A	N/A
"I'm trying to press the enter button but it's it falls under but it's not letting me I can only go on" – P001 "Oh, then I want to. I want to return. To put the M underneath, but it's not letting me… So I want to set out the same as above, but I can't because of the textbox." – P005		Edit code to allow return function in text area.	REP	Revised website code to allow return function in the text area.	SHOULD
	"And it's good that I've got your examples. It's definitely good that I've got your examples" – P005 "I think it's definitely good to have the examples. To help you along... It's really quiet. It's really quite good advice" – P005	N/A	N/A	N/A	N/A

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
"Right at this point, I would leave the site. Because I I've got nothing inspiring me I. I would love to. Eat healthier I would love to. Most importantly, exercise. Tell my condition. But this is all intellectual. It's asking me to know to. Although I guess I could type that in. But I haven't seen anything yet that says to me this is different. This will grab you. This will enable you. Not the first time, but you know since diagnosis. Give me some inspiration. You know, maybe I can get to with this programme" – P006		Insert content to illustrate how this platform is different and the benefits which can be gained.	NC, EXP (via PPI)	Inspirational content added to the getting started module was deemed sufficient.	N/A
Accessing Library and Connections and Contacts Page					
"Library. Hmm, erm. That was. I would not normally go to library. It was only my brain trying to think it through so…The probably should be something on the front saying useful information or something." – P001		Change to supporting information	EAS, EXP (via PPI)	Revised 'Library' to 'Extra Information'	MUST
"I think it could be more pleasing to the eye" – P001 "I mean, the only thing is it's very quiet, isn't it?" – P002		Redesign layout with mirrored layout to dashboard	IMP, REP	Mirrored dashboard to confusing. Inserted image header to all hyperlinked pages,	MUST
"Support group OK, there's nothing. Or this is the homepage, isn't it? I probably go to about or maybe the library. I don't know really where to go. Help maybe help. Oh no. So it wouldn't help. It's not help, I'd go into		Revise the name of 'Connections and Contacts' to 'Support Information'.	REP, EXP (via PPI), EAS, IMP	Revised the name of this page to 'Groups and Contact Information' with a thumbnail image.	MUST

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
about. It's about the exercise about. It's about the people involved. There's nothing there. Library" – P007 "Erm. There's nothing jumping out with me right now. Like bonus content type of thing." – P002 "I don't think I would have found it without your help. You know what I mean? I can see how you would go into the library" – P007					
Help and Contact Us					
"But that one probably won't be. I'll go to the about page." – P001 "Usually on their website they will be a contact us at the bottom. but maybe in this one it will be in the about." – P002 "For a technical problem, possibly it depends what the problem is. But if I just wanted to contact you, ask you a question. I wouldn't think of going to help" – P003 "As you can see, it wasn't the first place I went to. Because I went straight to home. Thinking that might be. Something on there? And then I went to about…. I don't know a contact. At the top" – P005		Insert contact information onto the About page.	REP, EAS, EXP (via PPI)	Inserted hyperlinked email contact information and hyperlinked guidance to the help page. Furthermore, changed 'Help' to 'Contact'	MUST
	"I mean, it seems fairly straight forward. Your text box. You could say whatever you want" – P002	N/A	N/A	N/A	N/A

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
	"Yeah, yeah, that's really good" [the message function] – P005				
"I mean, it's nice providing this form, but it has that drawback that it's gone." – P003		Send carbon copy email to the participants registered email.	EAS	The platform will send a carbon copy email to the email address the participant has registered on the platform.	SHOULD
	"Yeah, I think that's really good [the pre-populated email field]. It's good because what you often see isn't it." – P006	N/A	N/A	N/A	N/A
"Yeah. I mean the other thing I'm thinking about is chat. You know when the chat things come up. That might be helpful. If someone is getting stuck" – P006		No possible change at the point.	NC	No change. Possibly in future pending size of team.	COULD
Feedback/Tracking					
	"That's quite good [the tracking module]. You know it gives people to. Keeps people engaged" – P002	N/A	N/A	N/A	N/A
"if you say it may be useful to write down some thoughts, on the aerobic exercises, exercises you did this week, so what ort of thoughts are you wanting me to write?" – P007		Added an extra information tab which gives two examples of thoughts.	EAS, EXP (via PPI)	Provided extra information tab with specific aerobic exercise examples. Examples were discussed with a dedicated PPI group of those caring for or LWBLC.	SHOULD
"Muscular strength. How would I rate my muscular strength? I don't know what to put there either" – P007		Added an extra information tab to provide some examples and	EAS, EXP (via PPI)	Provided extra information tab with specific strength exercise examples. Examples were	SHOULD

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
		questions to help guide participants.		discussed with a dedicated PPI group of those caring for or LWBLC.	
	"That's good, having the calendar you can just click on" – P005	N/A	N/A	N/A	N/A
	"This [the feedback] is, yeah, this is nice. Yeah. You get like a report. Yep, that's good" – P005	N/A	N/A	N/A	N/A
Explored Other Modules					
	"I would take that as in seven days they will unlock"	N/A	N/A	N/A	N/A
	"I like the video demonstration. That would be great." – P001 "That all looked good. Good information, good diagram, good video so. So yeah." P001 [Breathlessness module]	N/A	N/A	N/A	N/A
"When I pressed on the video, I didn't want to watch it all. And then I didn't know how to come out of it. That was the only thing."		Provide written instructions of video controls.	EAS	Provided written instructions with supplementary figures to illustrate video controls.	SHOULD
"If I haven't thought of after the first week. I haven't been motivated by the 2nd week. I'll probably give up. And not go back in again. So yes, I think it should be sooner. [motivation module]" -P001		Reduce the time delay of the motivation module from seven day to three days	EAS, EXP (via PPI)	Reduced the time delay of this module from seven days to zero.	MUST
	"yes, then I suppose when not overwhelmed with all different	N/A	N/A	N/A	N/A

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
	modules. Yeah, because if there was loads of modules, yeah. I think that's a good idea, actually, yes. Yes, because sometimes it can be overwhelming" [staggered release of modules] – P001 "Oh no, definitely, definitely. Something to keep people engaged and get them coming back" – P002 "A staggered approach is good. Yes… You want to keep them interested. You want to keep them going" – P003 "No, yeah yeah, I think it's. It's a good idea, really. Build it up" – P004 "I think staggered. Yeah, because otherwise. It's gonna be information overload" – P007				
"One of the questions. How many hours a night do you get sleep? Do you do anything to help people get more sleep? Is there anything sort of showing how to get a better night's sleep?" – P001		Provide more in-depth content on sleep in the Healthy Lifestyles module	EAS, EXP (via PPI)	Maintained summary tailored sleep content with a dedication sleep page in the Extra Information page.	SHOLD
"I mean, would safely not be best at the start" – P002		Reduce time delay to seven days for the safety module	EXP (via PPI)	Increased the initial safety content in the exercise plan module and delayed the safety module to seven days.	MUST
"This is quite a strong this question [smoking habits]. And as much as. It		Swap questions regarding cancer	EAS	Create an introductory message and replaced first	SHOULD

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
goes back to the stigma. That's a smoking disease. Should it be the first question" – P002		treatments received (Q2) with smoking habits (Q1).		question with a question regarding cancer treatments received.	
	"It's all good. They're all good questions" – P002 "So yeah, that was. That was very useful, yeah" – P004 [Health lifestyle module]	N/A	N/A	N/A	N/A
"But what's this benefits of physical activity? Are you going to be? I'm just wondering why that's down there. Shouldn't you be plugging the benefits? Early on maybe straight away…But you do need to get them in hooked in in the 1st place, don't you? So you need to sell some of the benefits upfront, like. Main benefit for me. Was working on fatigue. Almost all of us cancer patients. Fatigue is the thing. Consistent. Over 100% of her sort of thing" – P003		Reduce the time delay for the Benefits of Physical Activity module to seven days		Added in general and lung cancer specific benefits (with hyperlinked literature) to the introductory modules and reduced the time delay to seven days.	SHOULD
"I'm just wondering on this sort of thing. I've tried it myself. And not done very well with it. But would there be anything on there with mindfulness and stuff?" – P005		Integrate mindfulness into the prescription	NC	No change at the current stage. Mindfulness is a future direction.	WOULD
"And there's nothing in here that's making me. That's grabbing me or inspiring me. It's all logical to all rational. But not getting me emotionally. And I think it's a real conundrum" – P006				Hook, emotional hook? Inspiration?	

Negative Comments	Positive Comments	Possible Change	Reason for Change	Agreed Change	MoSCoW
"Maybe some examples of what they [cues and triggers] could be" – P006	"OK, good. I'm instantly thinking this is what I need… I really like that we are really excited about you and your interests. I reckon we need to have that blaring earlier" – P006 "I think I think this is really good. Because it is all about. Forming a new habit." – P006	Add an example of a cue and a possible response	EAS, EXP (research team)	Added an example of a cue and the associated actions/responses within the module under 'Habit Formation'	SHOULD
"Yes, I'm tilting my head. I'm wearing bifocals and that's really small… It's just a bit small"		Increase the size of the enabled and barriers figure	EAS	Increased the size of the enabled and barriers figure	MUST

Note: IMP: Important for behaviour change; EAS: Easy and uncontroversial; REP: Repeatedly; EXP: Experience; NCON: Does not contradict; NC: Not changed; MoSCoW: Must, Should, Could, Would.

13.3 Appendix Three: Ethical Approval Letters

13.3.1 Hull York Medical School Faculty Ethical Approval for the Think Aloud Interviews

HULL YORK MEDICAL SCHOOL

Hull York Medical School

Hull
University of Hull
Hull, HU6 7RX, UK

York
University of York
York, YO10 5DD, UK

T 0870 1245500
info@hyms.ac.uk
www.hyms.ac.uk

2 December 2020

Jordan Curry
Post Graduate Research Student
Hull York Medical School

Dear Jordan

20 49 – Usability of a Tailored Web-Based, Physical Activity Program for those living with and beyond lung cancer.

Thank you for submitting your application to the HYMS Ethics Committee.

The application has been reviewed by the HYMS Ethics committee with respect to the clarification received on 22 October 2020 and resubmission documents received on 23rd November 2020.

I am pleased to inform you that I do not have any HYMS specific ethical concerns and am happy to confirm HYMS Ethics approval.

On behalf of the Ethics Committee, we wish you success with this study.

Kind regards

Yours sincerely

Professor Thozhukat Sathyapalan
Chair
HYMS Ethics Committee

UNIVERSITY OF HULL · UNIVERSITY of York · Athena SWAN Silver Award

Figure 31: 13.4.1 Hull York Medical School Faculty Ethical Approval for the Think Aloud Interviews

13.3.2 Ethical Approval and Sponsor Letters for the Feasibility and Acceptability study.

HULL YORK MEDICAL SCHOOL

Hull York Medical School

Hull
University of Hull
Hull, HU6 7RX, UK

York
University of York
York, YO10 5DD, UK

T 0870 1245500
info@hyms.ac.uk
www.hyms.ac.uk

19 March 2021

Mr Jordan Curry
PhD in Medical Science
Hull York Medical School

Dear Jordan

21 16 – Feasibility and acceptability of an online web-based physical activity program, for those living with and beyond lung cancer.

Thank you for submitting your application to the HYMS Ethics Committee. The application has been reviewed on behalf of HYMS Ethics Committee with respect to the documents received on 17th March 2021.

I am pleased to inform you that I do not have any HYMS specific ethical concerns and am happy to confirm HYMS Ethics approval. Please send a copy of the HRA approval letter to the HYMS Ethics email address (ethics@hyms.ac.uk) when you obtain it.

On behalf of the Ethics Committee, we wish you success with this study.

Kind regards

Yours sincerely

Professor Thozhukat Sathyapalan
Chair
HYMS Ethics Committee

UNIVERSITY OF HULL

UNIVERSITY of York

Athena SWAN Silver Award

Figure 32: Ethical Approval and Sponsor Letters for the Feasibility and Acceptability study.

13.3.3 NHS Health Research Authority and Healthcare and Research Wales Approval Letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Cynthia Forbes
University of Hull
Allam Medical Building
Hull
HU6 7RX

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

08 July 2021 *(re-issued 06/10/2021)*

Dear Dr Forbes

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Feasibility and acceptability of an online web-based physical activity program, for those living with and beyond lung cancer.**
IRAS project ID:	**281450**
Protocol number:	**RS145**
REC reference:	**21/SC/0174**
Sponsor	**University of Hull**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Figure 33: NHS Health Research Authority and Healthcare and Research Wales Approval Letter

13.3.4 University of Hull Sponsor Approval Letter

UNIVERSITY
OF HULL

Dr David Richards, FEI
Pro-Vice-Chancellor (Research & Enterprise)
University of Hull
Hull, HU6 7RX
United Kingdom
T: +44 (0)1482 466732 | E: David.Richards@hull.ac.uk
w: www.hull.ac.uk

29 April 2021

Jordan Curry
HYMS

Dear Jordan

Project Title : Feasibility and acceptability of an online web-based physical activity program, for those living with and beyond lung cancer
RS145

I am writing to confirm that the University of Hull has agreed to act as sponsor, subject to approval being granted in accordance with the Department of Health Research Governance Framework for the project: "Feasibility and acceptability of an online web-based physical activity program, for those living with and beyond lung cancer".

Yours sincerely,

Dr David Richards, FEI
Pro-Vice-Chancellor (Research & Enterprise)
(Chair of University Research Committee)

cc Dean
Research Governance

Figure 34: University of Hull Sponsor Approval Letter

13.4 Appendix Four: Topic Guides for Interviews

13.4.1 Think Aloud Interviews Topic/Task Guide

--- Introduction Activity ---

1. Completion of The Entry Baseline Questionnaire

The Entry Baseline Questionnaire allows the researcher to collect self-report data on the participants disease status, health status, and socio-demographic information. This information will be used to help tailor the physical activity programmes for the participants.

Questions such as the following be asked:

a. When you log on you will be asked to fill out the online entry questionnaire. Can you walk us through your thoughts on the entry questionnaire? If you have any concerns about any question, please speak aloud your concern or thoughts.

2. Accessing and Opening a Physical Activity Session

The participants will be asked to locate and open the physical activity session within the online platform. They will be asked to locate the sessions where they think they would be located.

Prompts will be provided if the participant can not find the location.

Questions such as the following be asked:

a. Can you please locate and open a physical activity session?
b. Where do you think this should be?
c. Would this be where you thought it would? If not, where would you expect to find this section.
d. Please try locating the instructions for the exercises

3. Logging the Activity Session

After completing the opening of the sessions, the participants will be asked to walk through the physical activities chosen for them and provide feedback on the description, animation, and visual guide. This will primarily consist of verbal giving feedback on their thoughts while transitioning through the physical activity programme.

Questions such as the following be asked:

a. Is the written instructions clear for the physical activities provided?
b. Are the animations clear and useful?
c. What are your thoughts on the video visual aid?
d. Is the text size appropriate?

4. Accessing the Modules
    a. Can you please locate and complete the SMART Goals module as you would I you were normally using the website?
    b. Is the modules page where you thought it should be?
    c. Do you think the module page should be located elsewhere?

5. Setting a Personal Goal and Review Action Plan

Questions such as the following be asked:

a. Please locate the goal setting page
b. Please fill out a goal you would like to set relating to your physical activity levels.
c. How did you find the goal setting platform?
d. Does the action plan make sense?

6. Accessing the Connections and Contacts page

Questions such as the following be asked:

a. We have some information which is supplementary to the modules on the main dashboard, could you please locate the connections and contacts page?

b. Is this page is where you thought it would be?
c. If not, where should it be or how could it be better highlighted?

7. Could you locate the way in which you would seek help from us if you needed it?

Questions such as:

a. Could you try to locate where you would find a way of seeking the research team out for help or to report a problem you're having with the website or your activity programme?
b. Does the email page make sense?

8. Final thoughts on the website?

Questions such as:

a. How did you find the platform?
b. Is there anything you have thought about you would change?
c. Would you recommend something like this to those living with and beyond lung cancer?

13.4.2 Feasibility Study Topic Guide for Post-Study Interviews with Patients

1. Building rapport, confirming known details
2. Overall thoughts on the website?

a) Before we get into my questions, I wanted to give you an opportunity to tell me about any thoughts or reflections of the study and your use of the website. How has it gone? (open ended chat, actively listen to the participants thoughts).

3. Any previous or current barriers to engagement in physical activity?

a) Before starting the study, did you have any barriers which stopped you participating in physical activity?

b) Did the website help towards understanding your barriers and providing you with assistance to overcome these?

4. Impact of the study

a) Behaviour changes

   i. Did you find it easy to start the physical activity programme?
   ii. Where there any situations you did not want to do the programme? If so, what were they?

b) Attitude change

   i. Has this study and platform changed your thinking towards physical activity? (importance, enjoyment, satisfaction)
   ii. Mental health and wellbeing
   iii. Has the website had any impact on your mental health?

5. Strengths and Limitations

a) Usability:

   i. Did you find the website usable?
   ii. Was the website user friendly?
   iii. Did you find the website to be satisfactory? If so, why?

b) Is there anything you liked or did not like about the online platform?

6. Close

a) Thank you very much for taking the time to chat with me today, unless there is anything you would like to add or any further questions for me then that is the end of the interview.

13.5 Appendix Five: Published Manuscripts from the Doctoral Degree

13.5.1 Feasibility, acceptability, and efficacy of online supportive care for individuals living with and beyond lung cancer: a systematic review.

Permissions:

Supportive Care in Cancer (2021) 29:6995–7011
https://doi.org/10.1007/s00520-021-06274-x

REVIEW ARTICLE

Feasibility, acceptability, and efficacy of online supportive care for individuals living with and beyond lung cancer: a systematic review

Jordan Curry[1] · Michael Patterson[1] · Sarah Greenley[2] · Mark Pearson[1] · Cynthia C. Forbes[1]

Received: 6 March 2021 / Accepted: 4 May 2021 / Published online: 18 May 2021

Abstract

Purpose To examine the evidence of the feasibility, acceptability, and potential efficacy of online supportive care interventions for people living with and beyond lung cancer (LWBLC).

Methods Studies were identified through searches of Medline, EMBASE, PsychINFO, and CINAHL databases using a structured search strategy. The inclusion criteria (1) examined the feasibility, acceptability, and/or efficacy of an online intervention aiming to provide supportive care for people living with and beyond lung cancer; (2) delivered an intervention in a single arm or RCT study pre/post design; (3) if a mixed sample, presented independent lung cancer data.

Results Eight studies were included; two randomised controlled trials (RCTs). Included studies reported on the following outcomes: feasibility and acceptability of an online, supportive care intervention, and/or changes in quality of life, emotional functioning, physical functioning, and/or symptom distress.

Conclusion Preliminary evidence suggests that online supportive care among individuals LWBLC is feasible and acceptable, although there is little high-level evidence. Most were small pilot and feasibility studies, suggesting that online supportive care in this group is in its infancy. The integration of online supportive care into the cancer pathway may improve quality of life, physical and emotional functioning, and reduce symptom distress. Online modalities of supportive care can increase reach and accessibility of supportive care platforms, which could provide tailored support. People LWBLC display high symptom burden and unmet supportive care needs. More research is needed to address the dearth of literature in online supportive care for people LWBLC.

Keywords Lung neoplasms · Supportive care · Online · Feasibility · Review

Introduction

Lung cancer is the leading cause of cancer-related death internationally for both men and women [1]. It is a debilitating disease which has a large effect on quality of life (QoL) [1]. Though the median life expectancy for people diagnosed with lung cancer remains poor, advances in screening and curative treatments for lung cancer have contributed to the 9% reduction in mortality over the last decade and extended life expectancy [2, 3]. Increasing survival rates have been reported [4, 5], however, curative treatments can elicit a myriad of adverse physiological and psychological effects which can reduce QoL (e.g. fatigue, dyspnea, and depression) [1, 6, 7]. In fact, people living with and beyond lung cancer (LWBLC) have reported greater unmet psychological and physiological needs in comparison to other types of cancer [8, 9]. Unmet needs are those needs which do meet the level of support required for optimal health [10].

Supportive care can be defined as care that helps an individual living with and beyond cancer and/or their immediate family or caregivers cope throughout the treatment pathway, from diagnosis to continuation through the illness or death [5]. Evidence suggests that supportive care needs for people LWBLC have noticeably increased [11]. A systematic

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Figure 35: Published systematic review.

review examining the supportive care needs of people living with lung cancer reported nine distinct domains of supportive care needs: physical, psychological, spiritual, cognitive, communication, social, daily living, practical, and informational [12]. The nine domains highlight the considerable burden among people LWBLC and the importance of supportive care interventions.

The internet and digital technology have become an important resource used within the oncology community, both for people living with and beyond cancer and oncology professionals [3]. Utilizing digital technology to deliver oncological supportive care has attracted significant interest over the recent years [13–15], with the potential to deliver tailored, inexpensive care while achieving mass reach [16, 17].

Thus far, online health and supportive care services have largely focused on breast and prostate cancer [17, 18]. Few online supportive care platforms exist for people LWBLC, despite the need and potential benefits to patients [13–15]. Though reviews have explored the use of online and digital interventions among mixed cancer types [17, 19], specific cancer-related needs and symptom burden vary considerably [17]. Those who live five or more years post-lung cancer diagnosis are referred to as 'Long-Term Lung Cancer Survivors' (LTLCS) [20]. In comparison to their age-matched counterparts from other types of long-term cancer survivors, LTLCS display the lowest QoL [20, 21]. In the USA, an estimated one in four LTLCS are living with significant restrictions in physical functioning and depressive mood symptoms [20].

McAlpine et al. (2015) critically examined the efficacy of online interventions for cancer patients, highlighting the uncertainty of the benefits with mixed results [17]. Among the 14 studies included in the McAlpine review, the majority focused solely on breast cancer with only three studies independently reporting lung cancer, head and neck cancer, prostate cancer, and four reporting mixed cancer types. McAlpine and colleagues illustrate that though there is increasing interest in online technology within oncology care, there is a lack of literature regarding efficacy. This may be partially due to the small portion of studies which present a quantifiable and a clinically meaningful evidence-base [17].

To appropriately develop and appraise literature for people LWBLC, cancer type must be used as a moderator, allowing specific evaluation on the feasibility, acceptability, and efficacy of online technologies for people LWBLC. Thus, this review aims to examine the evidence of the feasibility, acceptability, and potential efficacy of online supportive care interventions for people LWBLC. For the purpose of this review, online supportive care will be defined as interventions delivered using online mediums which aim to meet a person's physical, social, informational, spiritual, practical, and/or psychological needs during the diagnostic, treatment, and follow-up phases of the cancer spectrum [22].

This review will examine individuals LWBLC. For the purpose of this study, LWBLC is any individual who has had a diagnosis of lung cancer or cancer within the lungs.

Methods

The review adheres to the reporting of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses [23]. A standardised data extraction form [24] was adapted for the extraction and review of all data. Ethical approval was not required.

Eligibility criteria

Eligibility of studies was based upon inclusion and exclusion criteria developed a priori (PROSPERO ID: CRD42020171847). A study's eligibility was based on whether it met the following conditions: (1) examined the feasibility, acceptability, and/or efficacy of an online intervention aiming to provide supportive care for people LWBLC; (2) single arm or RCT study pre/post design; (3) if a mixed sample, presented independent lung cancer data. Studies were excluded based on the following conditions: (1) mixed sample data was presented with no individual lung cancer data (mixed cancer types); (2) articles were not provided in English; (3) full text articles were not available.

Search strategy

The databases EMBASE, Medline, PsychINFO via OVID, and CINAHL via EBSCOhost were searched from their inception up to April 2020. MeSH terms were identified for the key concepts in Medline and the equivalent adapted for subsequent databases. The development of the search strategies, per database, was completed with the assistance of an Information Specialist (SG). Boolean operators were used to combine MeSH terms and keyword terms to develop a pilot strategy. The pilot strategy was executed in Medline and refined to ensure the relevance of the search output (see Online Resource 1). The search strategy for Medline, EMBASE, and PsycINFO focused on the following: lung cancer AND (Internet OR social media/online supportive care interventions). Whereas the terms in CINAHL were lung cancer AND social media platforms AND internet platforms. All searches were conducted by a single author (JC).

Study selection

All articles identified through the database searches were exported to a citation management software (EndNote, X9.2), wherein duplicates were removed. Rayyan citation screening software was used post-deduplication by two

authors (JC and MPa) to screen titles and abstracts against pre-specified inclusion criteria. Disagreements were discussed and resolved by mutual consensus.

Data extraction and methodological quality assessment

Data from the included studies were extracted using a data extraction form, which was developed by the research team following a recommended template [24]. Data regarding study setting, participant characteristics, study design, intervention procedure, outcome results, and findings relating to feasibility, acceptability, and efficacy of the intervention were extracted. The extraction form was piloted by two of the authors (JC and CF) to ensure it captured all relevant information on paper. No changes were made, and the remaining articles were extracted independently by JC, with 100% of the articles also extracted by a second author (MPa). The two authors had one disagreement regarding the extraction of qualitative text from one article [15], but was resolved by mutual consensus with input from a third author (CF).

The methodological quality of the studies was assessed via the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields [25]. This tool provides independent subscales for methodological assessment of qualitative and quantitative data. The tool allows for a broad assessment of quantitative studies including non-randomised, pilot, and feasibility studies. The tool selected for this review was with consideration of the study designs [26, 27] and prior literature [28, 29] in mind. The tool was chosen based on the importance of including a wide range of study designs, as it has been noted that within single study designs, aspects such as feasibility, reliability, validity, and utility are variables often unmeasured [30].

Study quality was rated in accordance with the following accepted scoring methods, > 80% "strong", 71–79% "good", 50–70% "adequate", and < 50% "poor" [28, 29, 31]. If any uncertainty surrounding the initial assessment of the level of bias within a study was noted between the two authors, a member of the research team (MPa) assisted in reaching a consensus. Studies were not excluded from the synthesis of this review based on the rating of study quality.

Outcomes

The following outcomes were assessed to ascertain feasibility: (1) recruitment and retention rates, (2) recruitment barriers, (3) intended implementation, (4) cost of implementation. Outcomes assessing acceptability were: (1) acceptability and satisfaction, (2) intervention adherence rates, (3) intervention burden, (4) noted adverse effects. Efficacy was reported for RCTs only. The outcomes relating to efficacy was assessed by the effect of supportive care relative to the comparison group for the outcome measured.

Results

Study selection

A flow chart detailing the study selection process is presented in Fig. 1. A total of 2468 publications were identified from the following databases: Medline, EMBASE, PsycINFO, and CINAHL. One additional article was identified through hand searching. After the removal of duplicates, 2111 articles were included in title and abstract screening and 128 studies were included in full text screening. Finally, eight articles were acknowledged as meeting the eligibility criteria and were included in data extraction.

Risk of bias/methodological assessment

Findings from the methodological quality assessment are presented for quantitative measures in Table 1 and qualitative measures in Table 2. Based on the assessment conducted independently by two reviewers (JC and CF), six studies were assessed for quantitative methods [32–37] and two studies assessed for both quantitative and qualitative methods [13, 15]. Based on quantitative methods, eight studies were rated as strong [13, 15, 32–37]. For qualitative methods, one study was rated strong [15] and one adequate [13].

Study characteristics

This review included two RCTs [33, 36] and six pilot and feasibility studies [13, 15, 32, 34, 35, 37]. The included studies were carried out in seven different countries, (two in South Korea [33, 34], one each in the USA [37], France [32], Canada [35], Netherlands [13], Taiwan [36], and the UK [15]). Of the eight studies, seven comprised solely of individuals LWBLC [13, 15, 32–36], one study explored both carers and individuals living with and beyond gastrointestinal cancer or lung cancer [37]. Specifically, of the studies focusing on independent lung cancer populations, four focused on Non-Small Cell Lung Cancer (NSCLC) [13, 33, 34, 36], one focused on surgical excision [32], one explored patients with lung cancer, receiving a specific course of radiotherapy [15], and unresectable thoracic neoplasia [35].

Five studies reported the cancer disease stage, ranging from I to IVb [32–36], one study reported the ASA Physical Status Classification System (ASA) [37], and two studies did not report the stage of cancer [13, 15]. Treatment types reported were chemotherapy [34–36], thoracic radiotherapy [15], and maintenance therapy [32]. One study reported the extent of surgery participants had [13] and two did not report

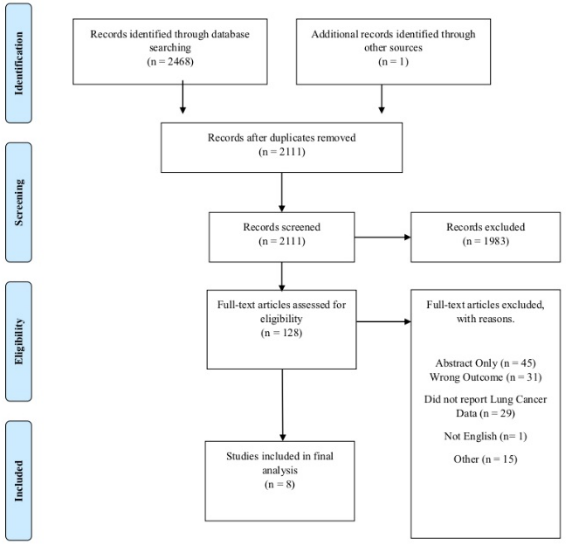

Fig. 1 PRISMA flow diagram [23]

any treatment information [33, 37]. Further information regarding the study characteristics can be found in Table 3.

Intervention characteristics

The three primary domains explored within the eight studies were education ($n = 1$) [36], physical activity and exercise [13, 35, 37] ($n = 3$), and self-evaluation and symptom monitoring ($n = 2$) [15, 32]. Two studies of the eight combined exercise and symptom management ($n = 2$) [33, 34].

One study focused on investigating the impact of a web-based health education program on global quality of life, quality of life-related function, and symptom distress over a 3-month period [36]. Another 3-month intervention explored the outcomes of home-based pulmonary rehabilitation (PR) regarding exercise capacity, dyspnea symptoms, and QoL in adult receiving treatment for NSCLC [34]. One of the interventions explored the use of tele-health in two mediums: ambulant symptom and physical activity monitoring (S&PAM) and a web-accessible home-based exercise program (WEP) [13].

The majority of the supportive care was delivered via mobile phone-based applications ($n = 4$) [13, 15, 33, 34], with other mediums including websites ($n = 1$) [36], web-based applications ($n = 1$) [32], video conferencing ($n = 1$) [37], and a Tele-Rehab Station ($n = 1$) [35]. The Tele-Rehab Station consisted of an all-in-one computer system running on a Windows 8 interface. The computer station, developed by the Centre for Interdisciplinary Research in Rehabilitation and Social Integration in Quebec City, was equipped with bio-mechanical and physiological sensors and equipment. The system supports videoconferencing via a connected webcam, providing a medium to deliver the audio-visual communication.

Three studies specified the use of theories and models to inform the design and development [15, 36, 37]. The theories used were as follows: Lafaro et al. (2019) used the Chronic care self-management model (CCM) [38] [37], Huang et al. (2019) is based on Symptom Management theory (SMT) [39] and the e-learning theory [40] [36], and Maguire et al. (2015) used the Medical Research Council (MRC) Complex Interventions Framework [41] [15].

Table 1 Illustrating the breakdown of quality appraisal scores and inter-rater reliability values for quantitative method studies

Author	Checklist item														Inter-rater reliability
	1) Question or objective sufficiently described?	2) Evident and appropriate design	3) Subject selection	4) Subject characteristics	5) Random allocation	6) Blinding of investigators	7) Blinding of subjects	8) Defined androbust outcome measures	9) Sample size	10) Analysis described and appropriate	11) Estimate of variance	12) Controlled for confounding	13) Sufficient Results	14) Results match Conclusions?	
Huang et al., (2019) [36]	2	2	2	2	2	N/A	N/A	2	2	2	2	0	2	2	1 (100%)
Park et al., (2019) [34]	2	2	2	2	2	N/A	N/A	2	2	2	2	N/A	2	2	1 (100%)
Ji et al., (2019) [33]	2	2	2	2	1	N/A	N/A	2	2	1	2	2	2	2	1 (100%)
Lafaro et al., (2019) [37]	2	1	2	2	N/A	N/A	N/A	1	1	2	1	N/A	2	2	1 (100%)
Timmerman et al., (2017) [13]	2	2	2	1	N/A	N/A	N/A	2	1	2	2	N/A	2	2	1 (100%)
Coats et al., (2019) [35]	2	2	1	2	N/A	N/A	N/A	2	1	2	2	1	2	2	1 (100%)
Maguire et al., (2015) [15]	2	2	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	1 (100%)
Denis et al., (2014) [32]	1	1	2	2	N/A	N/A	N/A	2	1	2	N/A	N/A	2	2	1 (100%)

Table 2 Illustrating the breakdown of quality appraisal scores and inter-rater reliability values for qualitative method studies

Author	Checklist item										**Inter-rater reliability**
	1) Question or objective sufficiently described?	2) Evident And appropriate design	3) Clear context for the study	4) Linked to a theoretical framework	5) Appropriate and detailed sampling strategy	6) Clear and detailed data collection methods	7) Complete, appropriate and systematic data analysis	8) Verification procedure(s) used in the study	9) Conclusions supported by results?	10) Evident reflexivity	
Maguire et al., (2015) [15]	2	2	2	2	2	2	2	0	2	0	1 (100%)
Timmerman et al., (2017) [13]	2	2	1	1	1	1	1	2	2	0	1 (100%)

Feasibility and acceptability

Of the eight studies, six were deemed feasible by the study authors [13, 15, 32, 34, 35, 37], with two studies not stating feasibility outcomes [33, 36]. Though, studies that did not explicitly state feasibility outcomes still presented recruitment and retention rates. Huang et al. (2019) reported 91.67% recruitment rate and 100% retention rate. Ji et al., (2019) reported 40.5% recruitment rate and 67.17% retention rate. Three studies did not report the recruitment rates [32, 34, 35]. The mean recruitment rate of the five studies was 62.83 ± 27.99% [13, 15, 33, 36, 37]. Only one study reported a recruitment goal, which was not met [15].

The mean retention rate for the eight studies was 84.77% (67–100%). In two studies, the loss to follow-up was due to the death of participants during the studies [15, 32]. Several concerns pertaining to recruitment were noted, such as little or lack of familiarity with digital technology and the internet, emotional burden, poor health status, lack of interest, knee replacement, scheduled surgery, and patients felt adequately supported by their clinical team and required no further supportive care [13, 15, 34, 37]. Reasons noted for dropout were emotional burden, complications following surgery, cancellation of surgery, and hospital transfer [13, 34, 37]. Of the eight studies, none reported cost or financial cost of the study. Majority of the studies require health care professionals, researchers, and equipment, yet the monetary costs were not discussed. One study highlighted the absence of costing the intervention as a limitation [13]. Detailed information on feasibility results can be found in Table 3.

Due to the varying study designs, adherence was assessed in only three studies [32, 35, 37]. Adherence rates and compliance rates were used as the two primary methods of assessing adherence within the given studies. The mean "adherence rate" was 84.5% (73.5–100%) in the three studies. Adherence rates were defined by the completion of forms [32], completion of exercise sessions [35], and mean sum of pedometer use preoperative and post-discharge [37]. Lafaro et al. (2019) presented adherence rate for both lung and gastrointestinal cancer combined, not as independent outcomes.

Five studies reported one or more measures of satisfaction, with majority of participants reporting they were highly satisfied with the interventions [13, 33–35, 37]. Three studies did not report measures of satisfaction [15, 32, 36]. One study reported that majority of participants felt reassured and the advice from the intervention was user friendly and easy to understand [15]. Of those which reported measures of satisfaction, two studies reported reasons for dissatisfaction. Reasons reported in one study were lack of interaction with health care professional, insufficient tailoring of exercises, inadequate insight into progression, and difficulty accessing via mobile phone [13]. The second reported dissatisfaction

Table 3 Study characteristics

Study details (author and year)	Population characteristics			Feasibility	
	Sample size; age	Location	Disease stage; treatment	Recruitment rates	Retention rates
Huang et al., (2019) [36]	Intervention $n=27$; mean: 61 Control $n=28$; mean 58.68	Taiwan	Exercise Group: IIIA: 0; IIIB: 6; IV: 21 Control Group: IIIA: 1; IIIB: 2; IV: 23 Treatment: Chemotherapy	91.67%	100%
Park et al., (2019) [34]	$n=100$; mean: 55.1	South Korea	Stage: II: $n=5$; III: $n=0$; IV: $n=95$ Treatment: Chemotherapy	No Information	90% (90/100)
Ji et al., (2019) [33]	Fixed-Interactive Exercise Group $n=32$; mean 60.50 Fixed Exercise Group $n=32$; mean 57.97	South Korea	Fixed-Interactive Exercise Group Stage: I: $n=13$; II: $n=3$; IIIA: $n=6$; IIIB: $n=1$; IV: $n=8$ Fixed Exercise Group Stage: I: $n=7$; II: $n=5$; IIIA: $n=7$; IIIB: $n=0$; IV: $n=13$ No Treatment Information	40.5% (64/158)	Fixed Exercise Group: (23/32): 71.88% Fixed-Interactive Exercise Group Stage: (20/32): 86.96% Total (43/64): 67.19%
Lafaro et al., (2019) [37]	Intervention group $n=18$; median: 74	USA	ASA: III: $n=12$; IV: $n=2$; V: $n=1$ No Treatment Information	86.96% (20/23)	90% (18/20)
Timmerman et al., (2017) [13]	Intervention group: Stage 1 $n=10$; median 56.6 Stage 2 $n=12$; median 59.5	Amsterdam	Disease Stage not reported Stage 1 Treatment: Lobectomy: n = 10; Pneumectomy: n = 0; Neoadjuvant: n = 1; Adjuvant: n = 3 Stage 2 Treatment: Lobectomy: $n=8$; Pneumectomy: $n=2$; Neoadjuvant: $n=2$; Adjuvant $n=1$	Consent Rate: 67%	67% (8/12)
Coats et al., (2019) [35]	Intervention group $n=5$; mean 62	Canada	Stage 3 IIIb = 3; Stage IVb = 2; Treatment: Chemotherapy	No Information	100% (5/5)
Maguire et al., (2015) [15]	Intervention group $n=16$; mean: 63.6	United Kingdom	No Disease Stage Information Treatment: thoracic radiotherapy	28.1%	5 died (11/16) 68.75%
Denis et al., (2014) [32]	Intervention group $n=42$; median: 62	France	Stage: I/II: $n=9$; IIIA: $n=15$; IIIB: $n=1$; IV: $n=17$ Current Treatment: None 36; Maintenance therapy 6 Previous treatment: Surgery 11; Radiotherapy 1; Concomitant radio-chemotherapy 13; Chemotherapy 17	Not reported	Two died (95.24%)

USA, United States of America; *ASA*, American Society of Anaesthesiologists was due the occurrence of system errors and difficulty in handling the application [34]. No study reported any adverse effects throughout the study duration. Detailed information of the acceptability results can be found in Table 4.

Efficacy

Efficacy outcomes are only reported for RCTs. Of the eight studies, there were two RCTs [33, 36]. Outcomes assessed included QoL, physical functioning [33], and symptom distress [36].

Quality of life

Participants who participated in an online-based health education program had a significant increase in global QoL in comparison to a control group [36]. All participants who participated in a mobile-based pulmonary rehabilitation platform exhibited an overall significant increase in QoL (visit one, 76.05 ± 12.37; visit three, 82.09 ± 13.67 ($P = 0.002$)), assessed using a visual scale (EuroQol-visual analog scale). However, a small, non-significant change in QoL was observed (visit one, 7.535 ± 1.817; visit three, 6.930 ± 2.849 ($P = 0.17$)) via the EQ-5D questionnaire (EuroQol 5 dimensions questionnaire) [33]. There was not a significant difference pre-intervention and post-intervention for QoL between the Fixed-interactive exercise group and Fixed exercise group for both visual scale ($P = 0.99$) or EQ-5D ($P = 0.50$) [33].

Emotional functioning

Participants who engaged in the online health education program reported significant improvements in emotional function in comparison to those who did not [36]. In fact, those who did not engage with the online health education program displayed a non-significant decrease in emotional function [36]. Significance was determined from baseline (T0) to three months after the program (T3) for both experimental and control groups via the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30).

Physical functioning

Participants who performed physical activity displayed an improvement in their physical function, assessed via their six minute walk distance (6MWD) over a 12-week period (visit one, 433.429 ± 65.595; visit three 471.250 ± 75.691 ($P = 0.001$)). However, no statistical significant difference ($P = 0.30$) was reported between the fixed exercise group (58.095 ± 73.663) and fixed-interactive exercise group (25.368 ± 66.640) [33].

Symptom distress

Participants who participated in an online education program had a significant reduction ($P < 0.05$) in the top ten significant symptom distresses from baseline (1.45 ± 0.08) to three months post program (1.26 ± 0.06), whereas the control group demonstrated a non-significant increase ($P = 0.530$) from baseline (1.41 ± 0.09) to post three months (1.73 ± 0.27) [36]. Data on symptom distress was collected via the symptom distress scale.

Discussion

This review aimed to examine the evidence of the feasibility, acceptability, and potential efficacy of online supportive care interventions for those LWBLC. The results show that online delivery of supportive care for people LWBLC is feasible and acceptable. However, the field of delivering supportive care in this population is in its infancy. To our knowledge, this systematic review is the first to explore feasibility, acceptability, and efficacy of online supportive care for people LWBLC.

Eight studies met the inclusion criteria, two of which were RCTs. The average recruitment rate was 62.58%, though this was not universally reported, and the average retention rate was 84.77%. Problems with recruitment and attrition are common among studies involving people living with and beyond cancer, especially people LWBLC [8]. The challenge recruiting people LWBLC stems from the high symptom burden and lower health performance status [8, 42]. Low rates of participation and consent are common among people living with and beyond cancer, people with advanced diseases, and those approaching palliative end of life care [43, 44]. Older adults (≥65y) are reported to be underrepresented in research, with a small increase of older adults in oncological clinical trials over the recent years [45]. Though, people LWBLC typically tend to be older individuals, with 44% of new diagnosis of lung cancer in the UK among those 75 years or older [46], yet the mean age for the included studies was 61 years. This affirms the aforementioned argument by Hurria et al. (2014) that older individuals are underrepresented in oncological research, suggesting that consideration should be given when interpreting the results for this population. The capabilities of older adults to use digital technology is often questioned within literature [34], although elderly adults are becoming increasingly literate using digital technology and eager to adopt new technologies [47].

Adding to the growing body of literature exploring the use of online supportive care for people living with and beyond cancer, this review shows emerging evidence that online supportive care platforms are also feasible and

Table 4 Intervention overview, engagement, and acceptability outcomes

Source (author and year)	Objectives and description	Engagement	Acceptability (satisfaction)	Conclusion
Huang et al., (2019) [36]	Objective: evaluate the effects of a web-based health education program on global QoL, QoL-related function, and symptom distress in patients diagnosed with advanced NSCLC The experimental group participated in the web-based education program twice a month for three months	Those who consented (55/60) completed all assessments	Satisfaction measures not discussed	The web-based program can improve global QoL, emotional function, and reduce top ten significant symptom distresses within the first three months post diagnosis and treatment of advanced-stage NSCLC patients Web-based health education can enhance self-learning to assist with coping with cancer, treatments, and side effects
Ji et al., (2019) [33]	Objective: explore the outcome of home-based pulmonary rehabilitation (PR) regarding exercise capacity, dyspnea symptoms, and QoL in patients being treated for NSCLC Participants were randomly allocated to a fixed exercise group or a fixed-interactive exercise group The fixed exercise group used only the fixed exercise program during the 12 weeks. The fixed-interactive exercise group received the app with the fixed exercise regimen for the first six weeks. Switching to an app with an interactive exercise regimen for the remaining six weeks	64 participants allocated to the two groups 49 made it to six weeks analysis; 43 made it to the 12 weeks analysis	Participant Satisfaction (Patient Global Assessment [PGA]): Week 6: $n = 39$, Mean (SD): 13.769 (3.681 Week 12: $n = 39$; Mean (SD): 15.077 (3.989)	Personalized mHealth PR can supplement traditional health care rehabilitation programs for NSCLC patients. Findings support the use of this technology to improve exercise capacity, dyspnea symptoms, and QoL
Denis et al., (2014) [32]	Objective: investigate whether patient self-evaluated symptoms transmitted via the internet could be used between pre-planned visits to indicate early disease relapse in lung cancer Patients report their weight and ten symptoms, such as appetite loss (anorexia), fatigue (asthenia), pain, cough, and breathlessness (dyspnea) weekly The physician would be notified via email when self-evaluated symptoms met a pre-specified criterion	564/691 of all forms were completed, which is 82% of the maximum Mean monthly compliance was 94% Mean weekly compliance was 79%	100% of participants felt reassured they were being followed by their oncologist	A weekly follow-up system using the internet deemed feasible to detect relapse or tumor progression with a high rate of compliance

Table 4 (continued)

Source (author and year)	Objectives and description	Engagement	Acceptability (satisfaction)	Conclusion
Coats et al., (2019) [35]	Objective: investigate the feasibility, adherence, satisfaction, and technical issues of a home-based telerehabilitation intervention for patients with unresectable thoracic neoplasia receiving chemotherapy The intervention was an eight-week home-based telerehabilitation program (three sessions of ~ 75 min per week) using the eChez-Soi telerehabilitation platform. The platform provided a combination of interactive exercises with real-time physiological parameter acquisition Sessions started off supervised but with study progression reduced to mainly unsupervised	The mean duration of supervised sessions was 67 ± 12 min. Total duration of all 75 supervised exercises sessions was 85 h. Mean time for cardiovascular exercise was 247 ± 48 min over the 15 supervised exercise sessions and 223 ± 111 min over the 8.6 ± 3.0 unsupervised exercise sessions. Mean duration of each cardiovascular exercise session was 18 ± 6 min and 26 ± 9 min during supervised and unsupervised exercise sessions	5/5 patients reported being quite satisfied (score of 4) or very satisfied (score of 5) with all aspects of the home-based telerehabilitation platform. Mean satisfaction score: 4.7 ± 0.4	Findings support the feasibility of a Tele Rehabilitation program (TELERP) and suggest the intervention may help patients overcome barriers to pulmonary rehabilitation services Participation in TELERP may assist improvements or maintenance in muscle strength and functional capacity for lung cancer patients on chemotherapy treatment
Timmerman et al., (2017) [13]	Objective: evaluate the feasibility of a Tele-healthcare application for operable lung cancer patients Stage One: Prior to the start of the study, thoracic surgeons and pulmonologists were given a short presentation about content and possible benefits of the symptom and physical activity monitoring S&PAM module Physiotherapists were introduced to the web-accessible exercise program (WEP) during a two-hour workshop Stage Two: The Remote Monitoring and Treatment RMT it consists of two modules: (1) a symptom and physical activity monitoring (S&PAM) system, and (2) a web-accessible exercise program with remote supervision by a physiotherapist	Ambulant S&PAM system: 100% of patients used the S&PAM system at least once Mean usage: Five—six days per treatment period WEP: Eight patients (67%) used the exercise portal at least 1 week following lung resection. Patients started 4 (n = 3), 5 (n = 2), 6 (n = 2), or 7 (n = 1) weeks following resection	S&PAM: most patients indicated that the monitoring system had good usability. All felt competent using the module (perceived self-efficacy score > 5) WEP: most patients were satisfied with usability of the module, except for two (score < 5) stating the program was difficult to access on mobile phone All patients felt confident in their ability to use the module	Findings support that remote monitoring and treatment is feasible to lung cancer patients both pre- and post-surgery Patients actively used the S&PAM and WEP modules prior and following surgery and perceived both as a beneficial contribution to their care A low level of adoption by referring physicians may reduce successful implementation

Table 4 (continued)

Source (author and year)	Objectives and description	Engagement	Acceptability (satisfaction)	Conclusion
Lafaro et al., (2019) [37]	Objectives: (1) determine the feasibility and acceptability of a personalized telehealth intervention, for physical activity perioperatively for GI and lung cancer patients and their caregivers. (2) describe the trends, trajectories, and patterns of both functional recovery and self-reported outcomes pre- and post-surgery The intervention consisted of five sessions. Session one was after baseline assessment and a minimum of seven—fourteen days prior to surgery via videoconferencing. Session two (in-person) functional re-assessment (6MWT, TUG, SPPB) and self-reported measures. Session two content was delivered post re-assessment. Sessions three, four, and five (telehealth) were completed at days two, seven, and two—four weeks post-discharge. All given outcomes were re-assessed at two—four weeks post-discharge. Acceptability was measured via a satisfaction survey. Pedometer data was collected throughout the study duration Strategies to overcome barriers to staying active after discharge were discussed	Preoperative pedometer adherence: 79%, post-discharge 68%. Median preoperative daily steps were 6324 The value decreased to 1050 during hospitalization, The value increased to 2927 in the first 2 weeks after discharge	Self-reported satisfaction: 3.2/4.0 93.3% of patients thought that the timing of the intervention was appropriate	The personalized telehealth perioperative physical activity intervention was feasible and acceptable for both adults undergoing GI or lung cancer surgery and their caregivers

Table 4 (continued)

Source (author and year)	Objectives and description	Engagement	Acceptability (satisfaction)	Conclusion
Park et al. (2019) [34]	Objective: determine the feasibility and efficacy of smartphone app–based PR on QoL, exercise capacity, and symptom management for patients with advanced lung cancer who were undergoing chemotherapy Patients were provided with the Smart Aftercare app, an Internet of Things (IoT) wearable device, a portable pulse oximeter, thermometer, scale, and resistance bands. The to-do list provided an alarm notification for daily tasks related to taking medication, performing rehabilitation exercise, and visiting the clinic on schedule This study consisted of a 12-week rehabilitation program. The Smart Aftercare app provided animation videos on stretching exercises, aerobic exercises, muscle strengthening exercises, and finishing (stretching) exercises. The Smart Aftercare app provided an animation video on pain control, nutritional support, and symptom management	90 finished the rehab program 85/90 completed all 6MWT tests	Satisfaction: 77% (69/90) reported they were satisfied 88% (79/90) reported they would recommend it to others 96% (86/90) stated they were paying more attention to their health and disease status since using the app	12 weeks of comprehensive smartphone app–based individualized PR seems to be an effective and feasible approach for improving exercise capacity, symptom management, and distress in patients with advanced NSCLC undergoing systemic chemotherapy

Table 4 (continued)

Source (author and year)	Objectives and description	Engagement	Acceptability (satisfaction)	Conclusion
Maguire et al. (2015) [15]	Objective: (a) explore the feasibility and acceptability of the Advanced Symptom Management System with patients with lung cancer receiving radiotherapy (ASyMS-R) and clinicians involved in their care; (b) assess changes in patient outcomes during implementation of the ASyMS-R in clinical practice Patients used the ASyMS-R at home during working hours (9 AM—5 PM), seven days a week, for the duration of their radiotherapy treatment in addition to one month after treatment. They were instructed to follow local procedures regarding out-of-hours care After completing the daily questionnaire on their mobile phone, patient's daily symptom data were sent to a central study server, where an integrated risk model analysed the symptom reports	89% of participants reported the self-care system was easy to understand and user friendly	Nine patients indicated that they had received enough training to use the ASyMS-R handset 100% of patients reported that they never or very rarely encountered problems in using the handset (n = 10; 100%), answering and submitting questionnaires (n = 9; 90%), reading the self-care information after submitting a questionnaire or again later (n = 10; 100%), or finding cancer information pages (n = 8; 89%)	This study demonstrated the potential to provide an accurate and acceptable assessment of radiotherapy-related toxicity and management in clinical practice. Therefore, effectively responding to the needs of patients in this study and facilitating the delivery of timely interventions. Participants reported the ASyMS-R to positively impact on their care and promote the timely reporting and management of their symptoms

QoL, Quality of Life; *NSCLC*, Non-Small Cell Lung Cancer; *PR*, Pulmonary Rehabilitation; mHealth, Mobile Health; *SD*, Standard Deviation; *TELERP*, Tele Rehabilitation program; *WEP*, web-accessible exercise program; *RMT*, Remote Monitoring and Treatment; *S&PAM*, symptom and physical activity monitoring; *GI*, Gastrointestinal; *6MWT*, 6 min walk test; *TUG*, Time Up and Go; *SPPB*, Short Physical Performance Battery; *IoT*, Internet of Things; *ASyMS-R*, Advanced Symptom Management System with patients with lung cancer receiving radiotherapy; *PGA*, Patient Global Assessment acceptable for people LWBLC. This aligns with the larger body of literature among breast [48, 49], prostate [16, 50], colorectal cancer [51, 52], and chronic obstructive pulmonary disease (COPD) [53, 54], a progressive chronic lung disease which has similar symptoms and QoL impact to lung cancer [55]. This evidence suggests that online supportive care is feasible and acceptable in these populations.

Engaging in supportive cancer care is important for management of symptoms and improvements in quality of life for people LWBLC [8]. In the current global Coronavirus Disease (COVID-19) pandemic, people living with and beyond cancer are at greater risk of experiencing serious illness if tested positive for the COVID-19 pandemic [56], particularly those receiving chemotherapy and/or radiotherapy for lung cancer [57]. Throughout the pandemic, the frequency of in-person assessments and programs have been severely reduced, leading to a variety of concerns such as, missed diagnosis, unnoticed development of new symptoms, unobserved disease progression, reduction in physical activity sessions, and access to educational resources. Literature has reported weekly symptom monitoring via a web-based patient-reported outcomes platform that was associated with increase survival for those living with and beyond metastatic cancer compared to standard care [58] and those LWBLC in comparison to standard imaging surveillance [59]. Therefore, the importance of delivering supportive care via online modalities is paramount. However, even before the COVID-19 pandemic, barriers existed supporting the implementation of any supportive care for people LWBLC. Economically, there is a considerable financial burden associated with lung cancer, both societal and personal [60]. The cost of travel is an out-of-pocket expensive which could be a barrier for people living with and beyond cancer to access appointments and treatments [60]. In addition, various studies have associated lower socioeconomic status (SES) with higher incidence of lung cancer [61, 62]. The use of digital technology and telehealth has become more prevalent since the COVID-19 pandemic [63], with an exponential growth in platforms such as videoconferencing [57], although the evidence pertaining to online supportive care for people LWBLC is still limited. The evidence that lung cancer is overshadowed in the literature by other forms of cancer is clear within both supportive care in both standard and online modalities [64, 65]. With the complexity of the current global climate, many individuals are unable to seek the supportive care usually provided. This systematic review provided a timely contribution to the sparse knowledge of online supportive care for people LWBLC.

To advance this area, more rigorous research must be conducted, building upon the available pilot-based studies, such as ensuring adequately powered samples and generalisability of results [66]. The studies conducted have shown to have a lower mean age than that of the average for a lung cancer diagnosis. Furthermore, RCTs using a clear randomisation process should be performed to explore the effects online supportive care can present in comparison to well-balance groups [67]. Conducting trials over multiple sites may prove useful regarding greater samples for recruitment. Furthermore, literature suggests that methodological appraisal is often misapplied when assessing non-randomised studies [26]. Studies must appropriately appraise methodological quality of their literature to provide high quality evidence.

Conclusion

Online supportive care for people living with and beyond cancer has shown promise within this review. Given the complexity of delivering cancer services online, the current global COVID-19 pandemic has highlighted the need for online supportive care for people living with and beyond cancer, specifically lung cancer [57]. The studies discussed in this review cover two primary domains of supportive care, symptom management, and increasing QoL, which have been highlighted as key components of supportive care [8]. This illustrates that key components of supportive care can be administered online, showing feasibility and acceptability. Though, the concept of adherence rates requires further exploration within this population. A recent shift has been observed from inpatient to ambulatory care for people living with and beyond cancer and an increased number of outpatients receiving treatment has rapidly increased [15] leading to more individuals being responsible for self-management of treatment-related toxicities within their own home. The use of digital technology such as mobile or web-based platforms to enable real-time communications could be vital in supportive care.

This review provides evidence that online supportive care programs for people LWBLC are feasible and acceptable. The conclusions are limited to a small number of studies, though the strong methodological quality of the studies provide strength in the results. With limited evidence presented from RCTs, it is difficult to determine efficacy. Though online supportive care within lung cancer is in its infancy, further larger RCTS and rigorous studies are warranted.

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Declarations

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13.5.2 Evaluating a web-based computer-tailored physical activity intervention for those living with and beyond lung cancer (ExerciseGuide UK): protocol for a single group feasibility and acceptability study.

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Pilot and Feasibility Studies

STUDY PROTOCOL

Evaluating a web-based computer-tailored physical activity intervention for those living with and beyond lung cancer (ExerciseGuide UK): protocol for a single group feasibility and acceptability study

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Abstract

Background: Lung cancer is the leading cause of cancer-related death globally. Physical activity and exercise provide unequivocal benefits to those living with and beyond lung cancer. However, few of those living with and beyond cancer meet the national physical activity guidelines. Various barriers exist for this population's engagement in physical activity and exercise, such as the lack of knowledge and lack of tailored information, little access to exercise specialists, fatigue, and mobility challenges. Digitally delivered programmes have the potential to address several of these barriers, with techniques like "computer-tailoring" available to enable the delivery of tailored content at a time and place that is convenient. However, evaluation of such programmes is needed prior to implementation. This protocol describes a single group study that will examine the feasibility and acceptability of an online tool (ExerciseGuide UK) that provides those living with and beyond lung cancer web-based computer-tailored physical activity prescription and modules underpinned by behaviour change theories.

Methods: Thirty-five individuals diagnosed with lung cancer, or cancer affecting the lung (e.g. pleural mesothelioma), will be recruited into a single-intervention arm. The platform will provide tailored resources and a personalised physical activity programme using IF-THEN algorithms. Exercise prescription will be tailored on factors such as self-reported specific pain location, exercise history, and current physical fitness. In addition, modules grounded in behaviour change will supplement the physical activity programme and will focus on topics such as exercise benefits, safety, goal setting, and tracking. The primary outcome will be assessed using pre-established criteria on feasibility and mixed-methods approach for acceptability.

Secondary outcomes will explore changes in the physical activity, quality of life, anxiety, and depression.

Discussion: This manuscript describes the protocol for a study examining the feasibility and acceptability of a web-based computer-tailored physical activity intervention for those living with and beyond lung cancer. The publication

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Figure 36: Published protocol paper

of this protocol aims to increase the transparency of the methods, report pre-determined criteria, and aid replication of the study and associated materials. If feasible and acceptable, this intervention will inform future studies of digital-based interventions.

Trail registration: ClinicalTrails.gov, NCT05121259. Registered on November 16, 2021.

Keywords: Lung cancer, Physical activity, Exercise, Telehealth, eHealth, Feasibility, Acceptability, User-friendliness, Usability

Introduction

Lung cancer is the second most diagnosed malignancy and the leading cause of cancer-related death globally [1]. Those living with and beyond lung cancer (LWBLC) may experience several curative treatment procedures, including chemotherapy, radiotherapy, immunotherapy, and surgery. Though potentially lifesaving, these treatments can lead to and exacerbate a number of long-lasting symptoms such as fatigue, loss of cardiorespiratory fitness, pain, and breathlessness [2–6]. Often, those LWBLC report feelings of low mood and depression, as they are forced [2–4] to accept the changes to their life caused by a diagnosis of cancer [7].

Physical activity and exercise are often used interchangeably within literature, though they are not synonymous [8]. Physical activity is defined as any bodily movement caused by the skeletal muscle which results in energy expenditure [9, 10]. Exercise is a subset of physical wherein an individual is in physical activity in a purposive, structured, and repetitive manner, with the intention of improving or maintaining one or more components of physical fitness [9, 11]. Engaging in a regular physical activity and exercise, in particular, is a recommended strategy for improving health and quality of life among cancer patients [12]. The American College of Sports Medicine (ACSM) has highlighted the benefits of physical activity that can elicit for those living with and beyond cancer [13]. Despite the increase in research in this area, the most robust evidence base is still primarily drawn from early-stage breast and prostate cancer survivors.

Nevertheless, amongst those LWBLC, physical activity and exercise has demonstrated to have several positive biological and physiological effects, such as reducing fatigue, anxiety, and depression while increasing muscle strength, increasing quality of life, and mitigating treatment side effects [14]. Furthermore, evidence supports the guidance for those living with and beyond cancer, including those LWBLC, to increase their physical activity post-diagnosis to increase survival outcomes [15, 16]. Cancer cachexia is a multifaceted syndrome with progressive loss of the skeletal muscle [17] and occurs in 20% of early stage lung cancer [18], 40% metastatic non-small cell lung cancer [19], and up to 69% of advanced lung cancer [20]. Increasing muscle strength and muscle mass may be beneficial in reducing the rate of muscular wasting and cancer cachexia [21]. However, the majority of this population worldwide does not meet the physical activity guidelines [22–25]. There are a multitude of reasons for this. In addition to common barriers to physical activity such as lack of time, access to facilities, and motivation, people LWBLC have disease-specific barriers. These can include fear of breathlessness, fatigue, pain, lack of knowledge about activity, symptom burdens, mood, and fear [14, 26]. People LWBLC have also reported a lack of physical activity recommendations and advice from oncology clinicians [27]. There is a clear need to explore and develop new supportive and survivorship care methods to better support patients. A study by Lin and colleagues (2013) interviewed people LWBLC and found that 70.4% of patients showed an interest in physical activity programmes. Furthermore, 69.1% of patients LWBLC reported they had the ability to participate in physical activity programmes [28].

A meta-analysis of patient-level data reported that supervised exercise programmes yield a greater quality of life and physical functioning improvements than unsupervised programmes [29], though both supervised and unsupervised exercise programmes were better than usual care control groups. Supervised programmes are thought to have greater efficacy owing in part to greater ability to provide personalised exercise programming and support. However, digital technology has been a promising method of providing personalised supportive care over a distance [30]. Digital health technology (also known as eHealth) has existed in health research for several years, though there has been an exponential growth throughout the coronavirus 19 (COVID-19) pandemic. A recent review exploring the feasibility of exercise interventions delivered via telehealth for those living with and beyond cancer highlighted that 6.8% of studies explored lung cancer, whereas breast cancer represented 62% [31]. Thus, it is critical that suitable digital technology is created to support those LWBLC, given the majority of research focuses on those living with and beyond breast and prostate cancer.

Those LWBLC tend to be older individuals (≥65y); within the UK, 44% of new diagnoses of lung cancer are

those ≥75 years [32]. Given the typical elderly nature of those LWBLC, web-based platforms may increase usability with larger fonts, images, videos, and designs that require less precise mouse manoeuvrability as compared to printed materials or smartphone apps [33]. Additionally, web-based platforms have the capability to deliver personal advice (a.k.a. computer-tailored programmes), educational resources, behaviour change advice, and self- and symptom-monitoring. Notably, these programmes and resources can provide a high-quality and personalised content, promote remote access, minimise travel, and allow the user to maintain a sense of anonymity while maintaining low overall cost [34–36]. Given this ability, it is possible to build on the foundations of movements such as exercise is a medicine and lifestyle medicine [37, 38].

Those LWBLC are more likely to become seriously ill if contracting the COVID-19 virus due to their older age or undergoing chemotherapy and/or radiotherapy, which suppresses their immune system [31]. Given the high symptom burden and the complexity of the treatment-related side effects, such as immunosuppression with chemotherapy agents, there must be an alternative to the typical face-to-face supervised approach. Digital health exercise interventions have previously demonstrated feasibility/acceptability for those living with and beyond breast, gynaecological, multiple myeloma, myelodysplastic syndrome, lymphoma, Hodgkin lymphoma, Leukaemia, non-Hodgkin lymphoma, endometrial, prostate, and metastatic prostate cancer [31, 34, 39]. However, our previously published review shows that online supportive care is in its infancy for those LWBLC, particularly for physical activity focused online supportive care [40]. Our study aims to conduct a feasibility pilot study of a computer-tailored web-based platform, ExerciseGuide UK, which will add to the limited available evidence for those LWBLC. This protocol details the steps taken to adapt an existing platform that has been used for those with a history of breast cancer [41, 42] and metastatic prostate cancer [39] for those LWBLC and describes the methods of the single-group feasibility study. Publication of this protocol intends to increase the transparency of the steps taken to adapt and develop this intervention and develop a more comprehensive understanding of scientific rigour and results.

Methods

Study design

This study is a single-group feasibility study. The participants will complete an 8-week web-based computer-tailored physical activity intervention with personalised educational resources. Mixed-methods analyses will be employed with primary outcomes exploring the feasibility and acceptability of the web-based platform. Secondary outcomes examining quality of life, anxiety, and depression will be collected via questionnaires. Physical activity and exercise will be collected weekly via tracking modules, wherein participants can self-report physical activities and exercises completed and any concerns. Fifteen participants will be invited to participate in post-study interviews will be conducted. Interviews will continue if not saturated.

The study has been registered on the ClinicalTrails.gov website [43] (ID: NCT05121259), and ethical clearance was obtained by the Health Research Authority (approval: 21/SC/0174). The reporting of the study protocol adheres to the Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) guidelines [44]. A participant timeline is presented following the SPIRT guidance in Table 1.

Study setting

The study is being conducted in Kingston upon Hull, UK. The participants will be identified and recruited via Hull University Teaching Hospital NHS Trust.

Recruitment began in January 2022 and will cease in May 2022 or when the sample size has been reached. The sample size was pre-specified at 35 individuals LWBLC. The sample size is based on a recent systematic review that examined the feasibility, acceptability, and potential efficacy of online supportive care for those LWBLC [40], literature regarding sample size for pilot and feasibility studies [45, 46], and clinical expertise from a senior lung oncology consultant.

Participants and screening

The participants will be recruited through the lung cancer clinic at Hull University Teaching Hospital. The primary investigator will disseminate the recruitment information with assistance from participating site oncologists to those who meet the inclusion criteria during routine appointments. Interested participants will contact a member of the research team to obtain informed consent, provide answers to any outstanding questions, and process baseline data collection. Figure 1 illustrates a flow diagram of participant engagement.

Eligibility

The participants will be screened against predetermined eligibility criteria and approved for physical activity by their clinician. The participants must have received a lung cancer diagnosis or cancer of the lung (e.g. pleural mesothelioma), either non-small cell lung cancer or small cell lung cancer. In addition, the participants must be 18 years or older, able to speak and communicate in English, be willing to provide informed consent, have access to a

Table 1 Showing SPIRT figure for the enrolment, baseline, intervention, and assessments

	Study Period				
	Enrollment	***Baseline***	***Exercise Intervention***		***Close out***
TIMEPOINT		***Week 0***	***Week 1***	***Week 8***	***Week 9***
ENROLMENT:					
Eligibility screen	X				
Informed consent	X				
Healthcare Team Approval	X				
INTERVENTIONS:					
Exercise Intervention			←——→	←——→	
ASSESSMENTS:					
Baseline Variables		X			
Post Variables					X
Qualitative Outcomes					X
Post Qualitative Interviews					X

smart device that can display the website (e.g. laptop or tablet), and have internet access.

The participants will be considered ineligible if they are under 18 years of age at the time of screening, unable to provide informed consent due to cognitive or linguistic inability, or have a physiological and/or cognitive impairment that would prevent or inhibit participation of moderate aerobic and resistance-related physical activity. In addition, the participants will be excluded if they have identified bone metastases in weight-bearing locations and/or spinal compression, which may inhibit or prevent their safe participation in unsupervised exercise.

Intervention

Intervention development and adaptions

Early development The original conception of the web-based platform on which ExerciseGuide was built and was developed by Vandelanotte and colleagues [47]. Previously ExerciseGuide has been adapted and used in oncological populations such as breast cancer [41, 42] and metastatic prostate cancer [39]. To ensure the adaption of ExerciseGuide for those LWBLC, an iterative adaptive process was undertaken (see Fig. 2).

A systematic review was initially undertaken to appraise the current literature regarding the feasibility, acceptability, and potential efficacy of online supportive care platforms for those LWBLC [40]. Subsequently, iterative patient and public involvement (PPI) workshops were conducted with volunteers who had experience with LWBLC as a patient, carer of someone, or family member. Think Aloud interviews were conducted with seven participants LWBLC via Zoom. Positive and negative quotes pertaining to each given task were presented in tabular format (see supplemental material 1). A detailed summary of the Think Aloud interviews can be found in supplemental material 2.

Final adaptions The agreed change was by a mutual consensus with the PPI members. An example of agreed change can be demonstrated within the formerly known library. The participants in the Think Aloud interviews struggled to find a location where extra information would be located and once found, believed the library looked "boring." Therefore, agreements were reached with the PPI group and research team to change the name "Library" to "Extra Information" and apply image thumbnails to the hyperlinks to provide a more inviting and interesting page (see Fig. 3).

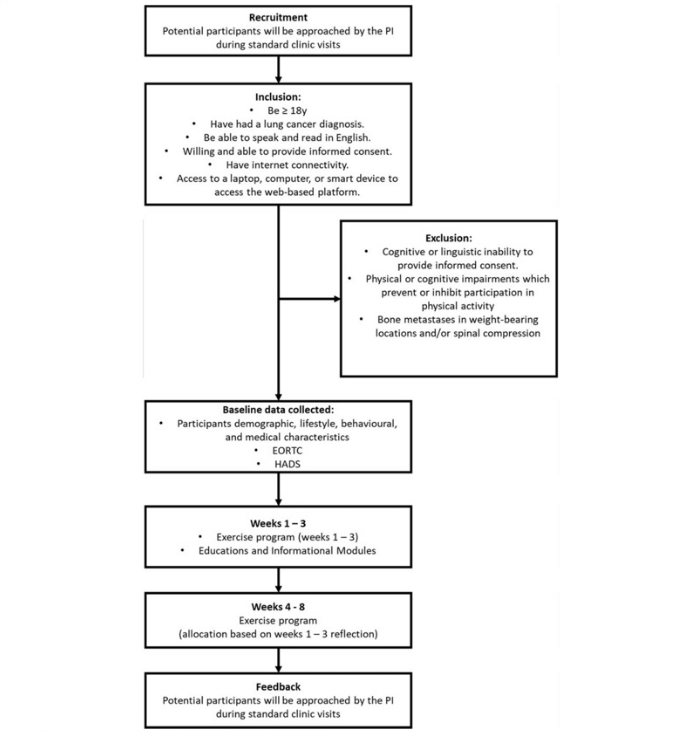

Fig. 1 Demonstrating the flow of participants throughout the study

Intervention description

ExerciseGuide UK consists of 18 modules released over 8 weeks. A complete list of the modules can be found in the supplementary material. The website architecture adopts a tunnelled approach, as opposed to free choice. A tunnelled approach allows users to access small batches of information over a pre-specified time and with a predetermined flow [48] opposed to immediate full access [49]. The tunnelled design and module release timings are illustrated in Fig. 4.

The dashboard (shown in Fig. 5) where modules become active throughout the intervention duration. Upcoming modules will be displayed on the dashboard with a countdown until they become accessible.

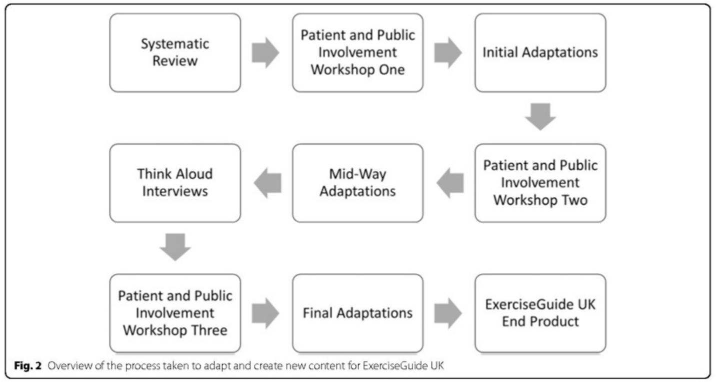

Fig. 2 Overview of the process taken to adapt and create new content for ExerciseGuide UK

Website tailoring
The website will deliver computer-tailored evidence-based modules, including an 8-week exercise programme and supporting information. The content of the modules will be tailored based on individual participant characteristics through an automated computer process using IF-THEN statements. Modules will contain questions that will have a corresponding message (or feedback item) in the database. Thus, IF a participant answers one or more questions, THEN the corresponding message(s) will appear in the module. Computer tailoring has been shown to increase efficacy and safety of behaviour change and physical activity by delivering personally relevant content [50–52]. An outline of the modules containing feedback items, their tailoring properties, and the behaviour change mechanism of action is detailed in Table 2.

Exercise prescription
The exercise prescription covers 8 weeks of tailored exercise. The adaptions to strength training are generally evident in individuals after 8 weeks [53, 54]. However, some studies highlight an increase in muscle cross-sectional area and strength after 2 to 4 weeks [55–57], likely due to neurological or connective tissue adaptations. Furthermore, 8 weeks of aerobic exercise has been illustrated to significantly improve aerobic capacity among those LWBLC [58].

The exercise prescription has been divided into two main categories: resistance-based exercise and aerobic-based exercise. Both components of exercise are based on participant-provided information. Exercise repetitions (reps) and sets are provided for the weekly programmes. Upon cessation of the week 1 to 3 exercise modules, participants will be asked to reflect on weeks 1 to 3 retrospectively. If too challenging, the frequency and intensity will be reduced. If the participants report the programme as appropriate, the programme frequency and intensity will slightly increase throughout weeks 4 to 8. Finally, if the participants report that the exercise programme was too easy, a larger increase in frequency and intensity will occur. Exercise safety information is provided in the exercise programme, prior to exercise prescription, and as a standalone safety module.

Participants will receive a minimum of two telecoaching sessions at the beginning of weeks 1 and 4 to review the exercise prescription, safety queries, and any questions. Activities will be prescribed based on questions surrounding physical limitations, pain, and exercise experience.

Resistance exercise There are twenty-two possible resistance exercises that can be included in the exercise prescription. The computer-tailored website allows tailoring the exercise prescription based on physical activity and exercise experience, current physical activity and

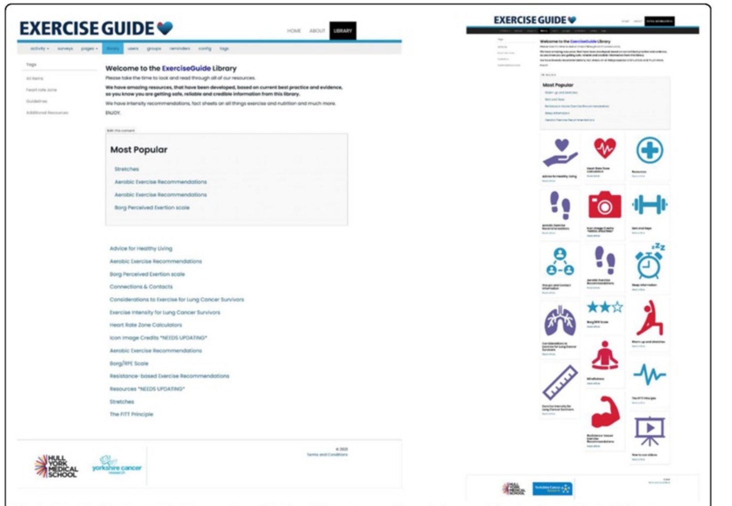

Fig. 3 Original (left) and revised (right) screenshots of the Extra Information page (formerly known as Library) on ExerciseGuide UK. Revisions were made based on Think Aloud interviews and agreement with the PPI group

exercise levels, and overall and specific limits to physical health and activities of daily living. A list of the exercises is provided in supplementary material 1. An animation demonstration and written instruction will accompany each exercise (see Figs. 6 and 7).

The intensity of the resistance exercises will be prescribed with a visual aid tool. In addition, the Rate of Perceived Exertion scale (see Fig. 8) and pain scale (see Fig. 9) will be provided to conceptualise perceived scoring. Participants are informed about aiming for the green zone of moderate activity for the exercises. Information to try contextualising the moderate activity zone will be provided in lay language. For example, referring to body heat and the ability to "talk and not sing," contextual comparisons which PPI members felt were valuable and understandable.

The frequency of resistance exercises will be 2 days per week for weeks 1 to 3, with eight to 12 reps maximum for two sets. At the end of week 3, the participants will be asked about their experience of the first 3 weeks. If the programme is perceived as "too hard", the exercise will maintain at a stable level with possible modification throughout. The dose will remain two sessions per week, with two sets and eight to 12 reps for week 4. The participants will be informed to maintain this dose throughout, though at weeks 5 to 8, and they can increase to three sets of any exercise if they feel able.

In contrast, participants who rate the programme easy will be provided with three sessions per week for the remaining 4 weeks with an increased dose of three sets and 8–12 reps. Those who found the programme mildly challenging but achievable will be prescribed 2 days per week for weeks 4 and 5 and 3 days per week for weeks 6, 7, and 8, with reps ranging from 8 to 12. The Borg scale (see Fig. 8) will be used to illustrate the level of perceived exertion for resistance training. The PPI group recommend this scale, limiting the information and scales provided. Moreover, Natio and colleagues (2019) reported the one to ten Borg Scale was useful for elderly non-small

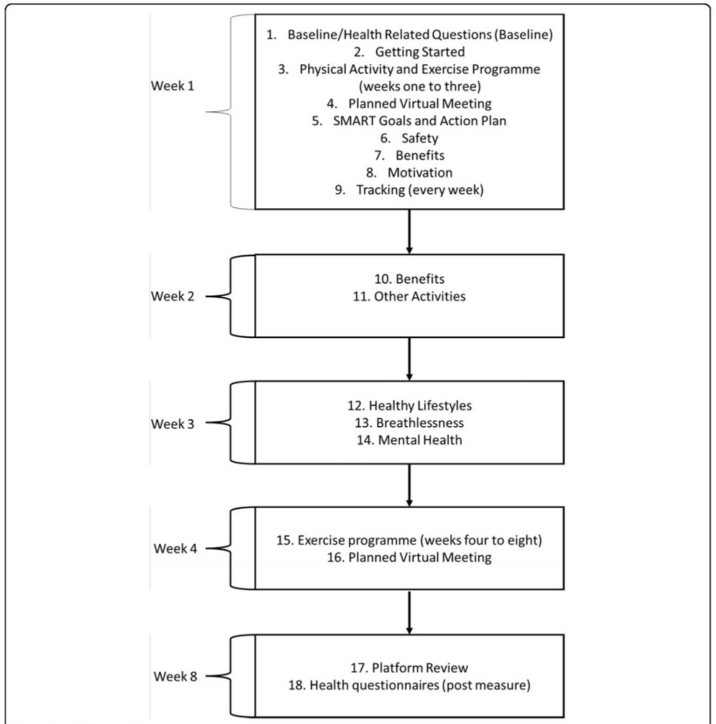

Fig. 4 Website flow over 8 weeks

cell lung cancer and pancreatic cancer patients performing resistance training [60]. The participants were informed to work at five–eight of their rate of perceived exertion.

The participants engaging in exercise sessions prior to participation in the study will be encouraged to continue their exercise but complete the prescribed exercises from ExerciseGuide UK. The participants will be encouraged by the exercise professional to engage in their own exercise regime in addition to ExerciseGuide UK if feasible.

Aerobic exercise Aerobic exercise will be based on their current activity levels. The aerobic physical activity information provided will help participants with suggestions for increasing activity and meeting the physical

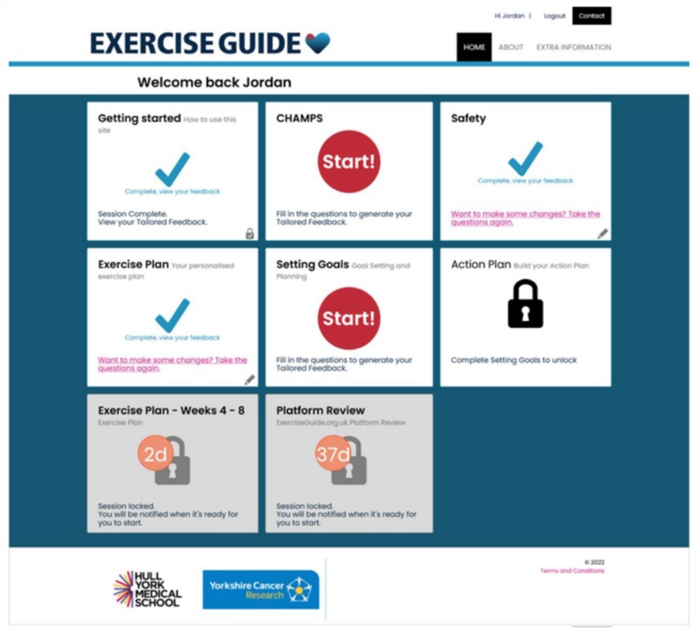

Fig. 5 Illustrating an example of the dashboard

activity guidelines (if appropriate) for those living with and beyond cancer [13, 61–63]. In addition, the information provided (see Fig. 10) will give examples of exercises with a collapsible drop-down option detailing supplementary information regarding aerobic recommendations and considerations covering the FITT (frequency, intensity, time, and type) principle in detail. Aerobic exercise information is provided based on the participants' current self-reported aerobic exercise. Using the government guidance of 150 moderate–75 vigorous minutes per week, the participants recorded their current level of aerobic activity. ExerciseGuide UK then illustrated how the participant can increase their aerobic activities in smaller bouts of aerobic activity to reach the recommended guidance [13].

Virtual meeting The participants will meet with one member of the research team at the start of week 1 and week 4 online using video conferencing software or via standard telephone calls. In both meetings, the researcher will walk through the exercise prescription, ascertain the safety of exercises for the participant, and encourage engagement with the programme. The efficacy of behaviour change interventions has been illustrated with human interaction and support, with improvements in adherence and effectiveness of digital interventions [64].

Table 2 Illustrating the breakdown of modules, description, tailoring, and mechanisms of action

Module	Module description	Tailoring	Mechanism of action
Getting started	Introductory module to the website. Demonstrating how to use and navigate the website.	No tailoring	● Knowledge ● Self-efficacy
Physical activity programme	Provide a personally tailored physical activity programme in two sections. Section one will cover week 1 to week 3. Section two will cover week 4 to week 8. Additionally, introductory safety information is provided.	Tailoring was based on pre-set questions which covered prior physical activity and exercise experience, physical health limitations.	● Knowledge ● Self-efficacy ● Intentions
SMART goals	Provide information regarding SMART goals. Linked to the Action plan. Participants will set their own SMART goal.	Personalised introduction with messaged based on previous goal setting habits.	● Knowledge ● Goals/behavioural Regulation ● Intentions ● Motivation
Action plan	Supported by the SMART goals module, the action plan guides participants to set a personally relevant and meaning plan to achieve their SMART Goal.	Not tailored. Participants are guided to set an action plan with specific questions. Ultimately setting a personalised action plan.	● Goals/behavioural Regulation ● Intentions ● Motivation
Exercise safety	Provide safety information for those LWBLC regarding being physically active and engaging in exercise.	Further in-depth guidance is provided for specific health- and cancer-related concerns.	● Knowledge ● Self-efficacy ● Beliefs about capabilities ● Needs ● Perceived Susceptibility/vulnerability
Exercise benefits	Provide informative content surrounding benefits of physical activity for those LWBLC.	Health issues and cancer-related side effects which may be improved via physical activity and exercise.	● Knowledge ● Optimism ● Self-efficacy ● Intentions ● Motivation ● Beliefs about consequences
Motivation	Content surrounding motivation, barriers and enablers to physical activity, and habit formation.	Identify and assistive feedback on specific barriers to physical activity and exercise.	● Emotion ● Attitude towards the Behaviour ● Values ● Motivation ● Automaticity
Tracking module	Provides an opportunity for self-monitoring of exercise and healthy lifestyle behaviours and outcomes.		● General attitudes/beliefs ● Self-regulation
Other activities	Covers information regarding what is physical activity, exercise, and physical fitness. Further information regarding non-conventional activities and exercises.	Tailored information provided around methods of getting in "other" types of activities within their daily lives.	● Knowledge ● Optimism ● Self-efficacy ● Intentions

Table 2 (continued)

Module	Module description	Tailoring	Mechanism of action
Health lifestyles	Provide informative content, both generally and lung cancer specific regarding lifestyle factors which may increase health-related quality of life.	Tailored information based on treatment type and lifestyle habits (smoking, alcohol, sleep, activity minutes), and personal values	● Knowledge ● Optimism ● Self-efficacy ● Intentions ● Motivation ● Beliefs about consequences
Breathlessness	Provide foundational information of what is breathlessness, causes, and exercises to help (both video and written demonstrations).	No tailoring	● Knowledge ● Self-efficacy
Mental health	Provides an introduction to mental health and lung cancer. Additionally, this module provides multiple links to external sources which discuss lung cancer and mental health-related factors.	No tailoring	● Knowledge ● Signage and support

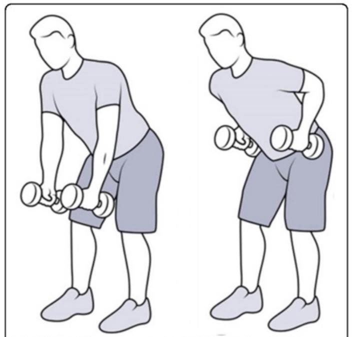

Fig. 6 Stills of the animation (via embedded graphic interchange format (GIF) files) of the standing dumbbell row

Additional intervention components

Action planning ExerciseGuide UK contains a module dedicated to developing an action plan. The action plan within ExerciseGuide UK includes a tunnelled transition following background and introductory information regarding SMART goals. To build the action plan, the website provides examples that help participants think of specific details in relation to being active (e.g. what activity, when, where, how long, and with whom). Upon completion of the questions, the website will offer a structured action plan. The action plan can be modified over the 8 weeks at the user's discretion and printed off.

Action plans have demonstrated an essential strategy for intended behaviour change by bridging the so-called intention-behaviour gap [65]. Action plans have been included on previous iterations of ExerciseGuide [66] and variations of the computer-tailored platform such as workplace sitting [67, 68]. Furthermore, a systematic review noted that action planning within eHealth interventions has been effective for behaviour change [69].

Tracking An online tracking module has been created to support participants to track their physical activity and general thoughts. The tracking module will provide a mix of open and closed questions regarding aerobic and resistance exercise, health-related fitness, motivation and habits, and general comments. Additionally, the tracking module will provide tailored feedback. This module will be released weekly, though a selection of data (motivation and health status) will be pulled through to subsequent weeks for graphical features (e.g. enablers and health/symptom check-in). Visual aids such as responsive graphs can present past and present data to show progress. The participants will be sent an email reminder upon the release of the tracking module.

Extra information The extra information page acts as a library of cancer-specific information written in layman's language.

Contact form The website contains an integrated contact form where the participants can email the research team directly. This integrated contact form auto-populations the participant's name and email for convenience. A copy of the email is sent to the participant's email they have registered with the platform.

Measures

Feasibility

The feasibility of the study will be assessed via the rate of recruitment and retention over the study duration.

Acceptability

The acceptability of ExerciseGuide UK will be assessed using a mixed-methods approach. The participants will be guided into a module with an integrated satisfaction survey upon completing week 8. This survey was modelled of the Systems Usability Scale with questions being tailored to ExerciseGuide. The satisfaction survey was adopted from the Canadian version of ExerciseGuide for those with a diagnosis of breast cancer. In addition, the participants will be provided with the opportunity for real-time module feedback using a five-point Likert scale (1—poor to 5—excellent) and open-ended feedback [70]. Finally, after completing the 8-week programme, 15 participants will be invited to participate in an interview to explore further the satisfaction of the online platform and virtual communication. These will be offered to participants following completion of the study.

Usability

In addition to the satisfaction survey will be the Systems Usability Scale [71]. The Systems Usability Score is a 10-item questionnaire with five responses ranging from "strongly disagree" to "strongly agree" [71]. The final question allows respondents to provide further comments in an open-ended format. The criteria for the System Usability Score is $\geq$ 68% [71, 72].

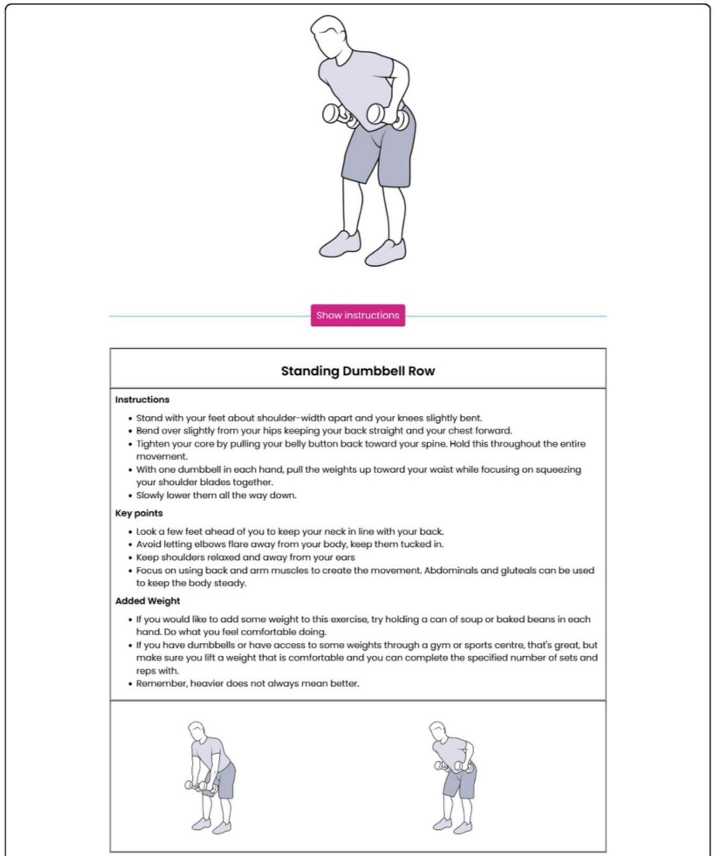

Fig. 7 Example of the extra information provided to the participants for the standing bumbbell row

RPE Scale (Rate of Perceived Exertion)	
Scale	Explanation
10	Maximum Effort
9	Very Hard Activity
8	Vigorous Activity
7	
6	Moderate Activity
5	
4	
3	Light Activity
2	
1	Very Light Activity

Fig. 8 Rate of perceived exertion (RPE) used on ExerciseGuide UK adapted from Borg (1982) [59]

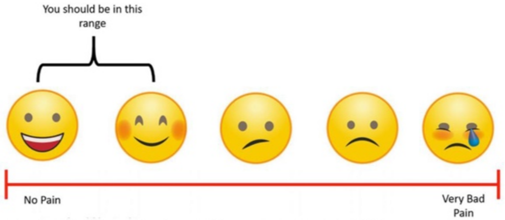

Fig. 9 Demonstrating the visual pain rating tool for resistance training exercises on ExerciseGuide UK

Website usage
Engagement will be assessed using ExerciseGuide UK stored database information and Google analytics integrated website tracking software [73]. The number of times a participant has entered a module answered questions, and tracking log will be counted to establish website and module engagement [74]. Furthermore, Google analytics will be used to examine the time spent on specific modules reading feedback or library articles, as well as to assess non-usage attrition (i.e. the process of participants not using ExerciseGuide UK as intended or at all). Participation in pre-, mid-, and post-telehealth sessions will be noted.

Health-related outcomes
Health-related outcomes will be collected at baseline upon registration to the website and immediately following the completion of week 8. The health-related outcomes being assessed pre- and post-study will be the quality of life, anxiety, and depression. Health-related quality of life will be explored via the 30-item European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-validated questionnaire (EORTC QLQ-C30; version three) [75]. The quality of life domains are divided into multi-item subscales, functional (e.g. physical, role, cognitive, emotional, and social), symptom scales

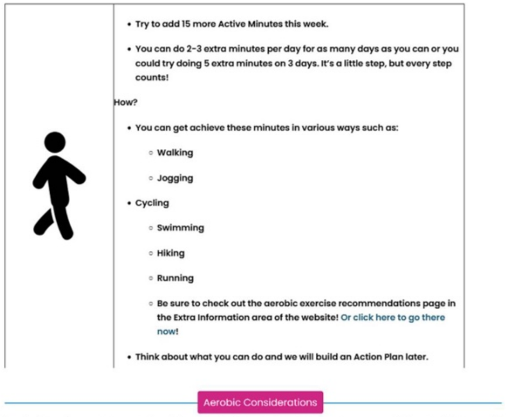

Fig. 10 Example-tailored advice for a participant who self-reported 50 physical activity minutes per week. The pink button will release a collapsible drop-down box detailing considerations for aerobic activity, including the FITT principle

(e.g. fatigue, pain, nausea/vomiting, and dyspnoea), financial hardship, and global health status.

Anxiety and depression will be measured using the Hospital Anxiety Depression Scale [76]. The Hospital Anxiety Depression Scale will measure anxiety and depression using a 14-item scale (seven items for depression and seven items for anxiety). The Hospital Anxiety Depression Scale has been illustrated to show an excellent screening of those with and without clinical symptoms of depression and anxiety to longer questionnaires (MADRS-S and STAI-S) using web-based platforms for those living with and beyond cancer [77].

Data management
ExerciseGuide UK website uses a modern framework (CakePHP) that provides a baseline security level. ExerciseGuide UK runs on a trusted hosting platform only over Hypertext Transfer Protocol Secure (HTTPS), using current Transport Layer Security versions. HTTPS is a secure method of sending data between a web server and a web browser. The passwords are never stored as plain text. They will be stored as a salted encrypted hash.

Data analysis

Pre-established criteria The feasibility will be assessed based on the pre-established criteria detailed below:

1. The recruitment target of 35 has been reached within the allocated 5 months.
2. Recruitment rate: ≥ 60%.
   a. Recruitment rate will be assessed by the number of eligible patients approached relative to the number of participants enrolling in the study.
3. Retention rate: ≥ 85%
   a. Retention rate will be assessed as the number of participants who complete 80% of the intervention over the 8-week duration.

Recruitment and retention rates have been established based on a recent systematic review of online supportive care for those LWBLC [40].

Acceptability will be assessed based on the following pre-established criteria:

1. System Usability Score ≥ 68% [71, 72]
2. Positive participant satisfaction illustrated in the end of study survey presented as a mean value on a scale
3. Positive themes identified in follow-up interviews

Quantitative data The quantitative data will be exported to SPSS version 26 (IBM, Chicago, IL, USA) for analysis. Descriptive statistics of the sample and each study measure. Data obtained from the EORTC-QLQ-30 and Hospital Anxiety Depression Scale will be analysed using a paired *t* test (non-parametric, Wilcoxon test). The weekly self-report tracking module will examine adherence to the exercise prescription. Changes in attitudes to physical activity, confidence, and burden will explored post-intervention.

Qualitative data Qualitative data will be obtained via two modalities. Firstly, open-ended questions will be provided in the satisfaction survey at the end of week 8 to elicit qualitative feedback. Any qualitative feedback provided will be exported to a single software for thematic analysis. Secondly, following the completion of the programme, 15 interviews will be conducted and will continue if not saturated. Interviews aim to expand on the quantitative satisfaction questions by exploring prior or current barriers to physical activity and the potential impact (e.g. behaviour and attitude change), usability, and friendliness of ExerciseGuide UK.

All interviews will be transcribed verbatim and analysed using thematic analysis. Using inductive coding, transcriptions will be interpreted, and codes will be generated. The strength of convergence of generated themes will be examined based on the overlapping frequency and range.

Sample size Given that this study is a feasibility study with pre-established criteria for success instead of a primary outcome assessment, a formal sample size calculation is not necessary [46]. The sample size for this study is a maximum of 35 individuals LWBLC. The sample size was based on the previous research into online supportive care for those LWBLC and clinician expertise. Firstly, previous research exploring online supportive care for those LWBLC was considered. A recent review reported a mean sample size of eight studies examining online supportive care for those LWBLC [40]. Of the eight studies, six were pilot and feasibility studies. The mean sample size over the six pilot and feasibility studies was 29 ± 33, which demonstrated satisfactory detection of feasibility and acceptability concerns. Furthermore, literature highlighted 35 participants is satisfactory per group [78]. Secondly, clinical expertise was sought out. Based on the recommendation from a senior academic lung cancer clinician based on the studies specified recruitment period (5 months) based on multiple considerations (e.g. caseload and eligibility criteria). Furthermore, the sample of 35 individuals consulted with statistician regarding to ensure adequate size to determine feasibility issues.

Discussion

The primary aim of this study is to explore the feasibility and acceptability of ExerciseGuide UK (an online supportive care platform) for those LWBLC. In addition, the publication of the protocol aims to increase the transparency and reliability of the study and methods.

Online supportive care has been a rapidly emerging field in exercise oncology over the past decade, especially since the inception of COVID-19 in March 2020. However, a recent review exploring the feasibility of exercise interventions delivered via telehealth for those living with and beyond cancer [31] highlighted a lack of research for those LWBLC. For example, of the 29 interventions Morrison and colleagues (2020) appraised, 6.9% of interventions were within those specifically LWBLC. Furthermore, no study explored exercise and telehealth for those LWBLC within the UK [31]. Data collected through the International Cancer Benchmarking Partnership has shown that over the past several decades, in countries with similar healthcare systems (Australia, Norway, Canada, Denmark, New Zealand, Ireland, and the UK), the UK has ranked lowest for 1-year lung cancer survival [79]. Thus, highlighting further research is paramount to address the below-average survival rate for those LWBLC.

ExerciseGuide UK provides a unique and novel method of providing those LWBLC with an 8-week tailored physical activity programme and personalised educational resources using distance-based methods. Supervised (in-person) exercise interventions are thought to be superior to unsupervised exercise programmes [29]. However, ExerciseGuide UK provides non-real-time supervision while using a distance-based approach. Though, there is limited existing high-quality evidence for those LWBLC. Those LWBLC often display a higher unmet symptom burden and lower quality of life than other prevalent cancer types [80]. Higher unmet symptom burdens and lower quality of life may lead to physical, psychological, and financial disparities, leading to unattainable or achievable standard in-person exercise programmes. Literature has demonstrated key benefits of digital technology

regarding accessibility, reach, and convenience through online or computer-mediated communication because it can mitigate temporal and geographical barriers [81–83]. ExerciseGuide UK can maintain personally tailored content for those restricted by location or schedule.

Though ExerciseGuide UK presents possible benefits for those LWBLC, there are some noted limitations. Firstly, while digital technology can reduce temporal and geographical barriers to interventions, this is dependent on several presumptions. Having access to a laptop, computer, or smart device (e.g. tablets and smartwatches) that would enable participation may be varied. Lung cancer incidence is higher for those living in deprived regions and with lower socioeconomic status [84]. However, reports illustrate that those living in urban areas have higher-speed Internet availability [85] compared to those living in rural. Overall, urban areas tend to be more socially deprived than rural areas [86]. Furthermore, the average cost of fixed data (broadband) and voice packaged monthly costs in the UK was £37.25 [87].

Secondly, research waste is an ongoing concern within health research. Up to 85% of research within health is understood to be wasted due to poor research design, inadequate reviews of literature, and unpublished research [88]. The meaningful involvement of the target population of an intervention may reduce the ongoing concern of research waste [89] while ensuring the intervention is appropriate and meaningful for end-users. ExerciseGuide UK has been adapted using an iterative approach with those LWBLC and their family members and qualitative interviews.

Lastly, recruiting those LWBLC into clinical research can be challenging [90]. The recruitment will occur in a lung cancer clinic with assistance from hospital oncologists.

Conclusion

ExerciseGuide UK provides a unique and novel approach to providing tailored physical activity programmes and educational resources to those LWBLC. However, there is limited high-level evidence within online supportive care for those LWBLC. Thus, the feasibility study exploring ExerciseGuide UK will provide insight into usability concerns that may be revised prior to larger-scale trials, potentially reducing research waste [91]. Building on the evidence collected as part of the feasibility and acceptability trial, the authors plan to revise the website and explore methods of facilitating digital technology usage within lung cancer, comparative assessment of those using a digital physical activity tool vs standard care, and further development of physical activity and health advice (e.g. nutrition).

Abbreviations

LWBLC: Living with and beyond lung cancer; PHP: Hypertext pre-processor; ACSM: American College of Sports Medicine; COVID-19: Coronavirus 19; RCT : Randomised control trail; PPI: Patient and public involvement; SMART Goals: Specific, Measurable, Attainable, Realistic, and Timely Goals; EORTC: European Organisation for Research and Treatment Of Cancer; SPIRIT: Standard Protocol Items: Recommendations for Interventional Trials.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s40814-022-01129-6.

Additional file 1: Table of change

Additional file 2: Think Aloud Interviews

Acknowledgements

We thank the patient and public involvement members for participating in the iterative adaption of ExerciseGuide UK.

Authors' contributions

The original conception of the platform was by CV and subsequent website conception by CV and CS. The first ExerciseGuide site was conceived by CS and CF with further programme development and adaptation from CF, CS, and HL. JC led the adaption of ExerciseGuide for this study with contributions from CF. JC led the manuscript's writing process with contributions from CF, CV, CS, HL, and MP. ML gave clinical input and recruitment facilitation with recruitment been carried out by JC and ML. The authors take responsibility for the protocol and approved the final version of this paper.

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Availability of data and materials

Not applicable

Declarations

Ethics approval and consent to participate

The ethical approval for the study using Think Aloud interviews was obtained from the Hull York Medical School Research Ethics Committee (reference: 20 49). Informed consent was gained from all participants. The ethical approval has been obtained for the feasibility trail of ExerciseGuide UK from the Health Research Authority and Health and Care Research Wales (21/SC/0174).

Consent for publication

Not applicable

Competing interests

The authors declare that they have no competing interests.

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Publisher's Note

13.5.3 Developing and testing the ExerciseGuide UK website for people with lung cancer: reflections on the added value of patient and public involvement within a doctoral degree.

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Research Involvement
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COMMENT

Open Access

Developing and testing the ExerciseGuide UK website for people with lung cancer: reflections on the added value of patient and public involvement within a doctoral degree

Jordan Curry[1*], Helen Roberts[2], Alan Smith[3], Diane Riley[3], Mark Pearson[1] and Cynthia C. Forbes[1]

Abstract

Background: Lung cancer has one of the highest incidence and mortality rates worldwide. Physical activity can provide those diagnosed with lung cancer with several physical and psychological benefits. However, the examination of digitally delivered physical activity to those with lung cancer is not as researched as other common cancers. Often, those diagnosed with lung cancer are older adults (65 years or older). Older adults are often wrongly assumed to lack digital skills, interest, and not engage with digital technology regularly. Although individuals are interested, would involving older people in designing of websites and apps result in better engagement?

Main body: In this article, the authors discuss the process of adapting a digital platform with a patient and public involvement group to provide those who have received a lung cancer diagnosis with a tailored physical activity program and health educational modules. We discuss the influence of recurrent patient and public involvement on the study, the patient and public involvement members, and the doctoral researcher.

Conclusion: Working with a patient and public involvement group over several months, especially potential users of a digital intervention, may enhance its relevance, accessibility, and usability. By engaging with patients, family, or caregivers for someone with lung cancer, the doctoral student gained insight into the needs of the study population and what to consider during development. All group members expressed their interest and enjoyment in their involvement, and several are now active members of a wider patient and public involvement network.

Keywords: Patient and public involvement, Digital health, eHealth, Usability, Co-design, Lung cancer, Physical activity

Plain English summary

This commentary describes how patient public involvement has been used to adapt a website called ExerciseGuide UK. This website provides a personalised physical activity program and education to those diagnosed with lung cancer. The programme is altered to allow for each patient's capabilities. Reflections on how the study affected both the

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Figure 37: Published commentary paper

researcher and the PPI members are discussed. The commentary gives the patient and public involvement members a voice in their involvement experience. It highlights the difference that their sustained involvement made to the study, the doctoral researcher, and those who were involved. Globally, lung cancer is a leading cause of cancer-related death and remains one of the most common types of cancer. Digital technology, such as websites, mobile applications, and smart wearable devices (e.g., Apple Watch and Fitbits), have increasingly been used in health research over the last few decades. Since the beginning of the COVID-19 pandemic in 2020, research into digital technology has increased rapidly. Individuals diagnosed with lung cancer may experience a large number of physically and emotionally limiting symptoms, such as a higher risk of severe illness due to infections. With the large symptom burden they experience, digital technology may provide alternative and more accessible methods which can be altered to suit and help their specific needs. The patient and public involvement group members had all either been diagnosed with lung cancer, cared for someone with lung cancer, or experienced lung cancer in their family.

Background

Lung cancer is the leading cause of cancer-related deaths globally [1]. Patients diagnosed with lung cancer often have a higher burden of symptoms than patients with other prevalent cancers and are less likely to receive support to manage these symptoms [2, 3]. Physical activity has many benefits for the physical and mental health of those diagnosed with lung cancer (see Fig. 1).

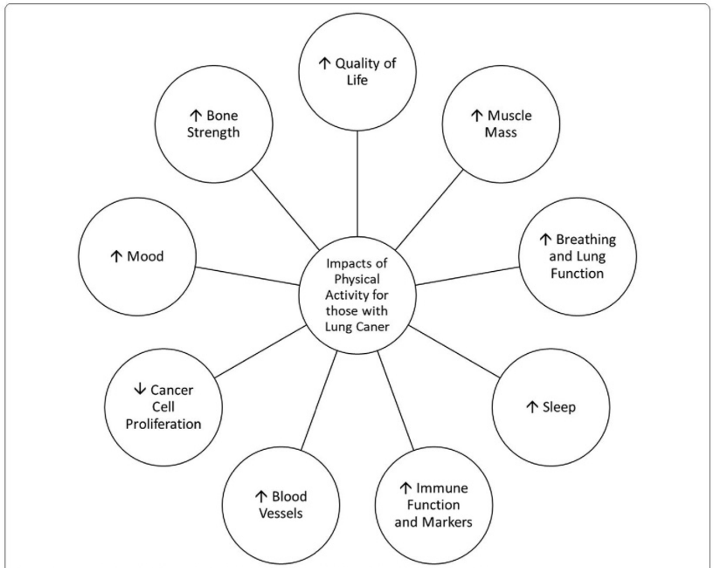

Fig. 1 Summary of the positive impacts physical activity can have for those living with and beyond lung cancer

Digital technology has been an emerging field of health research in recent decades. Digital technology has demonstrated that it can provide tailored physical activity programs to people at relatively low cost and is generally easily accessible [4]. However, patients do not use such tools as often as they could, despite expressing interest [4]. Therefore, the question remains, why are users not engaging with digital health tools? One common thought is that such tools lack user perspectives and input during the design phase [5, 6].

This study involved adapting an existing exercise website (ExerciseGuide) to provide a personalised physical activity program and education guided by behaviour change techniques that aim to overcome possible activity barriers for those who have received a lung cancer diagnosis.

This commentary focuses on how giving patient and public members a voice in this research was important, the influence of the patient and public involvement (PPI) group on the study, how involvement in this doctoral PPI impacted the PPI group, and how the doctoral researcher worked with the group online to adapt and co-design the website (ExerciseGuide UK) to test in a feasibility study.

Main body

Doctoral research and ExerciseGuide UK

The doctoral research concerning this commentary focuses on exploring ExerciseGuide UK, a web-based platform that allows tailored information for those who have received a lung cancer diagnosis based on IF–THEN rules. Essentially, *IF* an individual selects a statement, *THEN* they will be shown a pre-determined answer. ExerciseGuide UK has been adapted from previous versions of ExerciseGuide [7–11]. A detailed protocol of the adaptation and redevelopment of ExerciseGuide UK has been published [12]. ExerciseGuide UK is still hosted online but is currently closed for new user enrolment (https://www.exerciseguide.org.uk). The PPI was a key component in ExeriseGuideUK's adaptation and new content development.

Purpose of patient and public involvement

The purpose of conducting sustained PPI was to ensure ExerciseGuide UK was adapted and new content developed appropriately for those with a lung cancer diagnosis. By sustained PPI, we mean that we worked with our PPI group over a period of several months. ExerciseGuide UK was collaboratively revised through sustained PPI and feedback from qualitative Think-Aloud interviews. The number of PPI members involved varied over the three workshops. Four members attended the initial workshop. Three attended workshop two (two of the original group died in the intervening period, and one new person joined the group), and three attended workshop three. In total, five people were involved. Think-Aloud interviews were conducted with seven individuals who had a lung cancer diagnosis. There was no crossover between the PPI members and the Think-Aloud participants. Participants performed several pre-determined tasks on the website via Zoom and were encouraged to actively speak their actions and thoughts aloud. Further information regarding the Think-Aloud reviews are discussed in the published protocol [12]. All thoughts identifying areas of concern were brought to the PPI group for potential change.

Workshop delivery and feedback

In this section, we will provide a summary of the process taken to conduct the PPI workshops. Further information regarding key methods is presented in the published protocol paper [12].

Workshops

A series of face-to-face workshops were initially planned with support and guidance from the research team, who had previous experience and expertise in PPI. The first two workshops aimed to review the content of the ExerciseGuide UK program and explore four key areas:

(1) Understanding of physical activity concerning lung cancer
(2) Barriers to engaging in physical activity and digital technology
(3) Creating clear materials for study participants
(4) Module development within ExerciseGuide UK

The third workshop reviewed the findings from Think-Aloud interviews conducted among people with lung cancer. One final workshop was conducted to reflect on how the PPI shaped the intervention and the study. A recruitment flyer was developed and disseminated online (via Twitter) and through support groups for those affected by a diagnosis of lung cancer. Three members joined the PPI group in response to the recruitment flyer. Two members were invited from an existing PPI network, Involve Hull, based on their personal experiences of lung cancer.

Due to the Coronavirus-19 pandemic, all PPI workshops were adapted for online delivery. The research team were cautious about this transition to solely virtual PPI and lacked experience in this way of working. In practice, this increased the geographical reach of the PPI by involving people from outside the local area, including people living in cities and towns in the southwest and northwest of England. One member highlighted the positive benefits of virtual PPI in terms of how they felt able to engage with each other:

> *The medium of Zoom has certainly enabled me to participate living far away – PPI Member 2*
> *I am more prepared to break in and make my own contribution in this [Zoom], particularly online, instead of in a room where I would need to attract your attention, maybe stand up, people looking at me... it's much less intimidating – PPI Member 2*

However, although the geographical reach increased, individuals lacking digital skills or with limited or no access to digital technology were not included; therefore, their insights were not captured.

Feeding back to the group

All PPI sessions were recorded with group consent. Following the first two PPI workshops, a summary of the discussion was shared with the group. A traffic light colour coding method was used to identify which ideas would be taken forward, which were under consideration, and which could not be addressed within this study. The feedback allowed the group to see that their input had been heard and understood, provided further opportunities for reflection and ideas, and ensured the researchers recorded their comments accurately. The summaries produced were well received by the PPI group and encouraged them to sustain their engagement:

> *It is certainly motivation for me to get all this feedback and how it has been taken on board. Sometimes is it very difficult to know whether your input has been of any value or any notice of, so no, I really appreciate that, and it will certainly make me come back and do future PPI roles – PPI Member 1*
> *I think also you get more people who are keen to contribute when they can see their contribution has been seen, recognised, and been acted on...people won't actually contribute change if they don't feel that change is being acted on – PPI Member 2*

Reflections of patient and public involvement

Study revisions

After analysing seven Think-Aloud interviews, 24 proposed revisions to the website were brought to the PPI group for discussion. There were five main themes: (1) Understanding and Clarity, (2) More Information Needed, (3) Visual, (4) Functionality, and (5) Preferential. The PPI group agreed with 46% of the revisions proposed and, in collaboration with the doctoral researcher, found ways of improving the rest. Most of the proposed revisions centred on 'More information, 'Understanding and Clarity' and 'Preference'. This process resulted in a consensus on how best to adapt ExerciseGuide UK. Involving the PPI group ensured the right level of information was provided, and that information was clear, suitable, and appropriate for those with a lung cancer diagnosis.

For instance, the landing page of ExerciseGuide UK originally stated the website was for those "living with and beyond lung cancer". The PPI group did not feel this phrase was clear. Therefore, the statement was revised to read, *This personally tailored website is for those who have received a lung cancer diagnosis and aims to help you to become more active in a fun and educational way!*. Another example was the redesign and renaming of the library of additional resources. The name, Library, was unpopular with those who took part in the qualitative interviews, and the PPI group decided 'Extra Information' was more understandable. Figure 2 demonstrates how the design of this page was revised after discussion with the PPI group, with colourful icon thumbnails making the content more visible and navigation much easier.

Reflections of the PPI group members

Members of the PPI group commented on the impact that involvement has had on their understanding of PPI in health research.

> *For me, Involve [Involve Hull] has just opened my eyes up to a whole world that I didn't realise was out there [research and PPI]...it has opened my eyes up so much. To feel you can make a contribution is very energising – PPI Member 1*
> *It has been very interesting to see how much goes into these sorts of PPI activities. I had no idea it was governed by so many rules, regulations, protocols and things – PPI Member 2*

Two members commented that their involvement in this PPI positively impacted their perceptions of lung cancer.

> *It benefits me in realising I was not the only person with this [lung cancer], which you often feel like you are. So, it was interesting to meet others and hear their experiences – PPI Member 2*
> *For me, the good feeling about the fact that you can be involved in it, but for me, personally, like [PPI member 2] said... y'know realising some people with lung cancer can have a good life with it, some quality of life, sometimes they can enjoy together, which we didn't have. – PPI Member 3*

Doctoral student reflections

From the beginning of this doctoral degree, the primary aim was to adapt and develop an online platform to provide a tailored physical activity program and education.

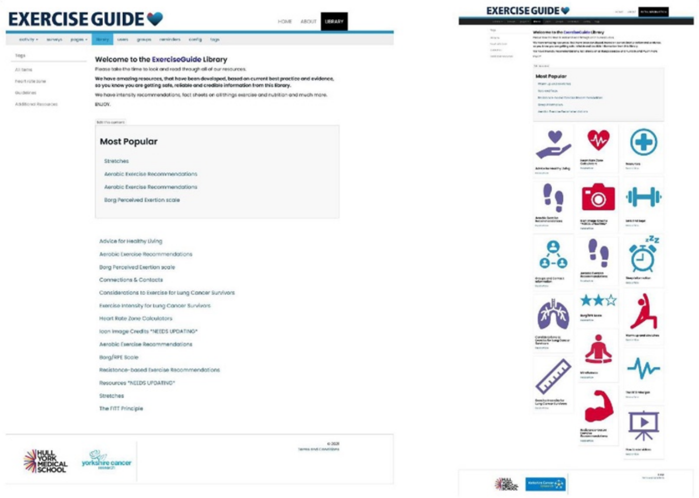

Fig. 2 Original (left) and revised (right) screenshots of the Extra Information page (formerly known as Library) on ExerciseGuide UK. Figured taken from [12]

Before redeveloping ExerciseGuide UK, a systematic review was conducted to explore the evidence regarding online supportive care for those diagnosed with lung cancer [13]. The platform underwent initial redevelopment using the findings from the review and existing knowledge gained from prior experience working as an exercise professional. Then, the PPI group was formed to gain feedback on the platform's prototype and assistance with further adaptations. Although the initial prototype was well received, suggestions were made to change certain aspects of ExerciseGuide UK. Reflecting on the process, it would have been beneficial to set up a PPI group before the redevelopment began so that the lived experience could guide the whole process. This way, time would be saved by collaboratively deciding what content and features to develop.

Opening up the website to critique from the PPI group was challenging as a doctoral student. After months of reviewing literature regarding the needs of individuals diagnosed with lung cancer, it was difficult to hear that the platform did not currently meet the needs of those with lung cancer as intended. Doctoral students seek feedback from their supervisors and other senior academics. However, as public involvement at doctoral level is unusual, they are less used to having their work critiqued by public members. Being exposed to feedback from those with lived experience who represent the population an intervention is designed for is a different learning process. It involves learning to accept that knowledge based on personal experience of health and care is equally valid to professional or academic knowledge and its benefits. In this case, the benefits were a better, more relevant and user-friendly website, and the personal learning and development of the doctoral student.

The doctoral student brought the findings from the Think-Aloud interviews to the PPI group for discussion and agreement. Each issue was presented, along with a proposed solution, and the group worked through these to agree how the website would be revised. All PPI and staff members agreed with the accepted changes. This meant that the final prototype was more appropriate for its target population and had greater clarity and overall usability.

Discussion

Involving the PPI group in the study multiple times clearly improved the final product. Following the Think-Aloud interviews, 54% of the proposed revisions to increase the platform's usability and acceptability were further revised with the PPI group. Even though it was sometimes difficult to hear criticism for a lot of hard work, usability and acceptability issues were likely to remain without this co-design process. Research waste is a serious concern, particularly in health sciences, with up to 85% of health research potentially wasted, possibly due to poor study design and conduct [14]. Ensuring PPI is involved in all research, including doctoral research, may reduce poor design, increase the level of appropriateness and usability for special populations (e.g. older adults), and encourage patient recruitment and retention to allow completion.

Although digital technology was the primary method of PPI during the Coronavirus-19 pandemic, it should not replace face-to-face involvement. Approaching PPI virtually without offering alternative ways of getting involved will exclude those not engaging with digital technology. The authors acknowledge that these individuals may have been excluded.

All members are now active in the University of Hull's PPI network (Involve Hull) and contribute to the university's ongoing research. The PPI contributors involved said being involved in this doctoral PPI was beneficial to them personally. For example, one PPI member highlighted hearing positive stories of others having a diagnosis of lung cancer was valuable to them. Their participation has also been beneficial to their awareness of different lung cancer outcomes, and when their suggestions were visibly heard and implemented, they felt good and motivated. Two PPI members of the PPI group are co-authors (Smith and Riley) of this commentary.

Doctoral students can benefit greatly from working iteratively to develop interventions with the input of PPI. Working closely with the PPI group on designing, adapting, and developing content for the intervention was extremely valuable in ensuring intervention success. Another benefit was a process of in-depth learning about how to address barriers and ease concerns about physical activity and digital technology.

Conclusion

Although PPI is not mandatory within doctoral research, it can ensure an appropriate, relevant, and acceptable intervention, reduce the possibility of research waste, and provide the research team with knowledge and expertise that they would not otherwise be able to access.

Abbreviation

PPI: Patient and public involvement.

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Author contributions

JC led the patient and public involvement workshops with substantial contributions from HR. JC led the writing and revising of this manuscript. AS and DR contributed their views on engaging within patient and public involvement in this doctoral research. HR, AS, DR, MP, and CF all made substantial contributions to this manuscript and helped revise the manuscript. All authors have read and agreed the final manuscript.

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Availability of data and materials

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Declarations

Ethics approval and consent to participate

N/A.

Consent for publication

N/A.

Competing interests

The authors declare that they have no competing interests.

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Publisher's Note

13.6 Appendix Six: Search strategy for EMBASE (via OVID)

1. exp Lung tumor/
2. (Lung adj2 (cancer* or neoplasm* or tumor* or tumour* or carcinoma*)).ti,ab,kw.
3. exp Cancer Survivor/ and lung*.ti,ab,kw.
4. or/1-3 [Lung Cancer Concepts]
5. exp internet/ or exp internet access/ or social media/ or mobile phone/ or smartphone/
6. Online Care.ab,ti,kw.
7. Online Support.ab,ti,kw.
8. eHealth.ab,ti,kw.
9. mHealth.ab,ti,kw.
10. Mobile Phone*.ab,ti,kw.
11. Smart Phone*.ab,ti,kw.
12. Smartphone*.ab,ti,kw.
13. Internet*.ab,ti,kw.
14. Mobile App*.ab,ti,kw.
15. Mobile Application*.ab,ti,kw.
16. Website*.ab,ti,kw.
17. eSupport.ab,ti,kw.
18. Digital Support.ab,ti,kw.
19. Web* Support.ab,ti,kw.
20. Telehealth.ab,ti,kw.
21. patient portal.ab,ti,kw.
22. exp Telehealth/
23. or/5-22 [Internet Concepts]
24. ((message or discussion) adj3 (board* or internet or online)).ti,ab,kw.
25. (chatroom* or (chat adj room)).ti,ab,kw.
26. ((online or discussion) adj3 forum*).ti,ab,kw.
27. (social media or Facebook or Twitter or Instagram or blog* or YouTube or WhatsApp).ti,ab,kw.
28. exp Blogging/ or online support group/
29. or/24-28 [Social Media and Online Discussions Concepts]
30. 23 or 29
31. 4 and 30

13.7 Appendix Seven: Black Data Extraction Form from Systematic Review

THE COCHRANE COLLABORATION®

Data collection form

Intervention review – RCTs and non-RCTs

This form can be used as a guide for developing your own data extraction form. Sections can be expanded and added, and irrelevant sections can be removed. It is difficult to design a single form that meets the needs of all reviews, so it is important to consider carefully the information you need to collect, and design your form accordingly. Information included on this form should be comprehensive, and may be used in the text of your review, 'Characteristics of included studies' table, risk of bias assessment, and statistical analysis.

Notes on using a data extraction form:

Be consistent in the order and style you use to describe the information for each included study.

Record any missing information as unclear or not described, to make it clear that the information was not found in the study report(s), not that you forgot to extract it.

Include any instructions and decision rules on the data collection form, or in an accompanying document. It is important to practice using the form and give training to any other authors using the form.

You will need to protect the document in order to use the form fields (Tools / Protect document)

Review title or ID

Study ID (surname of first author and year first full report of study was published e.g. Smith 2001)

Report IDs of other reports of this study (e.g. duplicate publications, follow-up studies)

Notes:

General Information

Date form completed *(dd/mm/yyyy)*	
Name of person extracting data	
Report title (title of paper/ abstract/ report that data are extracted from)	
Reference details	
Report author contact details	
Study funding source (including role of funders)	
Possible conflicts of interest (for study authors)	
Notes:	

Eligibility:

DO NOT PROCEED IF STUDY EXCLUDED FROM REVIEW

Population and setting

	Description Include comparative information for each group (i.e. intervention and controls) if available	Location in text (pg & /fig/table)
Proportion of lung cancer survivors in sample		
Setting (including location and social context)		
Inclusion criteria		
Exclusion criteria		
Method/s of recruitment of participants		
Notes:		

Methods

	Descriptions as stated in report/paper	Location in text (pg & /fig/table)
Aim of study		
Study Hypotheses		
Design (e.g. parallel, crossover, non-RCT)		

Study period/date (Start date and end-date of study)		
Timing of assessments and follow-up measures		
Notes:		

Participants

Provide overall data and, if available, comparative data for each intervention or comparison group.

	Description as stated in report/paper	Location in text (pg & /fig/table)
Total no. randomised (or total pop. at start of study for NRCTs)		
Age		
Sex		
Race/Ethnicity		
Location (urbanisation) Major city, regional, remote		
Severity of illness (stage)		
Type of cancer treatments received		
Time since diagnosis		
Co-morbidities		

	Description as stated in report/paper	Location in text (pg & /fig/table)
Other interventions received (additional to study intervention)		
Other relevant sociodemographic (Marital status, education, income, sexual orientation)		
Subgroups measured		
Subgroups reported		
Notes:		

Intervention groups

Copy and paste table for each intervention and comparison group

Intervention Group 1 –

	Description as stated in report/paper	Location in text (pg & /fig/table)
Group name		
No. randomised to group (specify whether no. people or clusters)		
Description (include sufficient detail for replication, e.g. content, dose, components; if it is a natural experiment, describe the pre-intervention)		

	Description as stated in report/paper	Location in text (pg & /fig/table)
Intervention development approach -Target audience involved? - Expert advisory panel involved? - Literature synthesis or original research conducted to inform development? - Pilot study conducted?		
Theory-base		
Behaviour change techniques used / Communication strategies		
Intended usage		
Strategies to ensure adherence to intervention (Intended usage) and/or enhance engagement (interest, attention and positive affect).		
Duration of treatment period		
Timing (e.g. frequency, duration of each episode)		
Delivery (e.g. mechanism, medium, intensity, fidelity)		
Providers (e.g. no., profession, training, ethnicity etc. if relevant)		

	Description as stated in report/paper	Location in text (pg & /fig/table)
Economic variables (i.e. intervention cost, changes in other costs as result of intervention)		
Resource requirements to replicate intervention (e.g. staff numbers, cold chain, equipment)		
Website domain name and status		
Notes:		

Outcomes

Copy and paste table for each outcome (interested in data relating to feasibility, acceptability and efficacy).

Outcome 1

Copy and paste table for each outcome.

	Description as stated in report/paper	Location in text (pg & /fig/table)
Outcome name		
Measurement tool		
Time points measured (specify whether from start or end of intervention)		
Time points reported		

	Description as stated in report/paper	Location in text (pg & /fig/table)
Outcome definition (with diagnostic criteria if relevant and note whether the outcome is desirable or undesirable if this is not obvious)		
Unit of measurement (if relevant)		
Scales: upper and lower limits (indicate whether high or low score is good)		
Is outcome/tool validated?		
Imputation of missing data (e.g. assumptions made for ITT analysis)		
Power calculation Added this		
Notes:		

Results

Copy and paste the appropriate table for each outcome, including additional tables for each time point and subgroup as required.

Feasibility

Recruiting participants		Location in text (pg & /fig/table)
Was the required/pre-specified sample size reached?		

How long did the recruitment period take?		
What was the response rate for participation?		
Were any obstacles to recruitment noted?		
Are characteristics of the study population consistent with the range of expected characteristics informed by the literature?		
Implementing the intervention		
Are there likely to be sufficient resources and ability to manage the implementation of the intervention in the long-term?		
To what extent was the intervention implemented as intended?		
What was the drop-out rate post-intervention and for any post-intervention follow-ups?		
Other notes relating to feasibility		

Engagement

		Location in text (pg & /fig/table)
Did most participants use the		

intervention as intended by the intervention developers? Answer only if intended usage was specified or can be reasonably assumed.		
Describe usage of the intervention.		
Were any measures of engagement assessed? (i.e., relating to participant's user experience – interest, attention, positive affect). If so, describe findings.		

Main outcome

For randomised or non-randomised trial - Continuous outcome

	Description as stated in report/paper	Location in text (pg & /fig/table)
Comparison		
Outcome		
Subgroup		
Time point (specify whether from start or end of intervention)		
Post-intervention or change from baseline?		

	Description as stated in report/paper	Location in text (pg & /fig/table)
Results Note whether post intervention (usually controlling for baseline) or change from baseline and whether other variables have been controlled for. Include mean and SD (or other variance), effect size if available + number of participants		
No. missing participants and reasons		
No. participants moved from other group and reasons		
Any other results reported		
Unit of analysis (e.g. by individuals, health professional, practice, hospital, community)		
Statistical methods used and appropriateness of these methods (e.g. adjustment for correlation)		
Notes:		

Applicability

Have important populations been excluded from the study? (consider disadvantaged populations, and possible differences in the intervention effect)	… *Yes/No/Unclear*	No
Is the intervention likely to be aimed at disadvantaged groups? (e.g. lower socioeconomic groups)	… *Yes/No/Unclear*	
Does the study directly address the review question? (any issues of partial or indirect applicability)	… *Yes/No/Unclear*	
Notes:		

Other information

	Description as stated in report/paper	Location in text (pg & (fig/table)
Key conclusions of study authors		
References to other relevant studies		
Correspondence required for further study information (what and from whom)		
Further study information requested (from whom, what and when)		

Correspondence received (from whom, what and when)	
Notes:	

13.8 Appendix Eight: Patient and Public Involvement Workshop Summaries

13.8.1 Workshop One Summary

Barriers and Concerns about Physical Activity and Digital Technology:

- The route to accessing physical activity/exercise support is not clear and not everyone receives such a referral or advice.
- Sitting at home can be bad for you, it is best to be in a situation wherein you have to participate in exercise.
- Exercise in group settings can promote feelings of anxiety and embarrassment. The feeling of holding the group back.
- Rehab courses are well established within the NHS for people with heart conditions and respiratory conditions, so why not for lung cancer (or cancer more generally)?
- Some do not see a physio again once they left hospital.
- Fear of breathlessness (this is more so specific to lung cancer). Fear of hurting yourself on equipment (e.g., falling off a bike).
- Treatments can cause severe bouts of fatigue, essentially wiping you out. But it is important you exercise. The levels of fatigue (and side effects) caused by treatment and cancer itself must be taken into account
- Feelings of fatigue post exercise (or the perception) can be very discouraging to the continuation of exercise.
- The lack of health care professional (e.g., physiotherapists) and support
- The act of not exercising and risking seizing up and finding it hard to restart
- At the moment of a cancer diagnosis, it's hard to absorb information pertaining to exercise. Reintroduce this information at two months post diagnosis?
- No follow up from NHS – not geared up to support patients emotionally or with physical activity after treatment – lack of joined up approach
- Medics have a pessimistic outlook about the prognosis for people with lung cancer and don't offer hope or positive messages about the benefits of physical activity – this is demoralising and does not encourage patients to exercise
- Most people think exercise means going to the gym and this is off putting

Physical Activity Guidance:

- Advise people that everyday activities such as making a cup of tea or walking upstairs do count as exercise and do have benefits'
- Get info across at the start of treatment, a website may be a good tool to look at when home to help increase exercise knowledge.
- Encourage people in general with lung problems, if they can do it, to go out for walks on fresh air or just to encourage them to sit outside.
- Concern about what individuals with lung cancer "can do" so sometimes it's easier to not be active.
- Not knowing the expectations of how and when to return to exercise. Exercising "too much" may be risky
- Lack of guidance from the moment of diagnosis on how to exercise or reintroduction to exercise.
- Lack of advice throughout the pathway, including survivorship, but it is still important.
- Lack of knowledge of the guidance of physical activity, which may restrict being active.
- One size fits all approach to physical activity guidance can be discouraging
- Guidance is good if you are in an area where prehabiliation is offered in advance of surgery
- Guidance is better if you are in an area with a specialist cancer hospital (e.g. The Christie)

Website Features:

- The need to tailor is **very important**; one size does not fit all! Not everyone is the same! Include a wide variety of exercises to cater or varying abilities
- It is important to take an exercise history prior to giving individuals exercise programmes.
- Motivation is important, the feeling of being encouraged can be very motivating. Mental motivators/achievements could be seeing progress. Rewards has that sense of achievement, which is beneficial.
- People will feel disheartened if you prescribe exercise and by week four, they are not reaching what you prescribed. (This may be a pro as this tailored approach should not have a one size fits all approach).

- Some people are more comfortable and competent to use technologies such as websites, so this barrier will always be present.
- Can the platform track other preferences than walking, for example, cycling and swimming? This may be important to some.
- Breathing exercises are a form of exercise, so we can start off slow and easy. “How to breath?” may be something to explore
- Ability to adapt exercise programme to take account of the progression of the disease, variations in levels of fitness over time – e.g., by assessing this again at various points after the baseline survey?
- Making the website adaptable and able to function on various devices (e.g., iPad or mobile device).
- Can you offer advice or a plan for everyday activities, modified to what you can do at home – currently the focus is on actual exercises

Understanding barriers to exercise and website adaptation for those living with and beyond lung cancer - Feedback

See below a summary of the above themes which were discussed during workshop one and what we are doing with your ideas!

What we already have…
• Tailored physical activity content • Tracking modules that show progress over time • Planning and goal setting modules • Ability to signpost to external groups and information • Ability to contact someone via email or phone • Information of physical activity guidelines for this population • Integrated questionnaire to see prior physical activity history

What we are going to change or add…
• A module on breathlessness • Breathing exercises • Updating Library to include local organisations and contacts • Add knowledge of physical activity which is not commonly thought about • Adding information on good smartphone applications to assist with the tracking of activity or assist with healthy behaviours

What we can't do right now but will do in the future…
• Integrate an online community within the website • Symptom monitoring systems • Interactions and management of additional long term conditions (e.g., Diabetes)

13.8.2 Workshop Two Summary

Recruitment methods

- Possibly with the information packs which are given out at diagnosis by cancer nurse specialists
- Treating physician/healthcare professional/consultant would be ideal
- Part of therapy (physio)
- Macmillan information and support services (could they display and distribute information about research studies?)
- Internet forums/research forums
- Posts online? Websites and social media

Physical Activity Questionnaires (SQUASH vs CHAMPS)

- CHAMPS seemed more favoured
- Some concerns around wording (Dutch made but mainly USA wording vs UK)
- SQUASH has a focus on working-age people, which might not suit this population
- CHAMPS seems clearer
- The importance of mental health was raised
- CHAMPS seems a little daunting with so many questions/items
- Pre-diagnosis level of activity?

Website

- Ethnicity – NHS Data Dictionary could be used as a standard list of categories
- Link in CHAMPS to activities they like - even provide links
- Maybe a bit more detail on why we ask demographic questions – at the start of the questionnaire – and how this relates to the activity programme

Mental Health Module

- A guide when diagnosed
- It must be personal as mental health is a very personal concept
- How people deal with problems, therefore very difficult to approach

- Not sure how to do it online, as in-person support may be more appropriate
- Pathway navigators – may be helpful to signpost these individuals?
- Maybe just a focus on help is out there and where to find – giving contacts

Nutrition

- Government changes the recommendations so maybe more informative with behaviour change advice included
- Various diets can be person-specific, and whether they want to take up such a thing
- Generic dietary information which would be personalised and specific to the individual's needs (tailored approach) would be helpful
- To have information about diets would be good, targeted to treatments or types.
- No real NHS recommendations for diet were given

Understanding barriers to exercise and website adaptation for those living with and beyond lung cancer - Feedback

See below a summary of the above themes, which were discussed during workshop two and what we are doing with your ideas!

What we already have…
• The CHAMPS questionnaire is ready to be added into the website. Your feedback suggested it was more appropriate and clearer for this population • Basic nutritional and dietary information is helpful. We have included this under healthy lifestyles. You mentioned the usefulness of this being tailored.

What we are going to change or add…

- We are going to change the current SQUASH questionnaire for the CHAMPS
- Review the ethnic categories in the baseline questionnaire against those in use within the NHS
- Mental health module on where to find some help and assistance with mental health.
- Clearer reasoning to why we are collecting personal demographic data (e.g., household income) in relation to health inequalities and disparities.

What we can't do right now but will do in the future…

- For each of the specific examples given on the CHAMPS questionnaire (e.g., senior centre or golfing), we can make specific feedback to encourage these behaviours/activities.
- Dedicated mental health module covering coping techniques and emotional wellbeing support.

13.9 Appendix Nine: Think Aloud Study Consent Form and Participant Information Sheet

13.9.1 Participant Information Sheet for Study Two (Think Aloud interviews)

Usability of a Tailored Web-Based, Physical Activity Programme for those living with and beyond lung cancer.

Participant Information Sheet

Invitation to take part in a research study

You are being invited to take part in a usability study of an online platform which aims to provide tailored physical activity programmes to those living with and beyond lung cancer. To help you to decide if you would like to take part, we have devised this sheet. It explains why we are exploring the platforms usability, what you will be asked to do, and why we are inviting you to take part. Please take your time to read the following information: you might want to discuss it with your friends or family. Alternatively, you can contact the research team and ask them to explain anything that is not clear to you.

What is the study about?

We are designing an online, web-based, physical activity programme, to provide a tailored physical activity programme for those living with and beyond lung cancer, to help improve quality of life, alongside other treatments they may receive. Previous research has shown that physical activity can help people living with and beyond cancer manage their symptoms and increase quality of life. Therefore, we would like to conduct a Think Aloud interview with you to gain a better understanding in how individuals will use the website. We also would like to know which parts you think are helpful and which parts you feel are not so useful. At the end of the interview, your feedback will help us alter the website and ensure design features and content are appropriate.

Why have I been invited to take part?

We are asking up to eight individuals who are living with and beyond lung cancer to take part. You have been invited because you may meet some of the criteria which we are looking for this study. The research team will contact you by telephone or email to discuss, answer any questions and see if you would like a chance to take part in usability study.

What will happen to me if I take part?

If you agree to take part in the study, you will then be contacted by a member of the research team who will invite you to attend the online interview. This will be arranged via telephone or email at a time of mutual convenience. The interview will take place on Zoom and will be recorded. Zoom is an online video conferencing software which allows users to engage in online discussions using audio and video chat. You will be asked to interact with the online platform, competing tasks such as, opening an activity session, logging a session, and completing the introductory questionnaire. In the unlikely event that something you tell us gives cause for concern, this will only be disclosed with your permission, or except as required by law. In the small chance of any adverse effect during the interview, the researcher will suggest you call emergency services. If you are unable, we will contact emergency services for you.

Do I have to take part?

No, it is up to you to decide whether or not you want to take part. If you decide to take part, you are still free to withdraw at any time without giving a reason. Though, you may offer to provide a reason voluntarily. To withdraw participants are required to contact any member of the research team and express your wish to evoke your right to withdraw. The research team will make a note of the reason for withdrawal, if the participants volunteer to provide one. The research teams' emails are detailed at the end of this document. Participants can withdraw themselves from the study and if chosen to do so, all data collected will be destroyed. If you chose to withdraw from the study, no personal data will be held, all personal data will be destroyed upon withdrawal.

What are the positives to be taken from participating?

The information that we get from this study will help us address some key areas and ensure the platform meets the needs for those living with and beyond lung cancer.

Are there any negatives to be considered should I decide to participate?

We do not anticipate that you will experience any disadvantages from taking part in the usability study, other than taking your time. However, it is possible that you may find some of the topic discussions may make you think about sensitive issues relating to your cancer. If you have any concerns, you will be able to speak about them with the researcher.

Will taking part in this study cost me anything, and will I be paid?

Participation in this study will not cost you anything and is undertaken on a purely voluntary basis. Unfortunately, it will not possible to pay expenses.

Will my involvement be confidential?

The University of Hull is the sponsor for this study based in the United Kingdom. We will be using information from your Think Aloud interview to help inform the design and development of the online platform. This means that we are responsible for looking after your information and using it properly. The University of Hull will keep identifiable information about you for 3-6 months after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information by contacting Mr Luke Thompson, Information Compliance Officer, University of Hull, l.thompson3@hull.ac.uk

If you agree to take part in the study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research. The information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research and cannot be used to contact you or to affect your care.

How do I make a complaint?

If you are not happy with your involvement in the study and feel unable to raise this directly with a member of the research team, or if you have any concerns about the way the researcher has carried out the study, or any other aspects of your care, you may contact:

Danielle Smith, Research Governance and Policy Manager, University of Hull.

Tel: 01482 466962 or d.g.Smith@hull.ac.uk

Approvals

All arrangements have been reviewed and approved by the Research Ethics Committee and Health Research Authority. The University of Hull has appropriate insurance and indemnity schemes in place relating to this research study.

Who can I contact for further information?

If you have any further questions about this research study, please do not hesitate to contact the researchers of this study:

Mr Jordan Curry Jordan.Curry@hyms.ac.uk

Dr Cindy Forbes Cindy.Forbes@hyms.ac.uk

Thank you for taking the time to read this information sheet.

13.9.2 Participant Consent Form for Study Two (Think Aloud interviews)

Participant Informed Consent Form

Study Title:	Usability of a Tailored Web-Based, Physical Activity Programme for those living with and beyond lung cancer.
Protocol Number:	1
Version and Date:	Version 1.0 14.09.2020
Study Design:	Think Aloud Interviews carried out on Zoom.
Sponsor:	University of Hull
Study Co-Investigators:	Dr Cindy Forbes Yorkshire Cancer Research,

Wolfson Palliative Care Research Group,

Hull York Medical School,

University of Hull,

HU6 7RX

01482 463741

Dr Mark Pearson

Yorkshire Cancer Research,

Wolfson Palliative Care Research Group,

Hull York Medical School,

University of Hull,

HU6 7RX

01482 463335

Examination of usability for an online tailored physical activity programme for those living with and beyond cancer.

Version: 1.2 Date: 23.11.20

Please tick the boxes

I confirm that I have read the information sheet dated 23.11.20 (version 1.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my medical care or legal rights being affected. ☐

I understand that the interview will be recorded to ensure that my views are documented accurately. ☐

I agree that anonymous quotations from my interview can be used in presentations or publications arising from this project. ☐

Patient Signature.................................. **Print Name**.. **Date**...................

Investigator Signature................................. **Print Name**... **Date.**..................

13.10 Appendix Ten: Summary of rankings per System Usability Scale item reported following the Think Aloud interviews.

Table 31: Think Aloud interviews per systems usability scale question response.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I think that I would like to use this website frequently	0	1	3	1	2
I found this website unnecessarily complex	4	1	1	1	0
I thought this website was easy to use	0	1	1	4	1
I think that I would need assistance to be able to use this website	3	2	0	1	1
I found the various functions in this website were well integrated	0	2	4	1	0
I thought there was too much inconsistency in this website	5	1	0	1	0
I would imagine that most people would learn to use this website very quickly	0	1	0	5	1
I found this website very cumbersome/awkward to use	4	2	0	0	1
I felt very confident using this website	0	1	1	2	3
I needed to learn a lot of things before I could get going with this website	6	0	0	0	1

Note: This table illustrates the number of participants which indicated each ranking per question.

13.11 Appendix Eleven: Definitions of the MoSCoW prioritisation technique

Table cited from “*Using the Person-Based Approach to optimise a digital intervention for the management of hypertension”* by Bradbury et al., (2018) (448).

Table 32: MoSCoW definitions

Criteria for prioritising which modifications to make (MoSCoW)	
Must	This modification must be made in order for the intervention to be effective in changing a participant’s behaviour (given what we know about the evidence base).
Should	This modification should be made if possible as it may impact effectiveness, but may be able to be delivered in a different way, or is in some way less critical than a Must have.
Could	This modification would be useful, but may be less critical to behaviour change than a ‘should have’ and may only be implemented if time and resources are available.
Would	This modification is not needed to support behaviour change, but could be useful if time and resources allow.

13.12 Appendix Twelve: List of Extra Information Pages

Table 33: Summary of Extra Information modules

Page Name	Brief Description of Contents
Advice for Healthy Living	A summary of key points from the Healthy Lifestyles module.
Heart Rate Zone Calculations	An explanation of why and how heart rate can be used within exercise prescription. Hyperlinks are provided to two websites to allow participants to calculate their heart rate ranges. A open access article from The University of Texas MD Anderson Cancer Centre on Exercise and Heart Rate for Cancer Survivors is also provided (525).
Resources	A list of hyperlinked resources to useful external resources were provided in this page. Resources including breathlessness, Physical Activity, general and lung specific, MacMillan Cancer resources, Nutrition, and Sleep.
Aerobic Exercise Recommendations	Considerations and recommendation for those living with and beyond lung cancer prior to engaging in aerobic exercise. This page provides a breakdown of the FITT principle with how this could be applied to aerobic exercise.
Icon Image Credits	Credits for the images used on ExerciseGuide UK.
Sets and Reps	A summary of the Sets and Reps information detailed in the Exercise Plan.
Groups and Contact Information	Contact information is provided for local hospitals and local charities for those living with and beyond lung cancer and charities which promote physical activity for those living with and beyond cancer.
Sleep Information	The sleep information provided an introduction to sleep and the importance it can have for those living with and beyond cancer. Tips and recommendations are provided for sleep and open-source resources and articles are provided via hyperlinks for further reading.
Considerations to Exercise for Lung Cancer Survivors	A more detailed list of safety and practical considerations for engaging in exercise pre- during, or post-treatment.
Borg/RPE Scale	The Borg scale used in the Exercise Plan modules is presented and explained here.
Warm up and Stretches	Explanation of what and why warming up and stretching may be important with examples provided.
Exercise Intensity for Lung Cancer Survivors	Varying methods of self-assessing exercise intensity are provided and explained, including the Talk Test, Targeted Heart Rates and the Borg Scale.
Mindfulness	An introduction to what Mindfulness is and how it may be beneficial for those LWBLC. Hyperlinks to open-source research papers are provided for further reading. The page breaks down soe of the benefits and discusses each one in turn. Benefits include Immune Function, Sleep, Cancer-Related Fatigue, and Cancer-Related Stress. Additionally, some tips are provided with links to external resources.

The FITT Principle	The FITT principle is explained with an image to convey how it can be used for Cardiorespiratory Endurance, Muscular Endurance, Muscular Strength, and Flexibility.
Resistance-based Exercise Recommendations	Recommendations and information regarding the FITT principles for resistance-based exercises. Information regarding bone metastasis is provided in case of future development.
How to use Videos	Explanation on how to use the embedded videos on ExerciseGuide UK using images and descriptive text.

13.13 Appendix Thirteen: Recruitment Flyer

Figure 38: Front page of the feasibility and acceptability ExerciseGuide UK study recruitment flyer

SUPPORTING PEOPLE WITH LUNG CANCER TO BE MORE ACTIVE

Hello, my name is Jordan Curry

I'm a researcher at Hull York Medical School. I am studying how online support can help people with lung cancer to be more active.

We have adapted a website to deliver tailored physical activity programs to those living with and beyond lung cancer. We want to test whether the website is appropriate to use for those living with and beyond lung cancer and if it helps improve their quality of life and helps keep them more active.

Are you eligible?

- Be 18 years of age or older.
- Have had a diagnosis of lung cancer or cancer affecting the lung.
- Be able to speak and read in English.
- Willing and able to provide informed consent.
- Have internet connectivity.
- Access to a laptop, computer, or smart device to access the web-based platform.

If you want to get involved, please email Jordan Curry at **Jordan.Curry@hyms.ac.uk**

HULL YORK MEDICAL SCHOOL

Date: 15/06/21; Version 1.1

Figure 39: Back page of the feasibility and acceptability ExerciseGuide UK study recruitment flyer

13.14 Appendix Fourteen: Feasibility and Acceptability Study Consent Form and Participant Information Sheet

13.14.1 Participant Information Sheet

Feasibility and acceptability of a tailored web-based, physical activity programme for those living with and beyond lung cancer.

Participant Information Sheet

Invitation to take part in a research study

You are being invited to take part in a study which aims to explore how individuals living with and beyond lung cancer use a website which aims to provide tailored physical activity programmes, and if it is beneficial for physical and mental wellbeing. This is known as a feasibility study. To help you to decide if you would like to take part, we have created this sheet. It explains why we are exploring the feasibility and acceptability (how well the website is received) of a website, what you will be asked to do, and why we are inviting you to take part. You are being invited to take part in a study of looking at whether a web-based, tailored physical activity programmes for those living with and beyond lung cancer is feasible and acceptable. Please take your time to read the following information: you might want to discuss it with your friends or family. Alternatively, you can contact the research team and ask them to explain anything that is not clear to you.

What is the study about?

We are exploring using a web-based platform to deliver tailored physical activity programmes to those living with and beyond lung cancer. The aim of the programme is to help improve quality of life during and after treatment for lung cancer. Previous research has shown that physical activity can help people living with and beyond cancer manage their symptoms and increase quality of life. We want to explore whether this platform is feasible and acceptable within the population of those living with and beyond lung cancer. The means we want to know if the programme will be practical and suitable for those living with and beyond lung cancer.

Why have I been invited to take part?

We are asking a minimum of fifteen individuals who are living with and beyond lung cancer to take part. You have been invited because you may meet some of the criteria which we are looking for this study. The research team will contact you by telephone or email to discuss, answer any questions, and see if you would be interested in taking part in the study.

What will happen to me if I take part?

In this research study we will use information from you. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

If you agree to take part in the study, you will be given access to the website to complete the introductory questionnaire. The introductory questionnaire will provide the website with enough information in order to tailor the physical activities to you. Additionally, the introductory questionnaire will collect information on your physical and emotional health and wellbeing state. This will allow the research team to examine any changes over the course of you using the website. However, before engaging in any modules or exercises, you will be guided through how to safely perform the exercise which could be offered on the website. You will be guided by the research team, including an experienced exercise professional and a physiotherapist, who will ensure you have the correct and safe form. Upon completing the exercise safety phase, you will be provided with the opportunity to ask any final questions before the you will be given full access to the website and the study will officially begin. We would request you have a phone nearby in case you are in need to request help. This could be a mobile telephone or house telephone. It is advised you have another adult nearby, when possible, while participating in the physical activity programme.

The web-based platform will ask you to complete up to three physical activity sessions per week, for eight weeks. Additionally, there will be modules for you to make and track goals and log any thoughts you may have relating to your physical and emotional health or the platform and the exercises. There will be a contact and expert/member of the research team which will allow you to directly email a member of the research team through the online platform. The physical activity sessions will be tailored to you and your specific needs and health status. You will also be asked to fill out online questionnaires weekly, which will be on the website. The questionnaires will be collecting information regarding your physical and emotional health, in addition to some questions regarding how you find the platform. Following the physical activity intervention, we may ask you to participate in an interview. The interview will explore satisfaction and usability in more depth. The interview will be conducted in person or online (using Zoom). The information collected on the website is safe and meets all the requirements for GDPR. The interviews will be recorded using Zoom and stored on a secure network file, using the Hull York Medical School secure OneDrive and Virtual Private Network (VPN). People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. At the end of the study, we will save some of the data in case we need to check it and for future research. We will make sure no-one can work out who you are from the reports we write.

Do I have to take part?

No, it is up to you to decide whether or not you want to take part. The purpose of this information sheet is to give you information about the study and to help you understand what taking part will involve. After reading this information sheet you will have the opportunity to discuss it further with the research team and ask any questions that you may have. You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

What are the positives to be taken from participating?

Physical activity has been shown to be beneficial to physical and psychological health and wellbeing in those living with and beyond lung cancer. Physical activity has been observed to reduce pain, fatigue, while improving physical function and mood. You may learn new ways to be physically active within your daily routine. Additionally, you will be helping the research team add to the emerging field of physical activity in oncological supportive care, specifically for those living with and beyond lung cancer.

Are there any negatives to be considered should I decide to participate?

We do not anticipate that you will experience any disadvantages from taking part in the study, other than taking your time. However, it is possible that you may become fatigued or experience mild discomfort after exercise.

Will taking part in this study cost me anything, and will I be paid?

Participation in this study will not cost you anything and is undertaken on a purely voluntary basis. Unfortunately, it will not be possible to pay expenses.

Will my involvement be confidential?

The University of Hull is the sponsor for this study based in the United Kingdom. The University of Hull will keep identifiable information about you for 3-6 months after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. In the event a participant loses capacity throughout the study, their identifiable information will be retained for 3-6 months. To safeguard your rights, we will use the minimum personally identifiable information possible. You can find out more about how we use your information by contacting The Data Protection Officer, dataprotection@hull.ac.uk.

If you agree to take part in the study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the details below for further advice and information:

Cynthia Forbes via email at Cindy.Forbes@hyms.ac.uk

You can also speak to the Research Governance and Policy Manager, University of Hull.

Tel: 01482 466962, Email: researchgovernance@hull.ac.uk.

Alternatively, please contact coo@hull.ac.uk

What will happen to the information from the study?

In this research study we will use information from you. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules. At the end of the study, we will save some of the data in case we need to check it and for future research. We will make sure no-one can work out who you are from the reports we write.

Approvals

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the South Central – Oxford C Research Ethics Committee.

Who can I contact for further information?

If you have any further questions about this research study, please do not hesitate to contact the research team:

Dr Cindy Forbes	Cindy.Forbes@hyms.ac.uk
Mr Jordan Curry	Jordan.Curry@hyms.ac.uk

Dr Mark Pearson Mark.Pearson@hyms.ac.uk

Dr Flavia Swan Flavia.Swan@hyms.ac.uk

Thank you for taking the time to read this information sheet.

13.14.2 Participant Consent Form

Participant Informed Consent Form

Study Title:	Feasibility and acceptability of a tailored web-based, physical activity program for those living with and beyond lung cancer.
Protocol Number:	Version 1.2 27/04/22
Study Design:	Single-Group Feasibility Study
Sponsor:	University of Hull
Study Co-Investigators:	Dr Cindy Forbes Yorkshire Cancer Research, Wolfson Palliative Care Research Group, Hull York Medical School, University of Hull, HU6 7RX 01482 463741 Dr Mark Pearson Wolfson Palliative Care Research Group, Hull York Medical School, University of Hull, HU6 7RX 01482 463335 Dr Flavia Swan Yorkshire Cancer Research, Wolfson Palliative Care Research Group, Hull York Medical School, University of Hull, HU6 7RX 01482 463150

Examination of usability for an online tailored physical activity programme for those living with and beyond cancer.

Version: 1.2 Date: 27/04/22

	please initial where applicable
I confirm that I have read the information sheet dated 15/06/2021 (version 1.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
I understand that if I participate in an interview, it will be recorded to ensure that my views are documented accurately.	☐
I agree that anonymous quotations from my interview can be used in presentations or publications arising from this project.	☐
I agree I can be contacted after the physical activity intervention for a possible interview.	☐
I agree I can be contacted three months after the intervention with a questionnaire to explore physical activity and behavior.	☐
I agree to my General Practitioner being informed of my participation in the study.	☐
I agree to take part in this study.	☐

13.15 Appendix Fifteen: Standards for Reporting Qualitative Research (SRQR) (399)

Table 34: The Standards for Reporting Qualitative Research and application for the ExerciseGuide UK feasibility and acceptability study.

Number and Topic	Item Description	Summary of Application	Location in Thesis
Title and Abstract			
S1: Title	Concise description of the nature and topic of the study. Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	The title indicated that a mixed methods approach was used but did not specify the qualitative methods	Chapter Six. (Page: 152).
S2: Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	The abstract at the start of the thesis summarised key components across the full thesis including the systematic review, user-centred design process, and mixed methods study	Page Two of Thesis
Introduction			
S3: Problem Formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	The introduction described the problem of requiring online support for lung cancer patients, and the systematic review and methods chapters justified the need for a qualitative approach	Chapters One and Two, and Three
S4: Purpose or research question	Purpose of the study and specific objectives or questions	The purpose and research questions were stated in the methodology chapter under section 2.1.3.5	Chapter Two and Eight
Methods			
S5: Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., post-positivist, constructivist/interpretivist) is also recommended; rationale	Research paradigms discussed with the Methodology regarding thematic analysis and overall qualitative approach. The feasibility and acceptability study in Chapter 6 used a qualitative approach guided by the person-based approach	Chapter Three and Six

Number and Topic	Item Description	Summary of Application	Location in Thesis
S6: Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and/or transferability	Researcher reflexivity was addressed through a self-reflective account using the Kolb model	Chapter Nine
S7: Context	Setting/site and salient contextual factors; rationale	Chapter 4 described the UK context and that patients completed the online intervention from their home	Chapter Four
S8: Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale	Chapter 4 explained the purposive sampling strategy guided by findings from the systematic review and input from experts	Chapter Four
S9: Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Ethical approval, consent procedures, and confidentiality were discussed in Chapter 4	Chapter Four
S10: Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	Chapter 4 described and justified the use of Zoom and telephone interviews	Chapter Four
S11: Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study.	Chapter 4 described the use of a topic guide and audio recordings	Chapter Four
S12: Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation	The number and characteristics of participants were described in Chapter 4	Chapter Four
S13: Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding and anonymization / de-identification of excerpts	Chapter 4 discussed transcription, coding, and data security procedures	Chapter Four

Number and Topic	Item Description	Summary of Application	Location in Thesis
S14: Data analysis	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	Thematic analysis guided by the Theoretical Framework of Acceptability was described in Chapter 6	Chapter Four and Six
S15: Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis, (e.g., member checking, triangulation, audit trail); rationale.	Member checking and dual screening were discussed in Chapter 6	Chapter Four and Six
Results/Findings			
S16: Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Key qualitative findings and themes were presented in Chapters 8 and 9	Chapter Eight and Nine
S17: Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings.	Supporting quotes were provided in Chapters 8 and 9	Chapter Eight and Nine
Discussion			
S18: Integration with prior work, implications, transferability, and contribution(s) to the field:	Short summary of main findings, explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Findings were related to prior literature in Chapter 9, which also discussed implications and contributions	Chapter Nine
S19: Limitations	Trustworthiness and limitations of findings	Limitations related to trustworthiness were identified in Chapter 9	Chapter Nine
Other			
S20: Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed.	No conflicts of interest were declared	N/A
S21: Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Sources of funding were acknowledged in the acknowledgements section of this thesis.	Page Seven of Thesis
Notes			

13.16 Appendix Sixteen: Study Three Systems Usability Score Breakdown

Table 35: Breakdown of systems usability scores and ranks for the ExerciseGuide UK feasibility and acceptability study.

Score	Adjective Rating (Letter Grade)	Threshold
75	Good (B)	68 – 80.3
75	Good (B)	68 – 80.3
95	Excellent (A)	>80.3
75	Good (B)	68 – 80.3
65	Poor (D)	51 – 68
77.5	Good (B)	68 – 80.3
80	Good (B)	68 – 80.3
77.5	Good (B)	68 – 80.3
65	Poor (D)	51 – 68
80	Good (B)	68 – 80.3
45	Awful (F)	<51
45	Awful (F)	<51
82.5	Excellent (A)	>80.3

13.17 Appendix Seventeen: Feasibility and Acceptability Study Outcome Measures

13.17.1 Baseline Demographics, medical characteristics, and lifestyle behaviour data

Table 36: Baseline questions for ExerciseGuide UK

Question	Answering Method	Answers
What is your relationship status?	Multiple Choice	Married / Common Law In a relationship (not living together) Single / Never married Divorced / Separated Widowed
What is your highest level of education that you have completed or currently completing?		Doctorate Professional degree (e.g. MBBS, EdD, etc.) Master's degree Bachelor's degree Professional certification Trades training Some college High school or equivalent (e.g. GCSE/O Levels) Less than high school No school
What is your current level of employment?		Employed full-time Employed part-time Employed casually Currently unemployed Retired Student Homemaker Currently on disability leave
For statistical purposes, we need information about your household income. All answers will be kept anonymous and confidential. Which category best describes the TOTAL INCOME of ALL household members, before taxes, for last year?		Less than 20,000 20,000 to 39,999 40,000 to 59,999 60,000 to 79,999 80,000 to 99,999 100,000 to 119,999 120,000 to 139,999 140,000 or more Prefer not to answer
What kind of area do you live in?	Multiple Choice	Large urban centre (population 100,000 or more) Medium centre (population 30,000 to 99,999) Small centre (population 1000 to 29,999) Rural area (population less than 1000)

Question	Answering Method	Answers
Please indicate with which ethnicity you most identify	Multiple Choice	White - British White - Irish White - Any other White background Mixed - White and Black Caribbean Mixed - White and Black African Mixed - White and Asian Mixed - Any other mixed background Asian or Asian British - Indian Asian or Asian British - Pakistani Asian or Asian British - Bangladeshi Asian or Asian British - Any other Asian background Black or Black British - Caribbean Black or Black British - African Black or Black British - Any other Black background Other Ethnic Groups - Chinese Other Ethnic Groups - Any other ethnic group Not stated Prefer not to answer
How tall are you?	Sliding Scale	140cm - 200cm+
What is your current weight in Kilograms?	Sliding Scale	35kg to 160kg+
Please tell us your age	Sliding Scale	18y to 99y+
There are four stages of cancer. What stage of cancer were you diagnosed with?	Multiple Choice	Stage 1 Stage 2 Stage 3 Stage 4 Don't know
What date were you diagnosed?	Calendar pop up	N/A
Are you currently receiving any treatment for lung cancer?	Multiple Choice	No Yes
Are you currently receiving chemotherapy?	Multiple Choice	No Yes
How many weeks have you been receiving chemotherapy?	Sliding scale	0 weeks – 52+ weeks
Are you currently receiving radiation therapy?	Multiple Choice	No Yes
How many weeks have you been receiving radiation therapy?	Sliding scale	0 weeks – 52+ weeks
Are you currently receiving Immunotherapy?	Multiple Choice	No Yes
How many weeks have you been receiving immunotherapy?	Sliding scale	0 weeks – 52+ weeks

Question	Answering Method	Answers
Did you have surgery as part of your cancer treatment?	Multiple Choice	No Yes
What type of surgery did you have regarding your lung cancer?	Multiple Choice	Lobectomy Pneumonectomy Wedge resection or Segmentectomy I do not know
Are you currently receiving targeted drug therapy?	Multiple Choice	No Yes
How many months have you been receiving targeted drug therapy?	Sliding scale	0 weeks – 52+ weeks
What type of treatments did you receive for lung cancer?	Multiple Choice	Surgery Chemotherapy Radiation therapy Targeted drug therapy Immunotherapy Other
How long has it been in years since you have been on ANY cancer treatment?	Sliding scale	0y to 20+y
Has a health professional ever told you that you have any of the following conditions?	Multiple Choice	Lung Disease Yes No Diabetes Yes No High Blood Pressure Yes No High Blood Cholesterol Yes No Arthritis Yes No Stroke Yes No Other Cancers Yes No Angina Yes No Depression Yes No Lymphedema Yes No Poor circulation legs or feet

Question	Answering Method	Answers
		Yes No
In general, would you say your health OVERALL is currently...	Multiple Choice	Excellent Very good Good Fair Poor
Which of the following best describes your current smoking behaviour?	Multiple Choice	Regular smoker (smoke daily) Occasional smoker Ex-smoker Never smoked
When you did smoke, how many cigarettes per day did you usually smoke?	Drop down box	1 – 100+ per day
During the past week, on how many days did you drink alcoholic beverages?	Multiple Choice	I did not drink any alcoholic beverages in the past week 1 day 2 days 3 days 4 days 5 days 6 days Every day Prefer not to answer
On the days that you drank in the past week, how many units of alcohol did you usually have?	Sliding scale	1 unit of alcohol to 50+ units to alcohol per day
One average, during the past week, how many HOURS per night do you usually sleep?	Sliding scale	1 hour of sleep to 14+ hours of sleep per night
During the past week, how often did you have trouble going to sleep or staying asleep?	Multiple Choice	None of the time A little of the time Some of the time Most of the time All of the time

13.17.2Programme Satisfaction Questions

Table 37: Post-ExerciseGuide UK programme review questions and summary of rating scores

	Strongly agree	Agree	Neither Agree nor Disagree	Disagree	Strongly disagree
The ExerciseGuide.org.uk website was credible	5	4	3	2	1
The ExerciseGuide.org.uk website was relevant to me personally	5	4	3	2	1
The ExerciseGuide.org.uk website met my expectations	5	4	3	2	1
The ExerciseGuide.org.uk website content was easy to understand	5	4	3	2	1
The ExerciseGuide.org.uk website was interesting	5	4	3	2	1
The ExerciseGuide.org.uk website was easy to use and navigate	5	4	3	2	1
The ExerciseGuide.org.uk website was unnecessarily complex	5	4	3	2	1
The ExerciseGuide.org.uk website features were well integrated	5	4	3	2	1
The ExerciseGuide.org.uk website was presented professionally, with appropriate content, colour and images	5	4	3	2	1
The ExerciseGuide.org.uk website was of benefit to me	5	4	3	2	1
The ExerciseGuide.org.uk website evoked negative emotions	5	4	3	2	1
The modules were useful to me	5	4	3	2	1
The action planning tool / activity was useful to me	5	4	3	2	1
The resources library was useful to me	5	4	3	2	1
The ExerciseGuide.org.uk website helped me to identify my physical activity goals	5	4	3	2	1
The ExerciseGuide.org.uk website has changed my attitude toward participating in physical activity throughout the cancer journey	5	4	3	2	1
The ExerciseGuide.org.uk website has increased my confidence to participate in physical activity	5	4	3	2	1
The ExerciseGuide.org.uk website added additional burden on me personally	5	4	3	2	1
TheExerciseGuide.org.uk website is something I would like	5	4	3	2	1

	Strongly agree	Agree	Neither Agree nor Disagree	Disagree	Strongly disagree
to continue to use on a regular basis					
The ExerciseGuide.org.uk website added (or would add if you are post treatment) value to my cancer care and service	5	4	3	2	1
The ExerciseGuide.org.uk website could be easily integrated into a part of routine care for individuals receiving a lung cancer diagnosis	5	4	3	2	1
Could you please elaborate on any of your above responses?					

13.17.3 Community Healthy Activities Model Program for Seniors (CHAMPS)

CHAMPS Activities Questionnaire for Older Adults

CHAMPS: Community Healthy Activities Model Program for Seniors, Institute for Health & Aging, University of California San Francisco and Stanford Center for Research in Disease Prevention, Stanford University

Figure 40: Community Healthy Activities Model Program for Seniors

This questionnaire is about activities that you may have done in the past 4 weeks. The questions on the following pages are similar to the example shown below.

INSTRUCTIONS

If you DID the activity in the past 4 weeks:

Step #1 Check the YES box.

Step #2 Think about how many TIMES a week you usually did it, and write your response in the space provided.

Step #3 Circle how many TOTAL HOURS in a typical week you did the activity.

Here is an example of how Mrs. Jones would answer question #1: Mrs. Jones usually visits her friends Maria and Olga twice a week. She usually spends one hour on Monday with Maria and two hours on Wednesday with Olga. Therefore, the total hours a week that she visits with friends is 3 hours a week.

In a typical week during the past 4 weeks, did you…							
1. Visit with friends or family (other than those you live with)? ☒ **YES** How many TIMES a week? 2 ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

If you DID NOT do the activity:

- **Check the NO box and move to the next question**

2

In a typical week during the past 4 weeks, did you …							
1. Visit with friends or family (other than those you live with)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL <u>hours a week</u> did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
2. Go to the senior center? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL <u>hours a week</u> did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
3. Do volunteer work? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL <u>hours a week</u> did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
4. Attend church or take part in church activities? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL <u>hours a week</u> did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
5. Attend other club or group meetings? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL <u>hours a week</u> did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
6. Use a computer? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL <u>hours a week</u> did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

In a typical week during the past 4 weeks, did you …							
7. Dance (such as square, folk, line, ballroom) (do <u>not</u> count aerobic dance here)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL <u>hours a week</u> did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
8. Do woodworking, needlework, drawing, or other arts or crafts? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL <u>hours a week</u> did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
9. Play golf, carrying or pulling your equipment (count <u>walking time</u> only)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL <u>hours a week</u> did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
10. Play golf, riding a cart (count <u>walking time</u> only)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL <u>hours a week</u> did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
11. Attend a concert, movie, lecture, or sport event? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL <u>hours a week</u> did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
12. Play cards, bingo, or board games with other people? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL <u>hours a week</u> did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

In a typical week during the past 4 weeks, did you …							
13. Shoot pool or billiards? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
14. Play singles tennis (do not count doubles)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
15. Play doubles tennis (do not count singles)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
16. Skate (ice, roller, in-line)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
17. Play a musical instrument? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
18. Read? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
19. Do heavy work around the house (such as washing windows, cleaning gutters)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

In a typical week during the past 4 weeks, did you …							
20. Do light work around the house (such as sweeping or vacuuming)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
21. Do heavy gardening (such as spading, raking)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
22. Do light gardening (such as watering plants)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
23. Work on your car, truck, lawn mower, or other machinery? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
****Please note: For the following questions about running and walking, include use of a treadmill.**							
24. Jog or run? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
25. Walk uphill or hike uphill (count only uphill part)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

In a typical week during the past 4 weeks, did you …							
26. Walk fast or briskly for exercise (do not count walking leisurely or uphill)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
27. Walk to do errands (such as to/from a store or to take children to school (count walk time only)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
28. Walk leisurely for exercise or pleasure? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
29. Ride a bicycle or stationary cycle? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
30. Do other aerobic machines such as rowing, or step machines (do not count treadmill or stationary cycle)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
31. Do water exercises (do not count other swimming)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

In a typical week during the past 4 weeks, did you …							
32. Swim moderately or fast? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
33. Swim gently? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
34. Do stretching or flexibility exercises (do not count yoga or Tai-chi)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
35. Do yoga or Tai-chi? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
36. Do aerobics or aerobic dancing? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
37. Do moderate to heavy strength training (such as hand-held weights of more than 5 lbs., weight machines, or push-ups)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

In a typical week during the past 4 weeks, did you …							
38. Do light strength training (such as hand-held weights of 5 lbs. or less or elastic bands)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
39. Do general conditioning exercises, such as light calisthenics or chair exercises (do not count strength training)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
40. Play basketball, soccer, or racquetball (do not count time on sidelines)? ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours
41. Do other types of physical activity not previously mentioned (please specify)? _______________________ ☐ **YES** How many TIMES a week?_____ ➔ ☐ **NO**	How many TOTAL hours a week did you usually do it? ➔	Less than 1 hour	1-2½ hours	3-4½ hours	5-6½ hours	7-8½ hours	9 or more hours

Thank You

13.17.4EORTC-QLQ-30 questionnaire

ENGLISH

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials: |_|_|_|_|
Your birthdate (Day, Month, Year): |_|_|_|_|_|_|
Today's date (Day, Month, Year): 31 |_|_|_|_|_|_|

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

Please go on to the next page

ENGLISH

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

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

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

1	2	3	4	5	6	7
Very poor						Excellent

Figure 41: EORTC-QLQ-30 questionnaire

13.17.5Hospital Anxiety Depression Scale (HADS)

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over you replies: your immediate is best.

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

Please check you have answered all the questions

Scoring:
Total score: Depression (D) ___________ Anxiety (A) ______________
0-7 = Normal
8-10 = Borderline abnormal (borderline case)
11-21 = Abnormal (case)

Figure 42: Hospital Anxiety Depression Scale

13.18 Appendix Eighteen: Patient Reported Outcomes from ExerciseGuide UK Feasibility and Acceptability Study

When exploring baseline vs post-study PROs (changes were assessed using post-measure – baseline measure), there was no statistical difference in QoL (4.86 ± 27.86; p = 0.554; CI: -10.42 - 20.14). To see if a change in a PRO score is meaningful, the minimally important difference (MID) is used. The MID is the smallest PRO change patients would perceive as important. Anchor-based methods are best for determining the MID, as they connect changes in the PRO to patients' own assessments of whether they've experienced an important change (526). Distribution-based approaches to determine the MID use statistical criteria from PRO scores. This may include the standard deviation, effect size, and standard error of measurement (527).Though, the mean change in QoL was close to the level of clinical relevance using an anchor based-MID by Koller and colleagues (2022), (= ≥5) (528). However, the mean change did not meet the threshold for a MID using distribution-based estimates of 11 (0.5 SD); 1 SEM = 9).

Neither of the functional or symptom scales displayed any level of statistical significance in mean change.

The mean change of fatigue was -6.48, meaning fatigue scores declined by a mean score of 6.48 from baseline to post-measures. Although no distribution-based MID was observed, fatigue did achieve an anchor-based MID improvement (change score: 6). Secondly, the mean change for dyspnea was -20.83. There was no anchor-based MID recorded, however, the mean change did surpass the 0.5 SD distribution-based estimate of 15 (1 SEM = 13). Thirdly, the mean change for appetite loss was -8.33, resulting in an anchor-based MID (change score: 8). Lastly, the mean change of constipation was -13.82. The MID for constipation was reached for both anchor (change score: 13) and distribution-based estimates at of 12, at a 0.5 SD (1 SEM: 10). Although not statistically significant (P ≥ 0.05), dyspnea demonstrated a MID (0.5 SD = 15; 1 SEM = 13), with a mean change of 20.38 ± 13.22 (CI: -41.67 - 5.56). Additionally, constipation demonstrated a (-13.89) did show distribution-based MID (0.5 SD = 12, SEM = 10) (528) and anchor-based MID improvement (threshold: 13). Pain displayed a nonsignificant (P ≥ 0.05) reduction (-15.28), which was close to the distribution-based MID (0.5 SD = 16, SEM = 12).

A breakdown of PRO data at baseline and post with mean change (standard mean change), p-value and CI (95%) is presented below in **Error! Reference source not found.** and CHAMPS in **Error! Reference source not found.**.

Table 38: Patient-reported outcome measures over the eight-week ExerciseGuide UK intervention.

				Bootstrap[a]	
	Baseline (n=12)	Post (n=12)	Mean Change (SDC)	P value	CI (95%)
EORTC QLQ-C30					
Quality of Life[1]	45.14 ± 24.24	50 ± 32.37	4.86 (27.86)	0.554	-10.42 - 20.14
Functional Scales[2]					
Physical Functioning	77.78 ± 23.67	81.11 ± 18.61	3.33 (22.30)	0.618	-8.33 - 15.56
Role Functioning	76.39 ± 29.70	75 ± 27.98	-1.39 (29.70)	0.88 [b]	-18.06[b] - 13.89 [b]
Emotional Functioning	81.95 ±23.79	83.33 ± 23.00	1.39 (9.67)	0.906	-17.36 - 19.44
Cognitive Functioning	83.33 ± 17.41	76.39 ± 27.94	-6.94 (9.28)	0.490	-26.39 - 9.72
Social Functioning	76.39 ± 29.69	73.61 ± 29.69	-2.78 (47.05)	0.852	-27.78 - 23.61
Symptoms Scales[3]					
Fatigue	34.26 ± 34.31	27.78 ± 30.15	-6.48 (40.33)	0.603	-29.63 - 14.81
Nausea and vomiting	9.72 ± 19.41	11.11 ± 21.71	1.39 (31.35)	0.888[c]	-15.28[c] - 19.44[c]
Pain	22.22 ± 29.59	06.94 ± 13.22	-15.28 (32.14)	0.178	-34.72 - 0.00
Dyspnoea	27.78 ± 34.33	6.94 ± 13.22	-20.83 (35.62)	0.109[d]	-41.67[d] - 5.56[d]
Insomnia	16.67 ± 22.48	33.33 ± 37.61	16.68 (30.15)	0.115[e]	2.77[e] - 36.11[e]
Appetite Loss	25.00 ± 40.51	16.67 ± 30.15	-8.33 (53.42)	0.598[f]	-36.11[f] -19.44[f]
Constipation	25.00 ± 35.18	11.11 ± 25.95	-13.89 (41.34	0.284[g]	36.11[g] - 8.33[g]
Diarrhoea	13.89 ± 30.01	11.11 ± 25.95	-2.78 (43.72)	0.842[f]	-27.78[f] - 19.44[f]
Financial Difficulties	11.11 ± 21.72	8.33 ± 28.87	-2.78 (38.82)	0.821[h]	-22.22[h] - 19.44[h]
Hospital Anxiety Depression Scale (HADS)[4]					
Anxiety	5.59 ± 5.14	4.50 ± 2.58	-1.08 (3.55)	0.319	-3.08 – 0.75
Depression	3.59 ± 2.81	3.17 ± 1.90	-0.42 (0.45)	0.394	-1.33 – 0.42

Baseline and Post data is given in Mean ± Standard Deviation; Mean Change is given with Standard Deviation Change (SDC); CI = Confidence Interval; CI – 95%; CI given in Lower-Upper values; Analysis was conducted using a Post – Pre model. a - based on 10,000 samples, unless otherwise stated; b - based on 9998 samples; c - based on 9978 samples; d - based on 9936 samples; e - based on 9933 samples; f - based on 9989 samples; g - based on 9986 samples; h - based on 9900 samples. 1 – Quality of Life is scored on a scale of 0 – 100, with higher scores representing a higher quality of life; 2 – Functional scores are measured using a 0 – 100 scale, with higher scores representing a higher level of functioning; 3 – Symptoms scores are measured using a 0 – 100 scale, with higher scores representing a higher symptom burden/greater impact of symptom; 4 – Hospital Anxiety Depression Scale, which provided two subscales to measure anxiety and depression independently. A score higher than seven signifies anxiety or depression.

Table 39: The Community Health Activities Model Program for Seniors (CHAMPS) Data

				Bootstrap[a]	
	Baseline (n=11)	Post (n=11)	Mean Change (SDC)	P value	CI (95%)
Frequency (per/week)	17.09 ± 10.17	25 ± 12.39	7.91 (15.51)	0.132	-0.64 – 16.82
Frequency of Moderate per/week	6.91 ± 7.09	8.73 ± 4.84	1.82 (2.35)	0.468	-2.73 – 6.45
Duration (hours/week)	10.25 ± 6.00	17.27 ± 9.28	7.02 (3.14)	0.064	0.98 – 13.30
Duration of Moderate (hours/week)	4.27 ± 4.22	6.68 ± 3.89	2.41 (1.42)	0.141	-0.45 – 5.16

Baseline and Post data is given in Mean ± Standard Deviation; Mean Change is given with Standard Deviation Change (SDC); CI = Confidence Interval; CI – 95%; CI given in Lower-Upper values; Analysis was conducted using a Post – Pre model. a: Unless otherwise noted, bootstrap results are based on 10,000 bootstrap samples.

13.19 Appendix Nineteen: Thesis Output Plan

Table 40: Thesis Output Plan

Topic/ Title	Type/ journals	Lead and Co-Authors	Submit by	Reference (if published)
Developing and testing the ExerciseGuide UK website for people with lung cancer: reflections on the added value of patient and public involvement within a doctoral degree	Commentary Research Involvement and Engagement (OA)	JC*, CF, MP, HR, DR, AS	July 2022	(1)
Evaluating a web-based computer-tailored physical activity intervention for those living with and beyond lung cancer (ExerciseGuide UK): protocol for a single group feasibility and acceptability study	Protocol BMC Pilot and Feasibility (OA)	JC*, CF, MP, ML, CV, CS, HE	April, 2022	(2)
Feasibility, acceptability, and efficacy of online supportive care for individuals living with and beyond lung cancer: a systematic review	Systematic Review Supportive Care in Cancer (OA)	JC*, CF, MP, MJP, SG	April, 2021	(3)
Feasibility and Acceptability of ExerciseGuide UK for those Living with and Beyond Lung Cancer: A single arm feasibility study.	Study Supportive Care in Cancer	JC*, CF, MP, ML, CV, CS, HE	May 2024	

Note: OA, Open Access; PPI, Patient and Public Involvement; *, Lead Author
Author Initial: JC, Jordan Curry; CF, Cynthia C Forbes; MP, Mark Pearson; HR, Helen Roberts; DR, Diane Riley; AS, Alan Smith; ML, Michael Lind; MJP, Michael Patterson