Implementing Exercise Rehabilitation into Clinical Practice for Individuals with Cancer

by

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Abstract

The purpose of this dissertation was to explore, identify and address gaps in exercise oncology evidence-based care for individuals with cancer, with a specific focus on implementation of cancer-specific exercise programming. Further understanding is needed regarding the poor rates of reported physical activity by individuals with cancer, despite the robust evidence of benefits for exercise towards disease-related symptoms. A series of integrated knowledge translation (iKT) studies was conducted to identify (Study One, Two and Three) and address (Study Four) the barriers to implementation of exercise oncology evidence into practice. A further objective of this dissertation was to provide research evidence to guide implementation of exercise programming in community and clinical contexts.

Study One, "Implementing Cancer Exercise Rehabilitation: An Update on Recommendations for Clinical Practice", examined: (i) the state of the evidence supporting exercise for individuals with cancer; and (ii) guidelines for integrating exercise programming in the cancer clinical setting. Preliminary evidence supporting the implementation of community-based exercise programs was summarized, along with the principles and goals of exercise and identified barriers to exercise among individuals with cancer. Finally, an interdisciplinary model of care was proposed for integrating exercise programming into clinical care including guidelines for medical and pre-exercise screening, exercise testing and programming considerations.

Studies Two and Three involved cross-sectional surveys and focus groups of individuals with cancer to identify and understand barriers and preferences towards accessing cancer-specific exercise programming. Study Two, "A Practical Approach to Using Integrated

Knowledge Translation to Inform a Community-Based Exercise Study", explored the needs of individuals with cancer prior to and following the Alberta Cancer Exercise (ACE-pilot) Feasibility Trial. Findings helped to inform implementation of a province wide cancer-specific, community-based exercise program: Alberta Cancer Exercise (ACE) Study. Participants identified a lack of exercise counselling and referral to local exercise programming by healthcare providers (HCPs). Study Three, "Virtual or In-Person: A Mixed Methods Survey to Determine Exercise Programming Preferences During COVID-19", explored the barriers to oncology exercise that arose because of the coronavirus disease-19 (COVID-19) pandemic with the rapid need to pivot to virtual exercise programming, requiring use of technology and technological proficiency to access programming virtually. In the context of COVID-19, as technology emerged to allow better access to the virtual delivery of cancer-specific exercise programming, implementation strategies shifted from in-person to virtual exercise implementation. Survey findings showed that a majority of respondents were uncomfortable attending in-person exercise due to COVID-19 and had limited experience engaging in exercise virtually — highlighting the need for (i) alternative modes of exercise programming delivery to address concerns over COVID-19 exposure; and (ii) technology training to remove a primary barrier towards engaging in virtual exercise.

Study Four, "Heal-Me Technology Counselling for eHealth (TeCH) study", examined implementation of technology training to support virtual exercise programming for individuals with cancer, as well as individuals with other common chronic disease groups (chronic lung disease, and liver and lung transplant). The TeCH study addressed the previously identified barrier of technology and involved the provision of technology support through standardized

one-on-one virtual orientations to the novel online Healthy Eating, Active Living, Mindful Energy (Heal-Me) Application. TeCH specifically examined the predictors of technology training time (TTT) required for chronic disease study participants to become proficient in using the Heal-Me Application to access multidisciplinary virtual exercise programming and nutrition support. Characteristics of age, self-rated technological proficiency scores, ethnicity and biological sex independently predicted technology training time: older aged participants, those self-identified as ethnic minorities and males were associated with higher TTT; higher self-rated technology proficiency scores were associated with shorter TTT.

In conclusion, an iKT approach identified actionable strategies to address the needs of individuals with cancer related to exercise in clinical and community-based contexts. Study One highlighted the established evidence of the benefits of exercise towards cancer and the lack of evidence around effective implementation of community-based exercise programs. Study Two identified a specific knowledge-to-action gap regarding lack of exercise counselling and referral to exercise programming by HCPs in a clinical context. Study Three re-contextualized barriers to exercise programming during COVID-19, identifying technology as a barrier to accessing virtual community-based exercise programming. Study Four implemented technology counselling sessions to access care virtually and identified independent predictors towards TTT.

Preface

This thesis is an original work by Kirsten Suderman. The following three research projects, of which this dissertation is a part, required and received research ethics approval from the Health Research Ethics Board of Alberta: Cancer Committee (HREBA.CC) and University of Alberta Health Research Ethics Board:

1. "ACE Survey and Focus Group", HREBA.CC-14-0153, 22-Aug-2016.
2. "ACE Exercise Programming Preferences in COVID-19", HREBA.16-0905, 05-May-2020.
3. "Heal-Me TeCH" University of Alberta Health Research Ethics Board, Pro00103715 23-Sept-2020.

As a paper-based dissertation, Chapters 2, 3 and 4 have all been published, with Chapter 5 in preparation for submission pending publication of the primary study findings. I am the primary author on all chapters, taking the lead role in all aspects of study conception, trial execution, analysis and writing for publication. All listed co-authors contributed to aspects of the research, data analysis and manuscript preparations. All published articles are approved by the respective journals for use in this dissertation (based on publication agreements). Chapter 2 was published in Current Cancer Therapy Reviews, with the co-authorship of Dr. C. McIntyre, Dr. C. Sellar and Dr. M. L. McNeely. Chapter 3 was published in the International Journal of Environmental Research and Public Health, with co-authorships Dr. Dolgy, J. Yurick, Dr. Sellar, K. Nishimarua, Dr. S.N. Culos-Reed and Dr. M.L. McNeely. Chapter 4 was published in Current Oncology, with co-authorships of Mx. T. Skene, Dr. Sellar, Dr. Dolgy, Dr. Pituskin, Dr. A.A. Joy, Dr. S.N. Culos-Reed and Dr. M.L. McNeely.

Dedication

This dissertation is dedicated to individuals and caregivers living with or beyond cancer and to fellow researchers and healthcare professionals working tirelessly to improve care for cancer and cancer-related treatments. I would also like to dedicate this work to my Grandpa, Fred Godberson, who lost his battle to cancer and was encouraging of my education from the very beginning. It is my hope that this work continues to further our understanding of how to face this disease and optimize rehabilitative care for those brave individuals and families fighting against it.

Acknowledgements

This dissertation is the result of mentorship, support and guidance from an amazing network of individuals, to whom I am forever indebted. I would like to sincerely thank my supervisor and mentor, Dr. Margie McNeely, who saw a unique path forward in combining my ongoing MSc Physical Therapy degree and interest in research. Your support gave this dissertation a heart and has culminated into successfully piloting the first combined MSc Physical Therapy / PhD in Rehabilitation Science for the Department of Physical Therapy. My appreciation for the profound impact you had on my career and life is immeasurable.

A very sincere thank you goes to my supervisory committee, Dr. Nicole Culos-Reed and Dr. Edie Pituskin for your expertise, guidance and insightful feedback throughout this journey. Your ongoing confidence towards this dissertation made for a collaborative experience that I am so grateful for. Thank you to my examining committee members, Dr. Doug Gross and Dr. Scherezade Mama for your thoughtful comments and discussion, and for taking the time from your busy schedules.

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This accomplishment is shared with you all.

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Glossary of Terms

Alberta Cancer Exercise (ACE-pilot) Feasibility Trial. A randomized controlled feasibility trial to inform a future implementation trial, the ACE Hybrid Effectiveness-Implementation (ACE Hybrid) study. The principal investigator was Dr. Margaret L. McNeely (1).

Alberta Cancer Exercise (ACE) Study. A hybrid effectiveness implementation study investigating implementation of an Alberta-wide clinic-to-community-based cancer-specific physical exercise program. The principal investigator is Dr. Margaret L. McNeely (2).

Cancer. Diseases wherein abnormal cell division occurs without control and has the propensity to invade nearby tissues (3).

Cancer Related Fatigue (CRF). "Cancer-related fatigue is a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning" (4).

Cancer Survivor/ Survivorship. Traditionally defined as, "The period following first diagnosis and treatment and prior to the development of a recurrence of cancer or death" (5). However, improvements in cancer treatments have led to a population of survivors living with incurable or advanced cancer who are not considered palliative, or appropriate for end-of-life care but will never enter remission. For previously published Chapters Two and Three, the expanded definition of cancer survivor/survivorship was used: "survivorship includes persons with metastatic disease, as many now live for extended periods with an advanced cancer diagnosis or recurrence; survivorship does not include issues related to a person's end of life (palliative care, end of life decision making, bereavement)" (6). However, recent terminology acknowledges not all individuals diagnosed with cancer identify with the label of "cancer survivor", reflected in a shift to person first language such as, '*individuals with cancer*' or, *'individuals living with or beyond cancer'*. Chapters Four, Five and Six reflect this changing terminology, referring to aforementioned cancer survivors as, '*individuals with cancer*'.

Capability, Motivation, Behaviour Change (COM-B) Model. A theoretically informed framework to understand behaviour change. The COM-B Model identifies behaviour change components to target in an intervention, from which implementation strategies can be selected to target the respective component (7).

Data Saturation. Saturation is reached when additional data do not lead to any new emergent themes (8), referred to as the point in coding when there are mounting instances of the same codes, but no new codes occur (9).

eHealth Literacy. "The ability of seek, find, understand and appraise health information from electronic sources and apply knowledge gained to addressing or solving a health problem" (10).

Electronic Health/ eHealth. "Cost-effective and secure use of information and communications technologies in support of health and health-related fields, including health-care services, health surveillance, health literature, and health education, knowledge and research" (11).

Ethnicity. "Membership of a group regarded as ultimately of common descent or having a common national or cultural tradition" (12).

Exercise. A form of physical activity resulting in an increase in energy expenditure over resting levels that is planned, and structured in terms of type, frequency, intensity and duration with the intent to maintain or enhance fitness and health-related outcomes (13).

Health-Related Quality of Life (HRQOL). "Refers to the physical, psychological, and social domains of health, seen as distinct areas that are influenced by a person's experiences, beliefs, expectations, and perceptions" (14). "On the individual level, HRQOL includes physical and mental health perceptions (e.g. energy level, mood) and their correlates – including health risks and conditions, functional status, social support and socioeconomic status. On the community level, HRQOL includes community-level resources, conditions, policies and practices that influences a population's health perceptions and functional status" (15).

Healthy Eating, Active Living Mindful Energy Application (Heal-Me App). An evidence-based theoretically informed nutrition and exercise application that can be tailored for multidisciplinary use across a range of chronic disease populations (16).

Heal-Me Personalized Online Nutrition and Exercise (PiONEer). A 12 week, 3-arm RCT to assess the acceptability, effectiveness and cost of Heal-Me app programming delivered alongside two levels of dietitian and exercise-specialist support. The principal investigator is Dr. Puneeta Tandon, and co-lead is Dr. Margaret L. McNeely (16).

Integrated Knowledge Translation (iKT). Involving knowledge users as partners in the research process to yield research that is more applicable, relevant and impactful to knowledge users (17). An iKT approach involves research that applies the principles of knowledge translation throughout the entire research process, from the planning and delivery stages through to the interpretation and application of findings (17).

Knowledge to Action (KTA) Model. The Canadian Institute of Health Research KTA Model is a process model used to describe and/or guide overall translation of research into practice through a stepwise process of knowledge creation, tailoring, and use (18).

Knowledge Translation (KT). "The synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the healthcare system" (17). KT involves a range of "interactions between researchers and knowledge users that may vary in intensity and complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user" (17).

Multi-Method/ Multimethod Design. "The is the conduct of two or more research methods, each conducted rigorously and complete in itself, in one project. The results are then triangulated to form a comprehensive whole" (19).

Physical Activity (PA). Any bodily movement requiring the contraction of skeletal muscles that results in a substantial increase in energy expenditure over resting levels. PA may include leisure physical activity and/or household or occupational related PA (20).

Quality of Life (QOL). "An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (21).

Race. "A group of people connected by common descent or origin" or "any of the (putative) major groupings of mankind, usually defined in terms of distinct physical features or shared ethnicity" (12).

Rehabilitation. "A set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment" (22). ***Cancer rehabilitation*** focuses on diagnosis and treatment of impairments from cancer, which may affect multiple aspects of an individual's function and subsequent quality of life (23).
Research Electronic Data Capture (REDCap). A secure, web-based application designed for research study data collection, provided by Women and Children's Health Research Institute (24).
Telehealth. "Use of electronic information and telecommunications and technologies to support long-distance clinical healthcare, patient and professional health-related education, public health and health administration" (25).
Theoretical Domains Framework (TDF). An integrative framework developed from a synthesis of behaviour change theories, used as a tool to apply theoretical approaches to behaviour change interventions (7). The TDF was derived from 33 identified behaviour change theories and were simplified into 12 domains and subsequent question frameworks to provide a thorough theoretical assessment of implementation problems (26).
Therapeutic Exercise. "Systematic performance of planned movements, postures or activities intended to alleviate or prevent impairments, improve function, minimize risk of injury and optimize overall health, fitness and well-being" (27).
Supportive Care/ Supportive Care Services/ Allied Health. Care delivered by physiotherapists, speech and language pathologists, occupational therapists, radiation therapists, dieticians/nutritionists, psychologists and social workers to improve the symptoms and quality of life of people with an illness or disease. It is defined as the provision of the necessary services for those living with or affected by cancer to meet all of their needs (physical, emotional, social, psychological, cultural, informational, spiritual and practical) (28). Supportive care may be given with other medical treatments from the time of diagnosis until the end of life (29).

Glossary of Terms References

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Chapter 1

Introduction

Chapter 1

Introduction

1.1. Overview of the Dissertation

Advancements in cancer-related detection and treatments have led to improved survival rates and the emergence of a growing population living with cancer-related physiological and psychological effects and comorbid conditions (1). An extensive body of evidence, including 16 guidelines from major medical or health-oriented organizations globally, recognize exercise as beneficial for individuals with cancer across the cancer spectrum (2). Despite the known benefits of exercise, less than 15% of survivors report meeting current physical activity guidelines for aerobic and muscle-strengthening activities (3). Cancer survivors have identified barriers towards exercise, including a lack of exercise counselling and referral from Healthcare Providers (HCPs) (4-6). Targeted efforts are greatly needed to bridge the knowledge-to-action, knowledge-to-practice, or "know-do-gap", (7) of integrating cancer-specific exercise programming into patient care (6,8-10). The purpose of this dissertation was to identify and address the know-do-gap related to barriers towards evidence-based practice for individuals with cancer. A further objective of this dissertation was to support the implementation of cancer-specific exercise programming using strategies to adapt and integrate evidence-based interventions within specific targeted practice settings.

The first section of this introduction provides an overview of cancer statistics, and the current state of the growing population of individuals living with cancer. The second section provides background on cancer-related treatments and the specific physiological and psychological side effects impacting quality of life. The third section of this introduction outlines the role of cancer-specific exercise as a means of care for individuals with cancer and summarizes the current state of exercise oncology. The introduction concludes with a summary of the field of knowledge translation within Canada, describing the theory and guiding practice models which informed this dissertation's research approach.

The main body of the dissertation consists of five chapters. Chapter Two provides an update on recommendations for implementing cancer exercise rehabilitation into clinical practice. Chapters Three, Four and Five contain a series of studies that form the main focus of

the dissertation, identifying knowledge gaps and implementing identified strategies to support cancer-specific exercise programming. Chapters Three and Four present the findings of cross-sectional surveys and focus groups that explore the barriers and preferences of individuals with cancer towards exercise. Chapter Five examines technology training as a strategy to support the implementation of virtual programming for individuals with cancer as well as other common chronic disease groups (lung disease, and liver and lung transplant). Chapter Six is a discussion on the culmination of the study findings, discussing the issue of cancer-specific exercise implementation and offering recommendations for clinical care and practice. General conclusions, practical implications, as well as future research directions, are also discussed.

1.2. Statement of the Problem

1.2.1. Cancer Statistics and Survivorship

Two in five Canadians will develop cancer in their lifetime (44% of men and 43% of women) (11). The most common cancers in Canada are lung (30 000), breast females (28 900) and prostate in males (24 600), with approximately 233 900 new cases in 2022 (12). The four most frequently diagnosed cancers (lung, breast, colorectal and prostate) account for 46% of all cancers (11). The rate of cancer diagnosis increases substantially with age, with around 90% of new cases occurring in Canadians who are 50 years of age and older (11). Twenty-five percent of Canadians will die from cancer, with 96% of cancer deaths in Canada occurring in people 50 years of age and older (11).

There is a growing population of individuals surviving cancer resulting from continuing improvements in early detection and treatment. In Canada, over the past 25 years, the predicted five-year age-standardized net survival rate has increased by 8.6%, with 63.7% of all individuals diagnosed with cancer surviving at least five years post-diagnosis (13). While cancer is the leading cause of death in Canada, mortality rates have declined for nearly all cancers at a rate of -1.9% per year since 2015 (both sexes, and all cancer combined), largely driven by decreases in lung and colorectal cancers in both males and females (11). In Canada, over 1.5 million are living with or beyond a cancer diagnosis and this number is expected to double by 2040 (11,14). Approximately two-thirds of the population of individuals surviving cancer are 65 years of age or older (1).

The landmark seminal report from the Institute of Medicine defines a *cancer survivor* as any person diagnosed with cancer from the initial point of diagnosis until death (15). Recent definitions recognize the impact around the individual diagnosed and include family members/ friends/ caregivers who are also impacted (16). For the purposes of this dissertation, 'cancer survivor' refers solely to the individual with a history of cancer. *Survivorship* has traditionally been defined as, "the period following first diagnosis and treatment and prior to the development of a recurrence of cancer or death" (15,17). Improvements in cancer treatments have led to a population of survivors living with incurable or advanced cancer who are not considered palliative, or appropriate for end-of-life care but will never enter remission (18). For the purposes of previously published Chapters Two and Three, the expanded definition of survivorship as outlined by the Canadian Cancer Research Alliance will be used. The expanded definition of survivorship includes persons with metastatic disease, as many now live for extended periods with an advanced cancer diagnosis or recurrence (16). Survivorship does not include issues related to a person's end of life (palliative care, end of life decision making, bereavement) (16). However, recent terminology acknowledges not all individuals diagnosed with cancer identify with the label of "cancer survivor", reflected in a shift to person first language such as, '*individuals with cancer*' or, *'individuals living with or beyond cancer'*. Chapters Four, Five and Six reflect this changing terminology, referring to aforementioned cancer survivors as, '*individuals with cancer'*.

1.2.2. Cancer-Related Treatments and Quality of Life

The population of those living with cancer and cancer related treatment effects is diverse. The majority of individuals diagnosed with cancer will experience effects from the disease itself, or due to its treatment. Treatments can include surgery, radiation therapy and systematic therapies including chemotherapy, hormonal/endocrine therapy, targeted therapy and immunotherapy (1). Treatments may be unimodal or multimodal, with multimodal treatments given either as sequential therapies, or in combination (19). Thus, treatment-related effects can result in extremely diverse, complex and debilitating physiological and psychosocial effects, potentially affecting multiple body systems (20-22).

Adverse effects of disease related treatments, may be immediate, resolving within days to weeks (acute effects), or persistent (long-term effects), lasting months to years after treatment has been completed, or presenting months or years after cancer treatments (late effects) (23). An umbrella term of 'persistent effects' has been used to describe both long-term and late-effects experienced by cancer survivors (23). *Long-term effects*, such as pain or fatigue, are adverse treatment side-effects that begin throughout, or shortly after treatment has finished, and persist for an indefinite amount of time (23). *Late effects*, such as lymphedema and radiation fibrosis syndrome, are distinct complications or toxicities that are often absent at the end of therapy, appearing months or years after treatment completion (23). Due to the diverse symptom-burden and impairments in function throughout and after treatment, cancer survivors may require one or more interdisciplinary allied health/supportive care services (e.g., physiotherapy, occupational therapy, speech language pathology, nutritionist, social work) at different times in the disease trajectory to restore optimal functioning (24-27) .

Impairments can be psychological and physiological and can extend well beyond the treatment period, negatively affecting quality of life (QoL) (20). Common psychological impairments include cancer-related fatigue, pain and psychosocial issues (distress, depression, anxiety) (22). Cancer-related fatigue (CRF), a state of unrelenting tiredness that manifests following a cancer diagnosis, is one of the most common side effects of cancer (20,28,29). CRF can persist from months to years, with survivors reporting exhaustion from even simple activities of daily living (28,29). Cancer-related pain is multidimensional, involving malignancy, treatments and psychosocial distress contributing to the presence and severity of nociceptive and neuropathic pain (30). In a systematic review and meta-analysis (52 studies, n=32,261), approximately one-third of cancer survivors rated pain levels as moderate to severe at cessation of treatment (31). Other common psychological effects experienced by patients include distress, depression, anxiety, low self-esteem, loneliness, poor body image and a lost sense of control (22). Fear of recurrence, experienced by up to 80% of those in survivorship, with persistent emotional distress have been identified as major contributors to clinical anxiety and/or depression (22).

Physiological impairments may be acute, or persistent (long-term and/or late effects) (23). Soft tissues are commonly affected by surgical procedures and radiation. Common soft tissue impairments may include: (1) pain from residual tissue damage from the cancer and/or its treatments; (2) lymphedema following surgical removal of, or damage to lymph nodes in the area (e.g., axillary, groin, neck); and (3) fibrosis of muscles and surrounding soft tissues from exposure to radiation, leading to contracture and loss of muscle mass (20,32). Additionally, chemotherapy may also have toxic physiological effects, including: (1) chemotherapy-induced peripheral neuropathy (CIPN), a neuropathy affecting the peripheral nervous system, leading to distal tingling, burning and numbness, balance deficits and motor effects such as loss of strength, muscle cramps and spontaneous movements; and (2) mild cognitive impairments (memory loss, lack of concentration) (19). Late-effects of chemotherapy (anthracycline-based chemotherapies and anti-HER2 agents such as trastuzumab) and radiation involving the chest can involve cardiotoxicity, leading to left ventricular dysfunction and potential heart failure (33,34). Bone effects such as osteopenia and osteoporosis can be seen as a result of hormone and radiation treatments (22). The risk of osteoporosis and subsequent fractures is increased by up to 20% for breast or prostate survivors who have received hormone treatment (35). Other common physiological effects may include general physical deconditioning, myopathies, adverse body composition changes (weight gain, cachexia), hematologic changes and dyspnoea (20,21).

Overall, physical impairments and related disability have a negative effect on QoL and participation in work and society, leading to a large economic burden of cancer on the healthcare system and workplace (11,36). Cancer survivors are approximately 1.4 times more likely to be unemployed than those without a diagnosis of cancer, and roughly 25% of survivors will not have returned to work two years post diagnosis (37).

1.2.3. Exercise Oncology

The growing population of individuals surviving cancer has led to the need for evidence-based care to support recovery from cancer-related treatments. An extensive body of evidence, including guidelines from 16 major medical or health-oriented organizations, recognize exercise as beneficial for individuals with cancer across the cancer spectrum (2). *Physica*

l Activity (PA) is defined as "any bodily movement requiring the contraction of skeletal muscles that results in a substantial increase in energy expenditure over resting levels" (38). *Exercise* for the purposes of this dissertation is defined as, "a physical activity causing an increase in energy expenditure and involving a planned or structured movement of the body performed in a systematic manner in terms of frequency, intensity and duration and designed to maintain or enhance health-related outcomes" (39). PA may include leisure-time physical activity (exercise) and/or household or occupational related PA.

There is a strong and extensive evidence-base supporting the positive effects of exercise on cancer-related symptom management, physical and psychosocial well-being and health-related QoL. More than 140 systematic reviews summarizing exercise and oncology trial findings have reported that exercise facilitates physical and psychosocial recovery and improves management of treatment related persistent and late effects (22,40-42). Moreover, current evidence suggests a positive association between physical activity and cancer outcomes of recurrence, cancer-specific mortality and all-cause mortality, predominately in prostate, breast and colon cancer (43,44). Many international guidelines now recognize and recommend exercise as beneficial for cancer related side effects (27,45). Notably, the 2019 American College of Sports Medicine Expert Consensus Statement on Exercise Guidelines for Cancer Survivors advised that cancer related benefits can be achieved through: (1) pre and post cancer-related treatment, 150 minutes of moderate intensity, or 75 minutes of vigorous-intensity, aerobic exercise per week (or an equivalent combination) and resistance training for major muscle groups at least twice per week (8-10 muscle groups, 2 sets of 8-10 repetitions); and (2) during cancer-related treatment, 90 minutes of aerobic exercise with or without two session per week of resistance exercise (2).

Having established benefits of exercise for individuals with cancer, the research focus is now shifting from efficacy (randomized controlled trials) to effectiveness (pragmatic trials and implementation studies)— namely closing the knowledge-to-practice gap by examining how best to integrate exercise counselling, referral and programming into oncology patient care (9). Reported rates of exercise by individuals with cancer are consistently low. Data from the 2013-2017 National Health Interview Surveys involving over 12,000 individuals with cancer found only

% reported meeting physical activity guidelines compared to those without a cancer history (3). The diagnosis of cancer itself represents a 'teachable moment' to introduce health behavior change (46). Moreover, Health Care Provider (HCP) promotion of exercise has been identified as a key strategy to improve survivor exercise adoption (47). However, HCP practices related to oncology exercise counselling and referral of individuals with cancer are limited, with significant barriers including the lack of availability of cancer-specific exercise programming to refer to (48). A Canadian study found that less than 20% of survivors had received education on the importance of exercise from any HCP at any point in the course of their cancer treatment (4). Further, 83% and 88% of patients reported not receiving any exercise counselling from their oncologist and primary cancer nurse, respectively (4). Studies outside Canada show similar findings, with only 9% of oncology nurses and less than 25% of oncology physicians referring individuals with cancer to exercise programming (49,50). While calls to action have been made for exercise to be integrated into oncology practice (51,52), there are significant barriers to implementing exercise in real-world settings at the individual, HCP, and healthcare system levels (48,53). These barriers to implementation are complex and have yet to be properly understood and addressed (48).

1.3. Context of Research Approach

1.3.1. Knowledge Translation (KT) and Integrated Knowledge Translation (iKT)

As a result of the robust evidence supporting the benefits of exercise towards cancer recovery, efforts towards promoting knowledge translation to support implementation of exercise for individuals with cancer have become forefront in the field. The Canadian Institutes of Health Research (CIHR) defines *knowledge translation* as, "a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the healthcare system" (54). Key concepts of KT include the synthesis, dissemination, exchange, and implementation of best evidence to improve health services and outcomes (55).

Integrated knowledge translation (iKT) was a concept defined by CIHR in the early 2000's to promote the collaboration between researchers and knowledge users (55). CIHR defines a *knowledge user* as, "an individual who is likely to be able to use research results to make inf

ormed decisions about health policies, programs and/or practices" (i.e. HCP, health care administrator, community leader, individual in a patient group or private organization) (54). The central premise of iKT can be described as involving knowledge end-users as partners throughout the research process to yield research that is more applicable and impactful (55). Thus, iKT involves research that applies the principles of knowledge translation from the planning and delivery stages of research, through to the interpretation and application of the findings (55,56).

The scope of KT includes the field of implementation science that aims to bridge the gap between evidence-based interventions and their uptake in clinical practice. Within implementation science there are two main categories — dissemination and implementation. Dissemination and implementation, while both encompassed by KT, are separate components within the contexts of both science and practice. First the two components have different end goals. Dissemination involves the study and spread of knowledge, while implementation is the uptake of research findings into clinical and policy contexts to change behaviour and practice. Secondly, the science and practice fields within each component are distinct areas of study.

KT thus involves four components: (1) *dissemination science*, (2) *dissemination practice*, (3) *implementation science* and (4) *implementation practice*. Dissemination specifically involves the spreading of knowledge or research (7). *Dissemination* can be defined as the, "promulgation of knowledge products to increase stakeholders' awareness of them or the specific and discrete strategies used to promulgate knowledge products" (7). Dissemination can be further categorized as dissemination science and dissemination practice. *Dissemination science* is concerned with how best to spread knowledge and can be defined as "the study of how evidence-based practices, programs, and policies can best be communicated to an interorganizational societal sector of potential adopters and implementers to produce uptake and effective use" (57). *Dissemination practice* is the actual spread of knowledge, "the purposive distribution of information and intervention materials to a specific audience" (58). Thus, dissemination science and practice are not about creation of knowledge or the actual practice uptake of knowledge, but rather the study of, and practical methods used to share research findings (7).

In contrast, implementation encompasses the innovation or integration of research into practice (7,59). Specifically, i*mplementation science* involves the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices in clinical, organizational, or policy contexts (59). The body of research surrounding implementation science is rapidly growing and has numerous applications towards informing evidence to clinical methodology and processes (60). *Implementation practice* is, "the use of strategies to adopt and integrate evidence-based interventions and change practice within specific settings." (58). Implementation practice builds from existing scientific and behaviour change theories and involves active interventions that aim to change practice and/or policy.

In recognizing the differences between the categories of dissemination and implementation science and practice, researchers can better orient themselves to the appropriate KT literature, evidence and goals. This dissertation comprises a series of integrated knowledge translation studies with knowledge end-users, namely individuals with cancer, as the focus of the planned implementation of exercise oncology programming. The context from which this dissertation is based is orientated in the field of *implementation practice*.

1.3.2. Guiding Practice Models: Implementation Taxonomy

Theory-based implementation strategies supporting the integration of exercise into oncology clinical care are slowly emerging in the literature, yet the absence of consistent evidence for successful KT remains (48). The last decade of implementation science research has led to the development of many theories, models and frameworks to facilitate the integration of evidence-based clinical practices. The complexity of the area calls for an orientating taxonomy to understand the current models, theories and frameworks used in the literature, and a clearer definition of their application to implementation science and practice as a whole.

The work of this dissertation used the taxonomy and organizational framework by Nilsen et al., developed for understanding the field of implementation in healthcare (60). The taxonomy distinguishes between three overarching aims: (1) describing the process, or steps involved in translating research into practice (process models); (2) describing or explaining what may influence implementation outcomes (determinant frameworks, classic theories, implementation theories); and (3) evaluating implementation (evaluation frameworks) (60). The first

two aims of the taxonomy informed the process model, determinant framework and implementation theory upon which this dissertation is structured.

1.3.2.1. Process Model: Knowledge-to-Action Process Model

Aim 1: Describing the process in translating research into practice (process model)

Process models can be used to describe and/or guide overall translation of research into practice (60). The Knowledge-To-Action (KTA) process model was used to orient and guide the implementation process for this dissertation, which aligned with cycle phases associated with (1) adapting knowledge to the local context and (2) assessing barriers and facilitators to cancer-specific exercise programming in our local context (7) (Figure 1).

KTA process model outlines steps in the process of knowledge creation, tailoring, and use, into a detailed implementation model (7). The model starts with a knowledge creation funnel representing knowledge inquiry (primary research studies), synthesis (systematic reviews and meta-analyses) and development of knowledge tools (clinical practice guidelines and frameworks). The action cycle consists of cyclical, stepwise items connected with bidirectional arrows: identifying the problem; adapting knowledge to local context; assessing barriers to knowledge use; selecting, tailoring and implementing KT interventions; and ongoing monitoring and evaluation for sustained knowledge use (7). The KTA Framework has been widely used to inform and guide implementation in a variety of fields (61).

Aim 2: Describing or explaining what may influence implementation outcomes (determinant frameworks, classic theories, implementation theories)

Implementation theories have been developed by researchers in implementation science to provide understanding and/or explanation of aspects of implementation practice. Determinant frameworks and implementation theory for this dissertation was based off the work of Michie et al. and involved the Theoretical Domains Framework (determinant theory) and the Capability, Opportunity, Motivation – Behaviour (COM-B) Model (implementation theory) (62).

1.3.2.2. Determinant Theory: Theoretical Domains Framework (TDF)

The Theoretical Domains Framework (TDF) is an integrative framework developed from a synthesis of behaviour change theories and is used as a tool to apply theoretical approaches to

behaviour change interventions (62). The TDF was developed in response to researchers recognizing that successful implementation of evidence-based research into practice was linked to behaviour change (63). The TDF was derived from 33 identified behaviour change theories that consisted of 128 constructs and were simplified into 12 domains and subsequent question frameworks to provide a thorough theoretical assessment of implementation problems (64). The current framework identifies 12 domains that influence practitioner clinical behaviour and behaviour change: (1) knowledge; (2) skills (physical and cognitive); (3) social/professional role and identity; (4) beliefs about consequences; (5) beliefs about capabilities (self-efficacy); (6) motivation and goals; (7) memory, attention and decision processes; (8) environmental context and resources (environmental constraints); (9) social influences (norms/reinforcement); (10) emotion; (11) behavioural regulation; and (12) nature of behaviours (62). These domains are specifically applicable to the KT area of practice implementation and for health policy evaluation (65). The TDF was reviewed by an international panel of 36 experts in behavior change, and found to have face, content and construct validity (64). TDF has been used in a large number of studies to assess implementation problems, and to inform the design of implementation interventions in a variety of health settings (66,67).

The advantage of using the TDF is that each domain can be mapped to corresponding capability, opportunity or motivation factors of the COM-B Model to develop theoretically informed implementation strategies (62). This is advantageous because it provides a systematic way to approach, map and understand findings in relation to chosen implementation strategies in a real-world/ clinical setting. The TDF was used in this dissertation work as: (1) a guide during development of surveys and focus group questions to ensure comprehensive coverage of all areas of behaviour change; and (2) to map findings to the corresponding components of the COM-B to develop theoretically informed implementation strategies.

1.3.2.3. Implementation Theory: Capability, Opportunity, Motivation -Behavior Change (COM-B) Model

The COM-B model was developed to understand behaviour change and contains three main inter-related factors: (1) capability: an individual's psychological and physical capacity to perform behaviours or activities; (2) opportunity: physical (environment) or social factors

(interpersonal influences) external to an individual that influence the behaviour; and (3) motivation: brain processes that direct behaviour (habitual and emotional responses, and analytical decision-making) (62). The COM-B helps to identify potential behaviour change components to target in an intervention. TDF construct findings can be mapped to their respective capability, opportunity and motivation factors and implementation strategies can be selected to target the respective component (62). The COM-B was used in this dissertation to map survey and focus group questions and study results to the three behaviour change factors (capability, opportunity and motivation), and guide subsequent implementation strategies. The COM-B has been successfully used in evidence-based healthcare implementation as a taxonomy to map strategies and identify barriers (68,69).

1.3.3. Researcher Positionality

Personal background and experience influence researcher's choices in philosophical positionality, methodology, theoretical alignment and questions asked. Thus, as the researcher, I will provide background and context regarding the positionality of my research.

I am the first student piloting the combined MSc in Physical Therapy (MSc PT)/ PhD in Rehabilitation Sciences (PhD RS) in the Faculty of Rehabilitation Medicine at the University of Alberta. Before enrolling in the combined program at the beginning of my MSc PT, I had an unexpected health event that affected the function of my left leg. The damage to my leg required me to relearn to walk and involved two years of rehabilitation, chronic pain clinics and specialist appointments. Once the acute danger of my condition had resolved, I found there was minimal healthcare support in terms of guidance or programming to help me regain function. While I was 'cured', I was living with long-term effects and my quality of life was a fraction of what I had formerly known. With the support of an interdisciplinary team and specialists in pain management, I recovered after two years of dedicated rehabilitation. I surpassed the odds given to me by my medical team (lifelong disability) and returned fully functioning, pain free and determined to advocate for the needs of patients.

Dr. Margaret McNeely had just received funding for the Alberta Cancer Exercise Feasibility Trial (ACE-pilot) when I was looking for a gradual way to return to the Faculty of Rehabilitation Medicine. At the time, I was unsure if I had recovered enough to return to my

MSc PT studies, let alone a career as a Physical Therapist (PT). I spent a year as a Research Assistant, working alongside individuals with cancer in Dr. McNeely's Cancer Rehabilitation Clinic. While listening to patients' stories of feeling hopeless and then seeing them regain strength and the lifeline rehabilitative exercise gave, I found many parallels to my own struggle of regaining quality of life and became motivated to support care for individuals with cancer. As a first step, I enrolled in a MSc in Rehabilitation Science, and with the support of the Faculty of Rehabilitation Medicine and Department of Physical Therapy and my supervisor, I was able to Fast Track to a PhD in RS and eventually the MSc PT/ PhD RS.

The MSc PT/ PhD RS gave me the unique experience of growing a clinical mindset while seeking to further the field of rehabilitation. I completed my MSc PT clinical courses and clinical placements, balanced with integrated research-focussed semesters. The projects in my thesis evolved from both the gap I found in the literature and the needs I experienced first-hand clinically as an MSc PT student. The integrated knowledge translation (iKT) approach of involving patients' perspectives towards exercise barriers, facilitators and preferences as they went through their cancer journey aligned to my own mission of supporting a patient-centered approach. The Canadian Institutes of Health Research Knowledge-To-Action Framework provided a stepwise map that guided the steps of my entire dissertation (Figure 1-6.).

With the lack of successful implementation of real-world exercise programming, a theoretical foundation was necessary. The work by Michie et al. that was gaining significant and successful traction in the healthcare implementation field provided a foundational framework to guide my projects that aligned symbiotically with the iKT approach. The Theoretical Domains Framework (TDF) provided behaviour change constructs to address, while the Capability, Opportunity, Motivation, Behavior Change (COM-B) Model provided a means to map constructs from the TDF for theory informed implementation strategies. While the COVID-19 pandemic changed the trajectory of my research – as it did with almost every one of my graduate student colleagues- the methodology and approach allowed for new investigation on the barriers to the novel virtual exercise programming implementation world.

While I would never wish my medical experience on anyone, I feel very fortunate to have had a successful rehabilitative journey, the honor to have grown a unique mindset the MSc

PT/PhD RS allowed and found a lifelong mission to help serve patients dealing illness to find themselves again.

1.4. Research Timeline

The data collection for the series of studies presented in this dissertation took place between 2016 and 2021 in the Cancer Rehabilitation Clinic, Faculty of Rehabilitation Medicine, University of Alberta in Edmonton, Alberta, Canada. Study One (Chapter Two) was an update on a 2006 previously published review on the state of the evidence supporting exercise for survivors of cancer, as well as guidelines for integrating exercise programming in the cancer clinical setting. This review aligned with the Knowledge-to-Action (KTA) cycle of determining the knowledge-to-practice or 'Know-Do Gap' (Figure 1.) (7). Following this review, a series of iKT studies was conducted to identify (Study Two and Three) and address (Study Four) the barriers to implementation of exercise evidence into practice.

Study Two (Chapter Three) was conducted in-person in Edmonton Alberta with data collected at two time points: (1) pre-ACE- pilot (July 2013); and post ACE-pilot (May 2016). Study Two involved cross-sectional surveys and focus groups of local individuals with cancer to explore barriers and preferences towards accessing cancer-specific exercise programming. Findings informed implementation of the province wide, cancer specific, community-based exercise program, the Alberta Cancer Exercise (ACE) Hybrid Effectiveness-Implementation Study. Study Two aligned with the KTA phases of 'Adapting knowledge to local context' and 'Assess barriers and facilitators to knowledge use' (Figure 1.). In the study, ACE pilot respondents identified a 'Know-Do' gap involving a lack of exercise counselling and referral. A series of projects involving (1) an electronic cross-sectional survey (Fall 2017) and (2) an in-person focus group (May 2018) of local oncology HCPs was conducted at the Cross Cancer Institute (70) (Appendix 1). A preliminary implementation pilot study was conducted in-person with an exercise referral screening tool for Head and Neck Cancer patients, with initial promising results (Spring 2019) (71) (Appendix 2). However, with COVID-19, research activities were suspended, thus the larger-scale hospital intervention became impossible, and this planned implementation study was not moved forward.

1.4.1. COVID-19 Impact

Evidence on barriers, preferences/facilitators to virtual exercise implementation is an emerging and needed area of research. Study Three (Chapter Four) was a cross-sectional electronic survey conducted of former ACE Study participants from August 2020 to September 2020. Study Three explored the barriers to exercise that arose through COVID-19 with the rapid integration of virtual exercise programming, use of technology and required technological proficiency to access programming virtually. The KTA phase of this study aligned with 'Assess barriers and facilitators to knowledge use' (Figure 1). As a result, my subsequent implementation strategies focused on virtual exercise implementation and the use of technology.

The Healthy Eating, Active Living Mindful Energy Application (Heal-Me App), is an evidence-based theoretically informed nutrition and exercise application that can be tailored for multidisciplinary use across a range of chronic disease populations (72). The Heal-Me App was in development prior to COVID-19, funds held jointly between Dr. Tandon and Dr. McNeely, and offered a feasible option for supporting exercise implementation virtually during COVID-19. Heal-Me allowed the virtual delivery of multidisciplinary exercise and nutrition programming remotely, while maintaining exercise and dietician professional and peer supports.

Study Four (Chapter Five) examined implementation of identified strategies for virtual exercise programming of cancer survivors as well as other common chronic disease groups (chronic lung disease, and liver and lung transplant). The Heal-Me Technology Counselling for eHealth (TeCH) study was conducted virtually from November 2020 to September 2021. Heal-Me Tech addressed the identified barrier of technology proficiency and involved the provision of technology support through standardized one-on-one virtual orientations to the novel online Heal-Me Application. This work aligned with the KTA phase of 'Select, Tailor and Implement Interventions' (Figure 1).

1.4.2. Study Purposes

The purpose of this dissertation was to: 1) summarize the state of evidence supporting exercise for survivors of cancer and provide an update on recommendations for integrating

exercise programming into the cancer clinical setting; 2) understand needs of individuals with cancer prior to, and following the Alberta Cancer Exercise (ACE) pilot randomized trial as a means to inform oncology exercise implementation; 3) to identify individuals with cancer barriers and facilitators towards engaging in virtual and in-person cancer-specific exercise during COVID-19 and inform ongoing cancer-specific exercise programming; 4) address identified technology-related barriers by individuals with cancer through the provision of technology counselling for the cancer population and other chronic disease populations (those with lung and liver diseases) accessing virtual multidisciplinary care.

1.4.3. Study Objectives

For the update on recommendations for clinical practice objectives were:

To provide an update on:

1. The state of the evidence supporting exercise for survivors of cancer.
2. Guidelines for integrating exercise programming in the cancer clinical setting.

For the Alberta Cancer Exercise pilot cross-sectional survey and focus group objectives were:

1. To share the findings related to survivor reported exercise preferences, barriers, and facilitators before and after participation in the ACE pilot trial.
2. To describe how the findings informed the design of the current five-year ACE Hybrid-Effectiveness Implementation Study.

For the Virtual or In-Person COVID-19 cross-sectional survey objectives were:

1. To understand the perspectives of individuals who had previously participated in standardized exercise towards (1) in-person and virtual exercise, and (2) the use of technology to access virtual exercise programming.
2. To understand the facilitators/preferences and barriers towards exercise during COVID-19 to inform ongoing cancer-specific exercise programming.

For the Technology Counselling intervention for chronic disease groups (cancer, chronic lung disease and lung and liver transplant) objectives were:

1. To evaluate the implementation of a standardized technology counselling support process for individuals with chronic disease (cancer, lung and liver disease) accessing virtual multidisciplinary care.

2. To explore the factors influencing technology training time among individuals with chronic disease accessing exercise and nutrition services through the Heal-Me application during COVID-19.

Figure 1-1. Knowledge to Action Process Model Dissertation Alignment

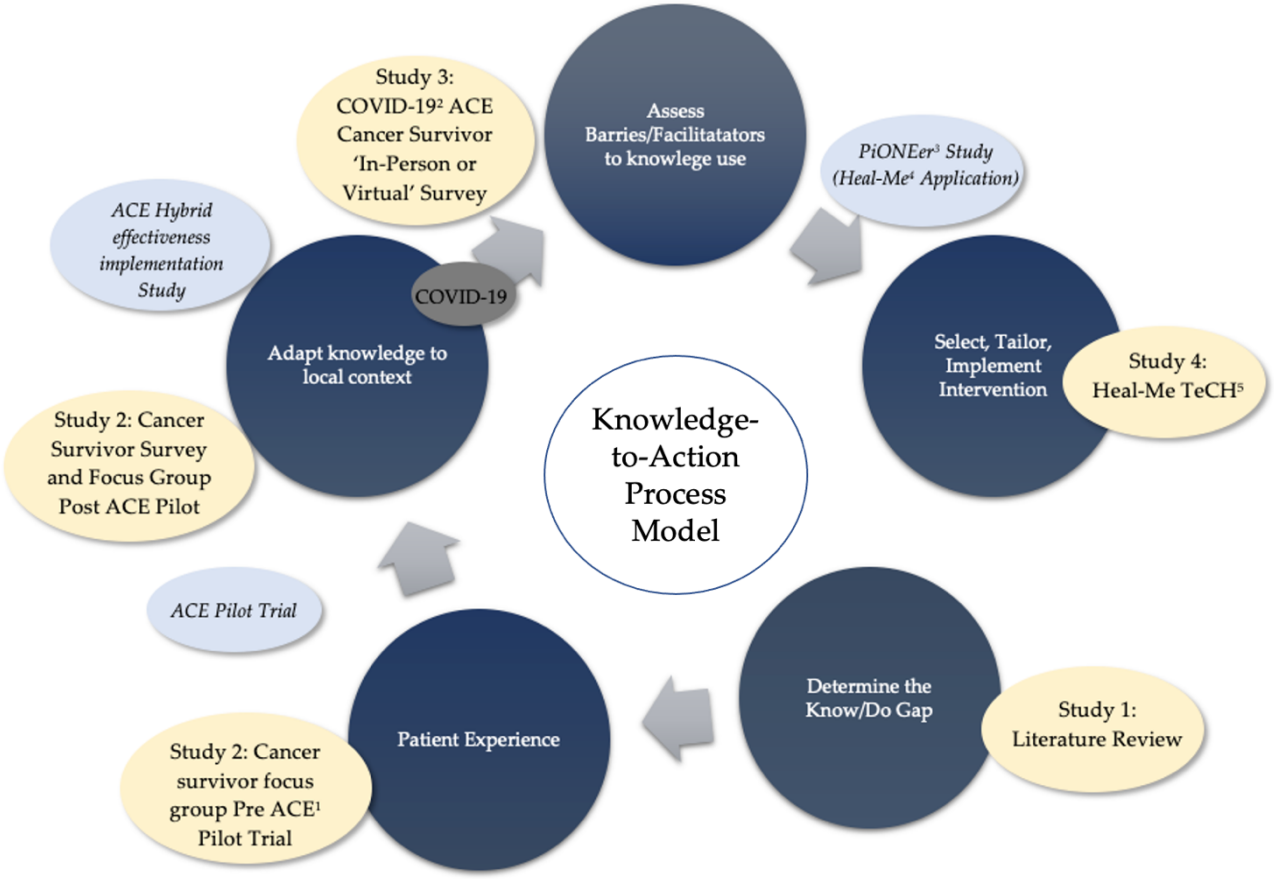

Figure 1-1. Knowledge-to-Action Process Model Dissertation Alignment

Adapted from: Graham ID. Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches [Internet]. Cihr. 2012. 1-30.

[1]ACE: Alberta Cancer Exercise;
[2]COVID-19: Coronavirus Disease 19
[3]PiONEer: Personalized Online Nutrition and Exercise Routines
[4]Heal-Me: Healthy Eating, Active Living, Mindful Energy
[5]TeCH: Technology Counselling for eHealth

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Chapter 2

Implementing Cancer Exercise Rehabilitation: an update on recommendations for clinical practice

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2.1 Abstract

A growing body of research evidence supports the benefit of exercise for cancer survivors both during and after cancer treatment. The purpose of this paper is to provide an update on our previously published review in 2006 on the state of the evidence supporting exercise for survivors of cancer as well as guidelines for integrating exercise programming in the cancer clinical setting. First, we provide a brief overview on the benefits of exercise as well as preliminary evidence supporting the implementation of community-based exercise programs. Second, we summarize the principles and goals of exercise, and the identified barriers to exercise among cancer survivors. Finally, we propose an interdisciplinary model of care for integrating exercise programming into clinical care including guidelines for medical and pre-exercise screening, exercise testing and programming considerations.

Keywords: Exercise, physical activity, rehabilitation, physical therapy, cancer survivors, pre-exercise screening.

Chapter 2

Implementing cancer exercise rehabilitation: an update on recommendations for clinical practice

2.2. Introduction

Exercise is a low cost and safe intervention for cancer survivors with beneficial effects on physical functioning and all aspects of health-related fitness, including aerobic and muscular fitness, and body composition (1, 2). Exercise has been found to reduce the severity of treatment-related adverse effects such as pain and fatigue (3-5), result in better quality of life, and improve chemotherapy completion rates, thus potentially optimizing treatment outcomes (3-7). Evidence also supports exercise as a strategy for secondary cancer prevention of common cancers including breast, colon and prostate (4,5,8,9). Despite the known benefits of exercise, less than one-third of cancer survivors report meeting the minimal public health guidelines for physical activity (2). Given the strength of the evidence supporting exercise, efforts towards implementation of exercise programming into clinical cancer care are warranted.

The purpose of this paper is to provide an update on the state of the evidence regarding exercise and exercise programming for survivors of cancer since our previous 2006 review (10). Updated evidence and topics include: (1) highlighting emerging evidence suggesting benefit from exercise for cancer mortality, recurrence and overall survival; (2) presenting recent cancer exercise guidelines and evidence on implementation of community-based programming; (3) proposing revised strategies to address the challenges and barriers to implementation and (4) presenting an interdisciplinary model of care for integrating exercise programming into clinical care.

2.2.1. Benefits of Exercise for Cancer Survivors

Over the past decade, many systematic reviews and meta-analyses have been performed examining exercise as an intervention for survivors of cancer. A recent two-stage systematic review and meta-analysis (11) provides a comprehensive summary on the state of the evidence on exercise for (1) cancer mortality and recurrence and (2) adverse effects of cancer and cancer treatments. In the first stage of the review, 36 articles (68,285 participants) including 32 prospective cohort studies and four RCTs examined the benefit of exercise for outcomes of

cancer mortality and recurrence, as well as all-cause mortality. The results showed that survivors with cancer participating in higher levels of exercise after diagnosis have a significantly reduced relative risk of cancer mortality (28-44%), cancer-recurrence (21-35%) and all-cause mortality (25-48%) when compared to survivors participating in no/ less exercise. Studies included in the review primarily involved survivors of breast, colorectal and prostate cancer; thus, a paucity of data exist supporting cancer outcomes for other types of cancer.

In the second stage of the review, the authors examined the effect of exercise on adverse effects of cancer and cancer treatments (11). A total of 23 RCTs (3,735 participants) and 40 meta-analyses (9,126 patients, including 257 reported studies) were evaluated. The most commonly reported outcomes of the included meta-analyses were fatigue (24 meta-analyses), quality of life (15 meta-analyses) and depression (11 meta-analyses). The most compelling evidence supported exercise for psychosocial outcomes of distress, anxiety and depression, as well as symptoms of fatigue during and after cancer treatments across cancer tumour types. The primary finding of the review was that survivors of cancer participating in higher levels of exercise were found to have fewer treatment-related adverse effects when compared to survivors who performed no/less exercise (11). Currently, findings of benefit for many adverse effects largely comprise studies involving the breast cancer population. Additional large scale RCTs are still deemed necessary to determine specific effects on understudied tumour populations and for further clarification on the optimal exercise prescription parameters (frequency, intensity, modality and volume) (11).

Overall, the research evidence aligns with recent position statements on exercise and cancer (12-14). The recently published guidelines by the Australian Society of Clinical Oncology, for example, recommend that: (1) exercise be integrated into cancer care and be considered an adjunct therapy to counteract the negative effects of cancer and its treatments; (2) all cancer healthcare providers/professionals (HCPs) promote physical activity and exercise and (3) all survivors be referred to an accredited exercise physiologist and/or physiotherapist with experience in cancer care (13). Guidelines published by Cancer Care Ontario in Canada, although similar, further recommend that survivors exercise in a group or supervised setting to obtain optimal benefit (14).

2.2.2. Evidence on Implementation of Exercise Programming

As a result of the growing evidence supporting exercise, efforts towards implementation of cancer-specific programming have begun to emerge (15-18). In this section, we summarize the findings from three large-scale community-based implementation programs.

One of the longest-running programs, Livestrong at the YMCA, is a cancer-specific community-based exercise program offered twice a week for 12 weeks (16). This program is funded by the Livestrong organization and is free of charge or offered at a low cost to participants. Group-based exercise programming is supervised by a YMCA exercise professional who has received a minimum of 28 hours of cancer-specific exercise training. Since its inception in 2008, the program has trained approximately 2,200 exercise professionals and cancer-specific exercise programming is delivered at 416 YMCA sites in 37 states across the United States. The program has served over 29,000 cancer survivors with program evaluation data available on 1,668 participants strongly supporting satisfaction with the program (16). Recent RCT data, from two Livestrong YMCA sites involving 186 participants (95 to Livestrong exercise and 91 to the control group), support short-term effectiveness of the program. Following the intervention, exercise participants reported significantly higher levels of physical activity (71% exercising at ≥ 150 minutes/week vs. 26% of controls; P<.05), improved six-minute walk test distance (group mean difference: 28.9 meters [95% confidence interval, 0.3-49.0; P = .004]) and better quality of life (group mean difference: 2.6 [95% confidence interval, 0.1-5.0; P = .04]) when compared to the control participants. No adverse events were reported. The majority of participants, however, had early-stage cancer and 53% had breast cancer. Beyond the findings of this RCT, objective data are lacking supporting the benefits of the Livestrong program over the long-term (19).

A community-based exercise program carried out in Texas called Fit STEPS for Life reported outcome data on 701 survivors with cancer at 2 years following program entry (17). Data collection took place at baseline, every 3 months during year 1 and every 6 months during year 2. Complete data were available on 177 participants (25%). The authors acknowledge high attrition from the program (40% at 6 months) suggesting the need for strategies to encourage ongoing participation in exercise among survivors. While findings

supported the positive impact of exercise on quality of life, data were not provided on physical fitness or other health outcomes (17).

A cancer-specific exercise program called Life Now based out of Western Australia reported both short and long-term results from a 3-month duration supervised community-based exercise program (15). The study comprised 600 survivors and 13 participating fitness centres. Data collection took place at baseline, 3 and 6 months. Four hundred and seven participants (68%) completed the full intervention, and 330 (55%) completed the 6-month follow-up. Attendance at exercise sessions was 79%. Significant improvements were reported in physical fitness, fatigue and quality of life postintervention with improvements in fatigue and quality of life remaining at 6 months. Importantly, the estimated monthly medical expenditure for participants was reduced both postintervention (13%) and at 6 months (11%) (15).

In summary, published implementation programs currently report high program attrition, suggesting the need for further exploration on the extent and nature (random or nonrandom) of program adoption, retention and dropouts. Moreover, the overall uptake of community-based exercise programming by cancer survivors relative to the larger population of survivors appears low. Finally, there is limited data supporting the benefit of programs for objective physical fitness outcomes, quality of life, cost-effectiveness, as well as general health and cancer outcomes in the long-term (20). As a result of these limitations, controversy exists over the optimal exercise-programming type and location (e.g. homebased versus supervised community-based) (21). Thus, further work utilizing implementation methodologies may help to better understand the critical factors affecting uptake and long-term adoption of exercise.

2.3 Principles, Goals and Barriers to Exercise

Research has shown that targeted exercise programs that include tailored exercise prescriptions are more successful in helping individuals with the chronic disease to incorporate exercise into their daily routines (25). As cancer is not a homogeneous disease, this finding likely holds true for the cancer population. Tailored exercise programs, that use all available clinical data and pay special attention to results of the exercise test and physiological training responses as important determinants, may best serve survivor needs. The exercise program

should be designed to increase or maintain the survivor's overall fitness and, when needed, address specific disease and/or treatment-related problems.

Many of the guiding principles of exercise prescription hold true in the cancer exercise setting. These principles include overload, adaptation, specificity and reversibility (26). Determining the optimal overload (intensity) is often a challenge in the cancer setting, as cancer treatments may have a profound effect on physiological systems, and therefore the status of, and response to exercise of a cancer survivor may fluctuate on a daily basis. Moreover, the need for ongoing 'modification' of programming should be anticipated, especially for survivors undergoing adjuvant cancer therapy and those with advanced disease. Adjustments for 'down days' and adverse effects ensures that exercise participation is safe and effective.

2.3.1. Goals of the Prescribed Physical Activity or Exercise Program

The goals of exercise will vary depending on the survivor's functional status, treatment trajectory and overall prognosis. Individualized exercise prescriptions can be used to target specific goals or outcomes, and are often based on the cancer-related time period. In a pre-treatment setting, exercise has shown benefit as a prehabilitation strategy to improve cardiorespiratory fitness prior to surgery, reducing both the risk of postoperative complications and length of postoperative hospital stay (27). Exercise may be prescribed to prevent or attenuate functional decline during treatment (or in palliative stages of the disease), address treatment-specific impairments and physical deconditioning following treatment, and optimize health and reduce the risk of recurrence and mortality during the survivorship stage (28, 29). In the survivorship setting, particularly for survivor groups such as adult survivors of childhood cancers and long-term survivors of early-stage cancer, exercise is imperative to reduce the risk of development of other chronic disease or to subsequently manage existing cardiovascular and metabolic disease (30). As such, different time-points in the cancer trajectory will have specific goals to be targeted with the exercise prescription (Fig. 1) (31).

2.3.2. Barriers to Exercise Training in Cancer Survivors

Key barriers to exercise in cancer survivors have been found to be related to treatment side effects, lack of time, and fatigue (32). As the average age of individuals affected by cancer is between 65 and 69 years old and 89% are over the age of 50 years at the time of diagnosis (22),

the aging process and existing co-morbid diseases often present additional barriers to exercise. Compounding the problem, survivors have identified a lack of knowledge among HCPs, as well as exercise specialists in the community regarding appropriate exercise prescription, and limited availability of cancer-specific exercise programs (33,34). A recent study revealed that only 20% of cancer survivors had received education on the importance of exercise, with 17% and 13% of patients receiving information from their oncologist and nurse respectively (33).

Barriers to exercise in survivors are also complex as they have been shown to change over the cancer trajectory. Recent research suggests that reported barriers to exercise during active treatment are often cancer-related (e.g. symptoms) while barriers to exercise following treatment are more commonly related to lifestyle factors (e.g. time, return to work, vacation) (35). Barriers may also vary depending on the setting of exercise (i.e. research-based exercise interventions versus community-based programs). While some barriers to ongoing exercise following participation in cancer-specific community-based exercise are similar to those of a structured research-based exercise setting, others like cost and return to work are unique (36). Ethnicity has also been reported to impact the perception of exercise barriers with Hispanic/Latina breast cancer survivors being more likely than Caucasian and African American women to report a lack of enjoyment from exercise and a lack of knowledge on how to exercise (37).

Long-term adherence to exercise is an acknowledged problem in the general population and other disease populations and appears to be no different for cancer survivors. Qualitative research suggests three main themes of barriers to exercise in long-term cancer survivors as psychological barriers (e.g. lack of motivation, fear, dislike of fitness centre environment), physical barriers (e.g. fatigue, physical co-morbidities) and contextual and environmental barriers (e.g. employment, proximity/access to facilities) (38, 39).

It is important to consider that key barriers reported by cancer survivors, such as fatigue, have the potential to be alleviated with appropriately prescribed exercise (11). However, as barriers to exercise have been identified as multifactorial (40), a multidisciplinary and multifaceted approach may be required to improve exercise uptake among survivors (41). It has been suggested that successful interventions and/or programs need to consider addressing

barriers that are cancer-related (e.g. lack of bladder control (42)), psychosocial (e.g. depression (41,42)), environmental (e.g. access to programs) or lifestyle related (e.g. living in a rural setting (43)). It is likely that overcoming barriers will require unique and relevant strategies that take these factors, and their potential combinations, into account.

2.4. Exercise Programming

2.4.1. Screening for Exercise Testing and Prescription

While participation in regular exercise has many benefits and is generally safe for most individuals, it is not without its risks. Exercise increases the risk of musculoskeletal injuries and cardiovascular events (44). The goal of exercise screening is primarily to remove barriers to begin exercising for low-risk individuals and reduce the risk of any adverse events during fitness assessments or exercise training (44). Screening of the cancer survivor helps to identify those at higher risk of an adverse event, and should include: a medical history covering both the cancer diagnosis and treatment received (45,46); other potential co-morbid conditions; determination of their current physical activity level and the intensity of the proposed exercise program (47).

Suggested steps for screening survivors are outlined in the Screening Decision Tree in Fig. (2). When high-risk individuals are identified through this initial screening (i.e. diagnosis of lung, head and neck, multiple myeloma, pancreatic cancers or brain tumors, and/or survivors with advanced recurrent cancer or metastasis to bone or other distant site), medical clearance should be obtained prior to the cancer survivor beginning an exercise program. This clearance may be sought from HCPs providing cancer care (e.g. oncologist) and/or those managing co-morbid conditions (e.g. family physician, cardiologist). Any pre-exercise evaluation completed as part of the medical clearance should be left to the judgment of the HCPs but may include a physical examination, an exercise test, and/ or laboratory tests (45). Comprehensive screening, as outlined in the Screening Decision Tree (Fig. 2), can effectively determine the most appropriate treatment pathway. For example, higher-risk individuals, or those experiencing severe or multiple cancer-related adverse effects, may require cancer rehabilitation services or supervised clinic-based exercise programming.

Prior to performing exercise testing, information must be collected on important diagnostic and treatment variables such as the survivor's type and stage of disease, type and status of cancer treatment (i.e. currently receiving cancer treatment or under active surveillance) and identify any acute or chronic effects related to cancer and/or treatment [45, 46]. Common late and long-term effects of cancer treatments impacting exercise can be viewed in Table 1. Screening must also include an assessment of risk factors for, and/or symptoms of, cardiovascular, pulmonary and metabolic diseases and identify other existing comorbid conditions such as osteoarthritis or osteoporosis. The American College of Sports Medicine has recently developed a pre-participation screening algorithm in an attempt to simplify the process for an individual to begin an exercise program (47). Another screening tool such as the Get Active Questionnaire is available from the Canadian Society for Exercise Physiology (website http://www.csep.ca) and may be a useful additive tool to identify individuals with comorbid disease(s) for whom exercise and/or exercise testing may be unsafe and require further medical clearance or guidance by an exercise professional.

Determining the survivor's current physical activity level and preferred intensity level of the exercise program may be helpful in establishing if additional medical clearance is required beyond the initial screening and to further guide fitness assessment choice and exercise prescription parameters. The exercise professional plays an important role in this determination to ensure the cancer survivor is ultimately directed to appropriate exercise programming.

2.4.2. Fitness Testing

Fitness testing should be performed prior to the initiation of an exercise program, and at regular intervals during and following programming where possible. Fitness testing results may be used to: a) quantify the current functional status of the individual; b) identify underlying comorbid conditions that may preclude exercise (e.g. hypertension) until further medical clearance is obtained; c) develop an appropriate exercise prescription to assist the patient in coping with and /or recovering from cancer and its treatments and d) monitor changes with training to help inform exercise prescription. In our experience, exercise testing may also serve as a motivational 'wake-up call' for survivors on their fitness status and can help

to inform fitness goals as well. The decision concerning the appropriate fitness tests to use for assessments will depend on the available equipment and facilities, the expertise of the exercise professional, and the survivor's general health and any limitations imposed by cancer/ treatment and existing comorbidities. In general, gold standard tests provide meaningful data on fitness to best guide individualized exercise prescription and are more sensitive and responsive to changes over time. These tests, however, generally require more expensive and specialized equipment and highly trained staff, and thus, are less feasible for implementation in the clinical and community settings (Table 2).

A recently published study examining the feasibility of fitness testing in a community-based exercise setting reported that measures of body composition (height, weight and waist circumference) and resting cardiovascular measures were feasible and of prognostic value [48]. Handgrip dynamometry and chair sit-to-stand, and the sit-and-reach test were feasible and provided meaningful data related to changes in strength and flexibility; whereas the back scratch, single-leg stand and timed-up-and-go tests were deemed less sensitive to changes. A submaximal treadmill test was shown to provide data supporting changes in aerobic fitness; however, due to the time needed for testing, it was deemed less suitable for the community setting. The authors recommended evaluating other potentially more feasible and sensitive tests for aerobic fitness, upper extremity flexibility and balance (48).

2.4.3. Exercise Programming

Proper staff training is essential to ensure exercise testing and training is both safe and effective. Requirements for supervision and monitoring will vary as a function of the survivor presentation, staff, facility location, and availability of resources (45). Any facility serving clinical cancer populations should have appropriately trained staff, the necessary medical equipment, and an emergency action plan. Exercise testing should be performed by well-trained personnel with adequate knowledge of exercise physiology (45).

To accommodate the large population of survivors, building capacity outside the cancer hospital setting is likely necessary and may be best achieved through partnerships with existing community facilities, and by supporting self-directed (e.g. home-based) exercise. Options for

programming may include supervised clinic-based, supported community-based and self-directed community/ home-based exercise programming (Table 3).

Safety must be a priority when designing and implementing exercise programs for cancer survivors. Contraindications/precautions to exercise training must be considered when planning an exercise program for survivors (Table 4). Survivors deemed at higher risk (e.g., survivor with a brain tumour) may be best served in a supervised clinical setting where additional monitoring can be performed during exercise sessions. This may include clinical evaluation to identify underlying instability and/or deterioration in clinical status, and monitoring of symptoms (e.g. fatigue), blood pressure (e.g. fluctuations during cancer treatment), heart rate (e.g. may be elevated during treatment) and other vital signs (e.g. oxygen saturation, dyspnea) prior to, several times during, and following the exercise sessions. A clinical exercise physiologist with expertise in cancer should supervise high-risk survivors (clinic-based setting) and oversee programming for low-to-moderate risk survivors (supported community- based setting) that is delivered by trained and certified exercise specialists. Educating the cancer survivor about normal (e.g. increased breathing rate) and abnormal responses (e.g. a feeling of uncomfortable breathing or tightness in the chest) to exercise training may be beneficial in potentially avoiding adverse events (47).

Determining the appropriate exercise prescription for high-risk survivors may be best served by an interdisciplinary team approach (49). At minimum, the team should include an oncologist, oncology nurse, exercise physiologist and physical therapist. Access to services of the supportive care team including occupational therapists, nutritionists, respiratory therapists, social workers and psychologists can be helpful in optimizing programming. A medical liaison is needed to assist in developing emergency medical plans, medical emergency procedures, and reviewing medical incident reports.

Whether implemented in the clinic or community, an initial exercise program should be of a minimum of 8 to 12 weeks duration to ensure that measurable improvements can be achieved. The program should begin conservatively and gradually progress over a period of several weeks based on the cancer survivor's response to training (e.g. monitoring of fatigue and soreness). Appropriate supervision and monitoring during this early stage will help to

optimize the success of the program by ensuring proper exercise performance and allowing modifications to the prescription. The exercise prescription should be designed to maintain and/or improve an individual's current level of fitness as determined, where possible, by the fitness assessment. This may require a prescription involving some or all the components of health-related fitness: cardiorespiratory fitness (aerobic training), muscular strength and endurance (resistance training), flexibility and balance training. Despite specific considerations that should be incorporated into exercise prescription for cancer survivors (45, 46), the guidelines provided for healthy adults (46) can generally be followed after taking the presentation of the individual survivor into account.

For some survivors, the functional status may be so impaired that excessive load or stress may occur with basic activities of daily living. In these individuals, it is imperative to address symptoms such as fatigue and ameliorate motor function, with the gradual introduction of exercise over time. These survivors may be better served by starting with functional activities and/or muscular strengthening exercises or a gentle exercise program until such time as they gain the adequate capacity to perform exercise at a level that targets physical fitness (44).

2.4.4. Promoting Exercise Behaviour Change

The diagnosis of cancer itself represents a 'teachable moment' to introduce health behavior change (50) and oncologist promotion of exercise has been identified as a key strategy to improve survivor exercise adoption (21). Physician recommendations, exercise advice and education have been shown to increase individual exercise levels, especially when in combination with exercise motivational materials, or telephone or community support (21,51,52). Importantly, research with older adults has shown that adherence to exercise is improved when the instructions received from HCPs are specific and understandable (53).

While oncologists and other HCPs in the cancer clinical setting are optimally placed to counsel survivors, only a minority of survivors report receiving exercise or referrals to exercise programs as a part of routine care (21). HCP identified barriers to exercise promotion exist at the institutional (i.e. time, lack of funding, lack of role definition), healthcare professional (i.e. personal limitations, lack of knowledge on exercise, negative view on exercise and

remembering to discuss) and survivor levels (i.e. perceived negative attitude towards exercise, availability of programming, physical effects of cancer, time and weather) (54). As per current exercise guidelines, HCP involvement in exercise counselling and promotion at key time points in the cancer trajectory is essential to optimize survivor adoption and adherence (21). Thus, further research is needed to determine how best to implement exercise counselling and promotion in the clinical setting.

2.5. Conclusion

A growing body of evidence supports the benefits of exercise for cancer survivors both during and following cancer treatments, and for long-term cancer and health outcomes. While community-based exercise programs are being implemented in many centres around the world, data are generally lacking in effectiveness. Moreover, preliminary findings suggest low uptake and retention of survivors to community-based exercise programs. Efforts to address survivor barriers to exercise, particularly those related to adverse effects of cancer, and programs that support survivors with a high-risk profile, are likely critical to the success of exercise programming implementation. Integrating oncologist and HCP exercise counselling and promotion into routine clinical care may prove valuable in increasing survivor exercise adoption and promoting long-term exercise behaviour change.

Table 2-1. Late and long-term effects of cancer treatments impacting exercise

Adverse Effect	Presentation	Common Tumor Types Affected	Common Causes	Exercise Considerations
Pain	Nociceptive: *e.g.*, aching, stabbing, cramping or throbbing Neuropathic: *e.g.*, allodynia, dysesthesias	Pancreas, bone, brain, lymphoma, lung, head and neck	Surgery to region Radiation Therapy Metastatic disease	Consideration of tissue integrity and tissue healing Timing of exercise with pain medications Low intensity exercise to start- monitor impact on pain
Fatigue	Unpredictable tiredness, unrelieved by rest or sleep and disproportionate to activity	All cancers	Radiation Therapy Chemotherapy (anemia)	Consider lower volumes and intensities of exercise during cancer treatment *i.e.* 60 minutes of low-moderate intensity exercise per week
Peripheral Neuropathy	Numbness, tingling and burning in fingers and toes	All cancers treated with a neurotoxic agent	Chemotherapy Biological Therapies	Higher risk of falls: avoid treadmill, uneven surfaces Avoid exercises with free weights
Dyspnea	Shortness of breath with exertion; uncomfortable breathing, inability to get enough air	Primary or metastatic lung cancer, head and neck	Surgery Chemotherapy (anemia) Radiation Therapy	Teach escape positions to use during exercise. Consider starting with resistance exercise program
Lymphedema	Swelling in limb or region from damage to local lymph node region	Breast, melanoma, gynecological cancers	Surgery: lymph node removal; Radiation Therapy to lymph nodes	Supervised resistance exercise program recommended as starting point Use of compression on limb during exercise
Myopathy	Weakness, exercise intolerance & fatigue Muscle pain/ tenderness	Brain/neurological Prostate cancer	Steroid-induced Hormone Therapy	Consider resistance exercise regimen with focus on strength training of proximal and extensor muscle groups
Bone effects	Osteopenia/ Osteoporosis Metastatic: osteolytic, osteoblastic lesions Pathological fracture	Osteosarcoma, Multiple Myeloma, Metastases to bone	Metastatic Disease Radiation Therapy to region Hormonal Therapy	Ensure adequate bone integrity prior to exercise testing and training Avoid rotation of spine, extremes of spinal flexion and extension
Cardiotoxicity	Arrhythmias Hypo/hypertension Symptoms of heart failure	Breast, Lymphoma, Testicular	Chemotherapy Radiation Therapy	Screening by cardio-oncology team Monitoring- vitals before, during, after exercise

Table 2-2. Suggested fitness tests for clinic and community

Fitness Testing	Exercise/Aerobic Capacity	Anthropometry	Flexibility	Muscular Strength	Muscular Endurance	Functional Mobility/ Balance
Definition	Ability to perform moderate-to-high intensity aerobic exercise for prolonged periods of time	Body composition refers the relative amounts of muscle, fat, and bone in the body [40]	Refers to the range of motion (ROM) through which a joint can move [40].	Maximal force that can be generated by a specific muscle or muscle group	Ability to sustain a muscle contraction or perform repeated contractions against a submaximal load	The integration and coordination of body systems: vestibular, visual, auditory and sensorimotor systems
Gold Standard Test(s)	Peak oxygen uptake ($VO2_{Peak}$), treadmill or bike protocol	Dual-energy X-ray Absorptiometry, Hydrodensitometry Plethysmography	Sit and reach; lumbar flexion & extension; shoulder and hip ROM measures	1-repetition maximum (1-RM)	Endurance bench or leg press test: (set weight or percentage of 1RM)	Sensory Organization Test (Neurocom)
Clinically Feasible Test(s)	Submaximal treadmill, cycle ergometer or shuttle test *e.g.* Modified Bruce, YMCA Bike Test; 20-meter shuttle run test	Height, weight, Body Mass Index (BMI) Waist and hip circumference	Goniometry measurement of shoulder and hip ROM	Submaximal: 8-10 repetition maximum (8-RM)	Push-up test and partial curl-up test	Berg Balance test: Falls risk Timed Up and Go Test (TUG)
Community Appropriate Test(s)	6 Minute Walk Test 400 Meter Walk Test	Height, weight, Body Mass Index (BMI)	Sit-and-reach test (hamstring/lower back flexibility)	Handgrip dynamometry	Plank Endurance test	Balance: 30 sec unipedal stance (Eyes open) Sit-to-Stand Test (30 seconds)

Table 2-3. Exercise Model of Care

Supervised Clinic-based Exercise	Supported Community-based Exercise	Self-directed Exercise
Status: high risk survivors -Moderate to severe adverse effects due to cancer, advanced cancers or associated significant co-morbid disease complicating ability to exercise	**Status: moderate risk survivors** - Mild to moderate adverse effects due to cancer -Previously sedentary profile	**Status: low risk survivors** - No or mild impairments, medically approved for unrestricted exercise, previously or currently physically active
Program Features: Supervised exercise setting; therapeutic exercise focus; monitoring vital signs and symptoms	**Program Features:** Supported community-based exercise in group format; modification of programming to address cancer-specific effects	**Program Features:** Provision of resources to support exercise; fitness testing to inform programming and progression over time
Team: Exercise physiologist and physical therapist experienced in cancer **Support:** Oncology medical and supportive care team for consult as needed	**Team:** Exercise specialist with cancer specific training **Support:** Exercise physiologist and physical therapist for adverse effects due to cancer	**Support:** Exercise specialist with cancer specific training for consult and fitness testing

Table 2-4. Potential Contraindications to Exercise Testing and Training

High Risk Situation/ Factor	**Potential Contraindication to exercise testing and training**

Factors related to cancer treatment	• Surgery: high risk period first 7-10 days following surgery
	• Radiation Therapy: acute skin or tissue reaction
	• Chemotherapy:
	  • Platelets < 50,000
	  • White blood cells < 3,000
	  • Hemoglobin < 10g/dl

Musculoskeletal	• Bone, back or neck pain of recent origin • Unusual muscular weakness • Severe cachexia • Unusual / extreme fatigue
Systemic	• Acute infections • Febrile illness: fever > 100° F (38° Celsius) • General malaise
Gastrointestinal	• Severe nausea • Vomiting or diarrhea within previous 24 to 36 hours • Dehydration • Poor nutrition: inadequate fluid and/or food intake
Cardiovascular	• Ejection fraction < 45% • Chest pain • Resting pulse > 100 b/min or < 50 b/min • Resting blood pressure > 160 mm Hg systolic and > 95 mm Hg diastolic • Resting blood pressure < 85 mm Hg systolic • Irregular pulse • SOBOE, swelling of ankles and
Pulmonary	• Severe dyspnea • Cough, wheezing • Chest pain increased by deep breath
Neurological	• Significant decline in cognitive status • Disorientation • Blurred vision • Ataxia • Seizures

Figure 2-1. Goals of the Exercise Program

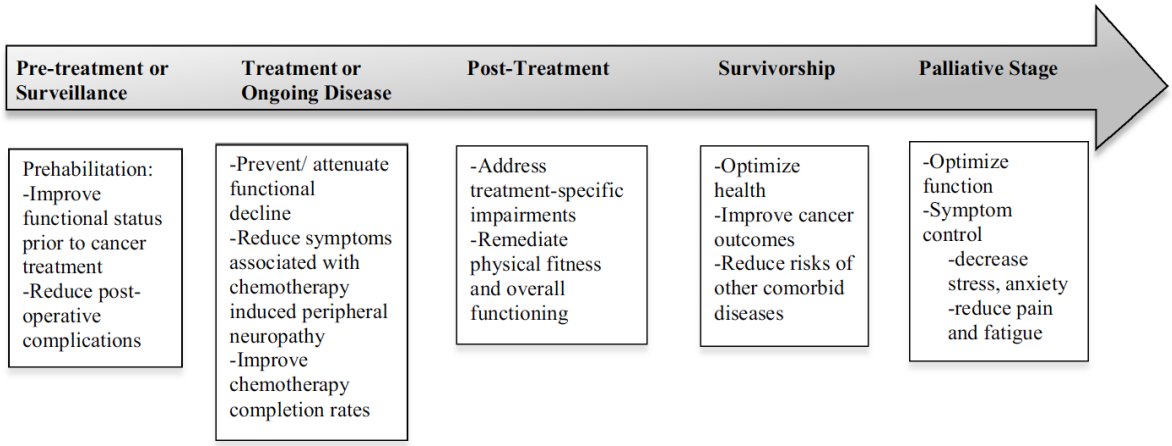
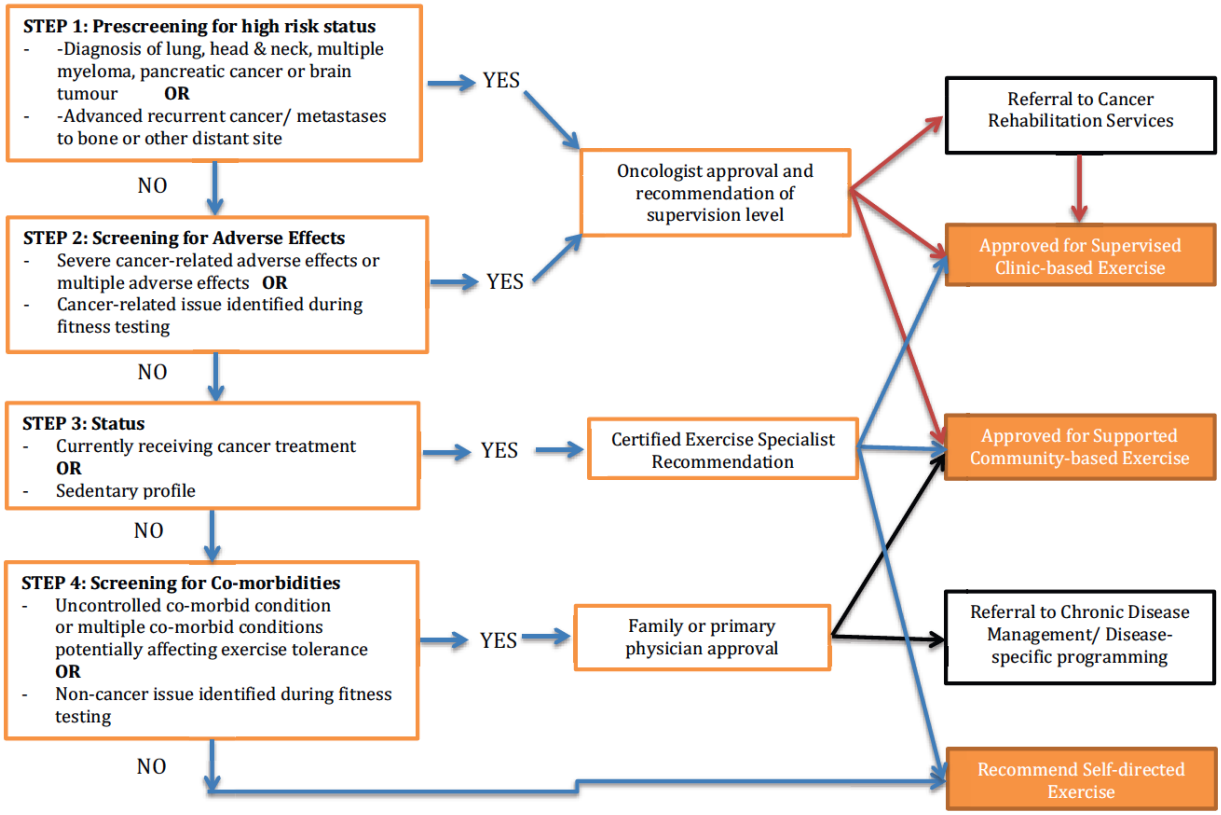


Figure 2-2. Decision Tree Based on Screening



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Chapter 3

A Practical Approach to Informing a Community-Based Exercise Study

Suderman K, Dolgoy N, Yurick J, et al. A Practical Approach to Using Integrated Knowledge Translation to Inform a Community-Based Exercise Study. *Int J Environ Res Public Health*. 2020;17(11):3911. Published 2020 Jun 1. doi:10.3390/ijerph17113911

3.1. Abstract

Background. Our aim was to understand cancer survivor needs prior to, and following the Alberta Cancer Exercise (ACE) pilot randomized trial as a means to inform implementation of a province-wide cancer-specific, community-based exercise program. **Methods.** Questionnaires and semi-structured stakeholder engagement sessions were conducted with cancer survivors to explore preferences, barriers and facilitators/benefits at two timepoints: (1) pre-ACE: prior to initiation of the ACE pilot trial (n = 13 survivors and n = 5 caregivers); and (2) post-ACE: following participation in the ACE pilot trial (n = 20 survivors). Descriptive statistics were used to summarize quantitative data from questionnaires. Stakeholder engagement data were analyzed using a framework analysis approach. Emergent themes were then mapped to actionable outcomes. **Results.** Pre-ACE, survivors indicated a preference for exercise programs that were (1) supervised by exercise specialists knowledgeable about cancer, (2) included support from other health care providers, (3) were held in community locations that were easily accessible. Post-ACE, participants identified (1) a lack of exercise counselling from health care providers, (2) the need for earlier introduction of exercise in the care pathway, and (3) supported referral to exercise programming. **Conclusions.** An integrated knowledge translation approach identified actionable outcomes to address survivor needs related to exercise in clinical cancer and community-based contexts.

Keywords: exercise; physical therapy; cancer; knowledge translation; implementation; barriers

Chapter 3

A Practical Approach to Informing a Community-Based Exercise Study

3.2. Introduction

3.2.1. Cancer and Exercise Evidence

There is a growing population of individuals surviving cancer. In Canada, over the past 20 years, the predicted five-year age-standardized net survival rate has increased by 8%, with 63% of all cancer patients surviving at least five years post-diagnosis (1). The term cancer survivor encompasses the entire continuum of cancer care, and is defined as any person diagnosed with cancer from the initial point of diagnosis, until death (2). Advancements in treatments, screening and technologies have led to improved survival rates, and resulted in a growing population of cancer survivors living with cancer-related treatment long-term and late effects, including decreased physical and psychological functioning and overall quality of life (3). Exercise is an intervention that has shown benefit in addressing the supportive care needs of this growing survivor population, with strong evidence establishing the positive effects of exercise on symptom management, physical and psychosocial well-being and health-related quality of life (4). Moreover, current evidence suggests a positive association between physical activity and cancer outcomes of recurrence, cancer-specific mortality and all-cause mortality, predominately in prostate, breast and colon cancer (4–6).

Despite the known benefits of exercise, the majority of survivors do not meet public health guidelines for physical activity, with survivors engaging in significantly less physical activity compared to those without a cancer diagnosis (7,8). Moreover, only 10% of cancer survivors were found to be physically active during treatment and only 20%–30% active post-treatment and into survivorship (9). The aging process and existing comorbid diseases present additional challenges to physical activity, with older cancer survivors less likely to meet physical activity guidelines than their younger counterparts (10). In more recent years, there has been a global initiative to encourage health care providers (HCPs) to include physical activity counselling and exercise referral into the care plans of patients with chronic disease (11). To date, however, there is limited evidence supporting implementation of feasible, effective and sustainable exercise counselling and referral practices, and program delivery within the

clinical oncology setting. Research into the preferences, barriers and facilitators of exercise from the survivors' perspective has revealed complex areas of need that are only partly addressed by current exercise guidelines (12–15).

3.2.2. Research Context of the Clinical Team

The Alberta Cancer Exercise (ACE) trial was a multi-centre randomized controlled pilot trial, performed to examine the feasibility and preliminary effectiveness of a cancer-specific community-based exercise program (16). The ACE trial (N = 80) was conducted from April 2015 to November 2017, and had two sites, Edmonton (n = 46) and Calgary (n = 34) in Alberta, Canada. The ACE pilot trial included an integrated knowledge translation (iKT) plan and series of iKT substudies aimed to identify the needs of key informants and address specific gaps related to our local provincial context. The ACE iKT strategy involved drawing on the perspectives of urban and rural cancer survivors and caregivers to inform the design of the pilot trial, and feedback from ACE pilot trial participants after study completion. The purpose of this paper is to share the findings related to survivor reported exercise preferences, barriers, and facilitators before and after participation in the ACE pilot trial, and to describe how the findings informed the design of the current five-year ACE Hybrid-Effectiveness Implementation Study (17).

3.3. Materials and Methods

3.3.1. Study Design

This study utilized a multi-method iKT approach to better understand survivors' preferences, barriers and facilitators to implementation of a province-wide community-based exercise program. The Knowledge-To-Action (KTA) model was used to inform the implementation process for the study (18), and aligned with cycle phases associated with (1) adapting knowledge to the local context and (2) assessing barriers and facilitators to cancer-specific exercise programming in our local context. A multi-method design including both quantitative and qualitative data collection, was used to enable a richer description of possible determinants that may influence successful implementation of the program (19). The study consisted of pre- and post-ACE questionnaires and stakeholder engagement group (SEG) sessions consisting of cancer survivors and, in the pre-ACE SEGs, caregivers. To achieve data

saturation, we aimed for a sample size of 10–15 cancer survivors at each time point, with 5–8 participants per session.

The questionnaires included collection of medical and demographic information, and current exercise behavior and exercise preferences. At both time points, the questionnaires were anonymous to encourage accurate reporting of survivor opinions towards exercise. The post-ACE questionnaire was optional, and included additional questions related to ACE pilot program satisfaction (20). The questionnaires were used to provide numeric and descriptive data for the purposes of analyses. SEGs were conducted as a formative evaluation to inform program design and improvement (21), and followed a semi-structured interview guide developed by the clinical research team. The SEGs were used to better understand survivors' needs related to implementing a cancer-specific community-based exercise program. Pre- and post-SEGs were conducted over multiple groups until data saturation was achieved. Each SEG was led by a trained facilitator, along with experts in cancer exercise physiology and physical therapy. Ethics approval for the study was granted by the Health Research Ethics Board of Alberta: Cancer Committee (HREBA.CC-14-0153). For consent forms refer to Appendix 4. For ethics approval refer to Appendix 5.

3.3.2. Data Collection

Cancer survivors and caregivers were recruited for the pre-ACE SEG using a convenience sample of urban and rural survivors and caregivers from the Cross Cancer Institute, identified by staff from physical therapy and/or radiation therapy. Survivors and caregivers taking part in the pre-ACE SEGs and anonymous questionnaires were not participants in the ACE pilot randomized trial. Post-ACE SEGs involved a convenience sample of ACE pilot trial participants. Upon completion of the ACE pilot trial, participants were invited to participate in SEG sessions and to complete an additional anonymous satisfaction questionnaire. To view the anonymous satisfaction questionnaire, refer to Appendix 6. To view SEG session questions, refer to Appendix 7. Caregivers were not included in the post-ACE SEGs, due to high ACE pilot trial participant interest in the SEGs. Survivor input was collected at two time points: (1) prior to ACE pilot study initiation, July 2013 (pre-ACE); (2) post-ACE pilot (Edmonton site), May 2016 (post-intervention). Informed consent was obtained from

participants at each time point. Each SEG session consisted of 5–8 participants, and lasted approximately 90 min. The SEG sessions involved discussion on the topics of the preferences, barriers and benefits/facilitators to programming, with questions differing slightly at the two time points. The SEG sessions started with participants providing individual written responses for brainstorming activities, followed by small group discussions. Small group membership was established a priori to ensure representation in each group of males and females, different tumor types and geographical locations, and in the Pre-ACE SEGs, involvement of at least one caregiver in each group. Additional probing questions were supplied when participants perceived questions to be unclear, or further information was needed. Independent observers were used to transcribe the discussion. Given the primary implementation focus, less in-depth analyses were planned, thus, independent observers were used to take abridged transcripts of notes using a laptop during the SEG sessions (21). The pre-ACE SEG involved three sessions to reach saturation, while the post-ACE SEGs had four sessions until saturation was achieved. Questionnaires were completed at the conclusion of each SEG. The questionnaires for the post-ACE SEG participants were optional, given the high study burden of questionnaires associated with the ACE pilot.

3.4. Data Analysis

Data from the SEGs were analyzed using framework analysis, a form of content analysis for identifying commonalities and differences in qualitative data, with a defining feature being structured matrix outputs involving rows and columns of summarized data (22). Framework analysis originated in large scale policy research, and has become increasingly popular in multi-disciplinary medical and health applied policy research to meet specific information needs with actionable outcomes [23]. Framework analysis is not aligned with one epistemological or theoretical approach, but can be adapted to various qualitative approaches that aim to generate themes, and offers valuable insight to inform implementation strategies (23).

After each SEG was completed, abridged transcriptions and written responses by participants were collected. Two researchers independently analyzed the abridged transcriptions and written materials from participants pre-ACE (CS, MM), and post-ACE (KS, MM). After initial coding, researchers collaborated to amend and refine codes, and develop

mapping framework tables in relation to barriers, facilitators and preferences towards exercise. After the data were coded, codes were mapped to respective frameworks and researchers reviewed the codes to identify prevalent themes. The themes were then reviewed, defined and categorized. This process occurred after each SEG session, until data saturation was achieved. Identified themes from the pre-ACE SEG informed the design of the ACE pilot randomized trial, and themes from both ACE SEG sessions informed the design of the current five-year Alberta Cancer Exercise Hybrid Effectiveness-Implementation Study (16,17).

Data from the pre- and post-questionnaires included both continuous and categorical variables. Basic descriptive statistics including frequencies, percentages and counts were calculated. Linking qualitative and quantitative data analysis involved building on quantitative descriptive statistical patterns through qualitative thematic findings that revealed the perspective and thought processes of participants (23).

3.5. Results

3.5.1. Description of Participants

A total of N = 33 distinct survivors and N = 5 caregivers took part in the study. Thirteen cancer survivors and five caregivers participated in pre-ACE SEG; and twenty ACE pilot participants engaged in post-intervention SEG groups and eighteen completed the post-ACE questionnaire. Seventeen ACE trial participants completed an anonymous optional post-study satisfaction questionnaire. The majority of participants in attendance at both SEGs were breast cancer survivors, with 54% pre-ACE, and 60% post-ACE. The second most common tumor type at both the pre- and post-ACE SEGs was head and neck cancer (23%, 20%), followed by gastrointestinal (16%, 10%), and lymphoma (8%, 5%). The most commonly reported age of participants identified in the category of 55–69 years of age (39%). The majority of survivors were female, with 69% and 85% pre- and post-ACE, respectively. Both pre-ACE and post-ACE SEGs consisted primarily of survivors who had received combined treatment including surgery, chemotherapy and radiation, 54% and 45%, respectively, with the second most common combined treatments pre-ACE involving surgery and chemotherapy (15%) and surgery radiation (15%), and post-ACE involving combined surgery and radiation (35%) (Table 1).

3.5.2. Pre-ACE Questionnaire Findings

Eighty-five percent of survivors completing the pre-ACE questionnaire indicated the need for exercise counselling in the clinical setting, with 77% reporting that exercise had not been discussed at any point during their cancer treatment or follow-up visits. The preferred location for exercise counselling to take place was at the cancer centre (54%), with delivery by multiple HCPs, including a strong preference for counselling from an exercise professional (62%). All participants preferred face-to-face counselling (77%) or written materials (15%), with delivery of counselling at multiple time points along the cancer treatment trajectory (69%) (Table 2).

3.5.3. Post-ACE Questionnaire Findings

Overall, participant satisfaction with the ACE pilot trial was 91%. From the post-study satisfaction questionnaire, only 7% of participants indicated that their oncologist or HCP had referred them to the ACE trial, with 93% indicating self-referral. Participants reported symptoms as somewhat improved to very much improved regarding physical functioning (88%), muscle strength (82%), overall quality of life (76%), fatigue (65%), energy levels (65%), activities of daily living (59%) and recovery from treatment (53%).

From the post-ACE questionnaire, a majority of participants (56%) preferred the ACE pilot trial format of two exercise sessions per week for a 60 min duration, with 94% preferring moderate-intensity exercise. Eighty-two percent indicated a preference for a combination of supervised and unsupervised exercise, with 77% preferring to exercise with other cancer survivors and 100% preferring a combination of aerobic and resistance exercise. Of note, 83% preferred to continue exercising at the location of the pilot trial and 76% perceived little to no difficulty in continuing to exercise independently post-intervention. The most frequently self-reported barriers to exercise (reported as often to very often) were muscle weakness, reported by 28% of participants, followed by symptoms of fatigue (17%), pain (11%), lack of enjoyment (11%) and weather (11%) (Table 3).

3.6. Stakeholder Engagement Group Findings

3.6.1. Exercise Preferences

At both pre-ACE and post-ACE SEGs, participants consistently indicated a preference for supervised and supported exercise programming that was accessible, affordable, and variable. All survivors indicated a preference for exercise programming that (1) was supervised by exercise specialists knowledgeable about cancer, (2) included support from other HCPs (e.g., physical therapy), and (3) had a variety of exercise delivery options, and (4) was held in community-based locations that were easily accessible.

Post-ACE SEG participants indicated a unique preference for tumor-specific programming to better address impairments and for the option to include caregivers in exercise programming. Post-ACE SEG participants also expressed the need for (1) better HCPs awareness and promotion of the exercise programming; (2) exercise counselling to occur earlier in the cancer treatment time period; and (3) formal referral to cancer-specific exercise programming.

Post-ACE SEG participants also identified a new theme of communication. Specifically, participants identified a need for multi-directional communication between survivors, health care professionals (HCPs) and exercise specialists to integrate tailored exercise through cancer treatment and survivorship.

> *"I may not have wanted or been able to take part in exercise when I was on treatment, but I would have liked to have known about the program and the option to take part later".*
>
> (ACE trial participant with lymphoma)

3.6.2. Barriers towards Exercise

Time was consistently identified as the main barrier to exercise across SEGs at both time points. Pre-ACE, participants identified risk of injury and lack of familiarity with use of exercise equipment and machines as a barrier to exercise. Unique barriers identified post-ACE included: (1) concerns over potential exposure to bacteria and viruses in a public fitness facility when immunocompromised; (2) return to work scheduling and ongoing medical appointments conflicting with ability to attend exercise sessions. Accessibility issues to the ACE pilot trial

included the downtown location of the community fitness centre due to parking fees, traffic, and seasonal winter road conditions.

> *"When I was on chemotherapy and my counts were low, I did not attend class".* (ACE trial participant with breast cancer)

3.6.3. Facilitators and Benefits of Exercise

Participant feedback at both pre- and post-ACE SEG time periods indicated benefits for physical fitness, wellness autonomy (control over one's health), increased knowledge regarding safe exercise practices, understanding cancer related physical limitations and motivation towards exercise.

> *"I knew it would be good for me, but I didn't think I would look forward to going or enjoy the sessions".* (ACE trial participant with breast cancer)

Post-ACE SEG participants specifically identified exercise programming that addressed tumor specific physical impairments (breast, head and neck and neurological tumors) as a facilitator towards exercise. Other specific post-ACE exercise facilitators included regular feedback from fitness assessments, and HCP support from an on-site physical therapist. A unique post-ACE benefit was exercise programming that was adapted/modified for cancer related symptoms of lymphedema, chemotherapy induced peripheral neuropathy, and shortness of breath. Additional unique identified benefits post-intervention included: (1) a needed "wake-up call" on low fitness levels; (2) the benefit of support and mentorship of fellow cancer survivor peers; and (3) increased confidence with use of resistance exercises and fitness equipment.

> *"The program has given me the confidence to re-enter society".* (ACE trial participant with head and neck cancer)

Exercise preferences, barriers and facilitators/benefits from both timepoints were synthesized to inform themes. Three emergent themes were identified related to the cancer care setting and four themes related to the community context (Figure 2). Findings were mapped to nine potential actionable items (Table 4).

3.7. Discussion

The purpose of this study was to utilize a multi-method iKT approach to identify cancer

survivors' exercise preferences, barriers and facilitators to inform implementation of a cancer-specific community-based exercise program. The central premise of iKT is that involvement of knowledge users, in this case cancer survivors, throughout the research process leads to research and outputs that are more applicable and helpful to the knowledge users (survivors) (24). As a formal methodological approach does not yet exist for iKT, we chose a multi-method approach that allowed us to efficiently identify key actionable strategies in a time-sensitive project. By using this multi-methods approach, we were able to provide more depth to the participant perspective, allowing a comprehensive understanding of local exercise preferences, barriers and facilitators (23). To our knowledge, this is the first study to explore using a multi-method iKT approach to inform future implementation of cancer-specific exercise programming in a community-based setting.

A primary finding of this study was the identified gap regarding the lack of exercise counselling and referral provided to survivors in the cancer clinical setting. A new theme of communication, encompassing survivors, HCPs and exercise specialists, was identified by participants as a prevalent patient need. Specifically, participants identified a preference and need for earlier introduction and integration of exercise counselling into care pathways, including referral to appropriate cancer-specific exercise programming during cancer treatment and into survivorship. The findings from the pre-ACE questionnaire suggest that few survivors received exercise counselling from their HCPs, and the post-ACE questionnaire reflected the gap in terms of exercise referral, with only 7% indicating referral from HCPs. The reported lack of exercise counselling and referral is not unique to our site. Another Canadian study reported that less than 20% of survivors had received education on the importance of exercise from any HCP at any point in the course of their cancer treatment (25). Further, 83% and 88% of patients reported not receiving any exercise counselling from their oncologist and primary cancer nurse, respectively. Additional studies suggest HCP exercise counselling rates are low, with less than 25% of oncology physicians actually referring survivors to exercise programming (26,27). These findings are not surprising given the lack of availability of cancer-specific exercise programming.

This study brings forward a unique comparison between survivors' perceptions of exercise programming (preferences, barriers and facilitators), prior to taking part in a formal community-based exercise program, to perceptions of survivors after having participated in the program. It is interesting to note that pre-ACE SEG participants reported concerns of increased risk of injury and lack of familiarity with exercise equipment as barriers to exercise, whereas post-ACE, SEG participants did not. In fact, post-ACE participants identified facilitators of ACE as a program that (1) was safe, (2) offered variability in exercise programming and (3) was led by an exercise specialist knowledgeable in cancer. Consistent with the literature, the main barrier of time, along with disease and treatment symptoms, and accessibility were reported by SEG participants at both pre- and post-ACE SEG time points (28,29).

Post-ACE benefits included maintenance or reduction in symptoms as shown in the post-study questionnaire findings, and motivation stemming from (1) survivor-peers, (2) an onsite knowledgeable exercise specialist and a physical therapist, and (3) baseline and post-study fitness assessments. Access to a physical therapist was found beneficial in tailoring exercise to address cancer therapeutic benefits (e.g., managing cancer-related fatigue, lymphedema, chemotherapy induced peripheral neuropathy) and other existing musculoskeletal concerns (30). There is a growing discussion in the literature regarding a lack of education connecting exercise benefits specifically to symptom management and survival benefits, with survivors receiving only general education, in turn leading to poor exercise adherence partly from not fully understanding the benefits (11).

Recent evidence, however, suggests that increased effort be placed on addressing barriers rather than emphasizing exercise benefits (31). From the survivor perspective, the complexity of barriers to exercise may outweigh any potential benefits. New barriers identified by this study included concerns over exposure to germs in a public facility (for those on active treatment), and accessibility issues due to the downtown program location, and associated parking costs. Thus, to improve exercise uptake, consideration should be given to address specific barriers relevant to the survivor and their phase in the cancer care continuum (pre-treatment, treatment, post-treatment, survivorship, remission, palliative), and efforts are needed to enhance exercise counselling practice and uptake (32).

Survivor exercise preferences have been discussed in the literature as wide ranging and diverse (33). Commonly cited preferences in the literature of moderate-intensity exercise and flexible programming (e.g., including home-based options) were also reflected in our post-ACE questionnaire, with 94% preferring moderate-intensity exercise and 82% preferring a combination of supervised and unsupervised exercise (33).

Of note is research emerging from the perspective of the HCP toward exercise counselling and referral for cancer survivors. The diagnosis of cancer itself represents a 'teachable moment' to introduce health behavior change (34). However, HCP exercise recommendations have been found to be general, rare and inconsistent, despite survivors expressing the need for more exercise counselling in the clinical setting (35). A survey of 120 Canadian oncologists found that 80% were unaware of any exercise guidelines for cancer survivors, and had a lack of knowledge on screening and identification of appropriate survivors for exercise referral (36). HCPs also cite a primary barrier of time in clinic, along with a lack of role definition in the responsibility for exercise education, uncertainty on optimal timing to initiate such a discussion, and perceiving a negative attitude towards exercise from survivors (35,37). In combination with our findings, a gap in exercise counselling of cancer survivors appears to exist both from the perspective of the survivors and HCPs. It is important to note the significant influence that HCPs, especially oncologists, can have on patients' exercise participation by giving effective, timely exercise advice and education (26,38). Further work is needed to bridge the exercise knowledge gap for both survivors and HCPs.

3.7.1. Limitations

A primary limitation of the present iKT study was the small convenience sample, with results limited in generalizability to primarily the breast cancer tumor group and the single setting; however, we reached data saturation, suggesting that our sample was adequate for our knowledge translation purposes. While there was less representation from other tumor groups, this was not surprising given that 50% of ACE trial participants (n = 40) were breast cancer survivors, and evidence related to exercise to date is largely based on data collected in the breast cancer population (4). The post-ACE questionnaire was optional for participants, limiting quantitative findings and overall generalizability. Caregivers were also not included in the post-

ACE SEG sessions, limiting our findings to participants alone. For future research, consideration should be given to sampling of other common tumor types such as prostate, colon and lung. The SEG sessions were only held at the Edmonton location, as similar work with breast and prostate cancer groups had been completed or was in process at the Calgary site (39,40). A further limitation was that the SEG sessions were not audio recorded. Audio recordings would have allowed us to ensure that important details were not missed; however, sessions included written feedback from survivors and independent observers were used to record the small group discussions. The post-ACE satisfaction questionnaire was anonymous; thus, we were limited in our ability to connect findings to participant characteristics of tumor type, gender, and age. This anonymity was to ensure that participants were comfortable in sharing their true experience and providing meaningful feedback.

3.8. Conclusions

Utilizing an integrated knowledge translation approach helped us to inform acceptable ACE program implementation and optimize survivor program satisfaction. A supported exercise program involving both a cancer-specific trained exercise specialist and physiotherapist may prove beneficial for addressing both physical fitness and cancer-related impairments simultaneously. The findings of this study were used to inform the ACE Hybrid Effectiveness-Implementation Study, with key actionable initiatives such as ensuring easily accessible community locations. To address concerns with exposure to bacteria and viruses in a public facility, potential actionable options could include supported home-based exercise, flexible programming options and/or entry into community-based exercise programs in the post-treatment time period. Given the patient-identified gap in communication about exercise for survivors, further research exploring the perspective of HCPs on exercise counselling and referral practices is likely the next critical step to inform integration of exercise into cancer care.

Table 3-1. Baseline Demographic and Medical Data

Participant Characteristics	Pre-Intervention	Post-Intervention
	(*n* = 13; *n* = 5), No. (%)	(*n* = 20), No. (%)
Sex		
Male survivor	4 (31)	3 (15)
Caregiver	1	
Female survivor	9 (69)	17 (85)
Caregiver	4	
Age		
26–39	2 (15)	1 (5)
40–54	4 (31)	6 (30)
55–69	6 (46)	7 (35)
>70	1 (8)	6 (30)
Tumor Type		
Breast	7 (54)	12 (60)
Caregiver	1	
Head and neck	3 (23)	4 (20)
Caregiver	1	
Lymphoma	1 (8)	1 (5)
Gastrointestinal	2 (15)	2 (10)
Caregiver	1	
Prostate	-	1 (5)
Other	1	-
Caregiver multiple myeloma		
Cancer Treatment		
Surgery, radiation, chemotherapy	7 (54)	9 (45)
Surgery, radiation	2 (15)	7 (35)
Surgery, chemotherapy	2 (15)	2 (10)
Surgery alone	1(8)	1(5)
Chemotherapy alone	1(8)	1(5)
Location of Residence		
Edmonton (urban)	12 (67)	16 (80)
Within 100 km of Edmonton	5 (28)	4 (20)
Rural > 100 kms	1(5)	-

Table 3-2. Pre-ACE Exercise Preferences, Barriers and Facilitators/ Benefits

Preferences Related to Exercise Programming: *n* = 13 Survivors and *n* = 5 Caregivers			
Where would you prefer to exercise?	Rank: 1. Community based, 2. Home based		
What type of exercise would you like to do?	Rank: 1. Aerobic, 2. Walking, 3. Resistance exercise		
How many times a week would you like to exercise?	Rank: 1. Two times per week; 2. Three times per week		
How long would you like each session to last?	Rank: 1. One hour per session		
What intensity of exercise would you prefer?	Rank: 1. Mild to moderate, 2. Moderate		
Who would you prefer to exercise with?	Rank: 1. Other cancer survivors, 2. Partner/support person		
Preferences Related to Exercise Counseling: *n* = 13 (%)			
Did you receive counseling about exercise at any point from diagnosis to treatment completion?	Not discussed: 10 (77)	Survivor-initiated discussion: 0 (0)	Oncologist-initiated discussion: 3 (23)
Would you have preferred to be counseled about exercise?	Yes: 11 (85)	Maybe: 0 (0)	No: 2 (15)
When would you prefer this counseling?	Before/during treatment: 2 (15)	After treatment: 2 (15)	Multiple time points: 9 (69)
Where would you prefer this counseling to happen?	Cancer centre: 7 (54)	Community fitness centre: 2 (15)	Any location: 4 (31)
Who should provide the counseling?	Exercise specialist: 8 (62)	Health care provider: 3 (23)	Other cancer survivor: 2 (15)
What would be your preferred format of counseling?	Face to face: 10 (77)	Written materials: 2 (15)	Other: telephone/internet: 1 (1)
Barriers to Exercise (*n* = 18)	**Facilitators (*n* = 18)**	**Benefits (*n* = 18)**	
Lack of time Instructors unfamiliar with cancer Injury risk Intimidation/insecurity in public facility Feeling unwell Symptoms, e.g., fatigue Financial: cost of program Lack of personalized exercise programming	Instructor who is knowledgeable Instructor who is fun Convenient location Free parking, public transit access Support of other health care providers: nurse, physical therapist	Increases fitness Better health and overall survival Improved mobility Emotional support Better mental health Confidence in exercise	

Table 3-3. Post-ACE Preferences, Barriers and Facilitators/Benefits and Satisfaction Questionnaire

Top Preferences Related to Exercise Programming (n = 18; Counts When More Than One Option Allowed)			
Location of program (n = 21)	Community fitness centre: 12 (57%); home/outdoors: 7 (33%)		
Type of exercise (n = 22)	Combined aerobic and resistance: 18 (82%)		
Frequency and Duration (n = 22)	2× or 3× per week: 16 (72%)		
Duration (n = 22)	50–60 min sessions: 16 (72%)		
Intensity (n = 22)	Moderate intensity (not exhausting, light perspiration): 17 (77%)		
Who would you prefer to exercise with? (n = 24)	Other cancer patients: 13 (54%), spouse/friend: 9 (38%)		
Barriers to Exercise Participation (n = 18)			
	Never	Rarely–Occasionally	Often–Very Often
Fatigue	4 (22)	11 (61)	3 (17)
Lack of enjoyment	11 (61)	5 (28)	2 (11)
Lack of self-discipline	6 (33)	11 (61)	1 (6)
Pain	7 (39)	9 (50)	2 (11)
Weather	12 (67)	4 (22)	2 (11)
Exercise is boring	14 (78)	4 (22)	-
Muscle weakness	6 (33)	7 (39)	5 (28)
Lack of time	12 (67)	5 (28)	1 (6)
Lack of confidence in exercise abilities	14 (78)	4 (22)	-
Facilitators/Benefits of Exercise program on (n = 17)			
	Very Much—Slightly Worse	No Change—Slightly Improved	Somewhat—Very Much Approved
Physical functioning	-	2 (12)	15 (88)
Muscle strength	-	3 (18)	14 (82)
Overall quality of life	-	4 (24)	13 (76)
Fatigue	-	6 (35)	11 (65)
Energy level	-	6 (35)	11 (65)
Ability to perform ADL	-	7 (41)	10 (59)
Treatment recovery	-	8 (47)	9 (53)
ACE Exercise Program Satisfaction (n = 17)			
	Not at All	A Little Bit/Somewhat	Quite a Bit/Very Much
How beneficial was the program?	-	-	17 (100)
How enjoyable was the program?	-	2 (12)	15 (88)
How supportive were your friends and family?	-	2 (12)	15 (88)
How motivated were you (to?) participate?	-	3 (18)	14 (82)
How difficult was it for you to participate?	6 (35)	11 (65)	-
How difficult will it be for you to continue to exercise?	9 (53)	7 (41)	1 (6)

Table 3-4. Translation of Themes to Actionable Items

CONTEXT	THEME	ACTIONABLE ITEMS
Cancer Care Setting	Need for exercise counseling from health care provider	- Determine health care provider preferences/barriers/facilitators towards exercise counseling and referral of cancer survivors to community-based exercise. - Incorporation of exercise counseling and referral by health care providers into cancer care pathway - Facilitate referral pathway from cancer care setting to community facility (e.g., safety screening, medical approval as needed, consent for sharing of personal information)
	Need for earlier introduction of exercise	
	Need for supported referral to cancer-specific exercise programming	
Community-Based Setting	Improved accessibility (e.g., locations)	- Consideration of accessible locations across provincial regions: expand community fitness partnerships - Development of ongoing relationship with community facilities
	Ease of participation (e.g., varied program schedule)	Where possible offer varied scheduling of cancer-specific exercise programming (e.g., morning/afternoon/evening options)
	Consideration of exposures relating to community environment	- Consideration of non-public facilities, home-based and/or flexible programming - Consideration of entry to community programming post-cancer treatment
	Tumor-specific programming options	Development of subset programming to meet specific needs (e.g., breast, head and neck, neurological tumor-specific exercise programming)

Table 3-5. Semi-Structured Stakeholder Engagement Group Question Guide

Pre-ACE	Post-ACE
If Alberta's Cancer Control were to develop a provincial cancer-specific exercise program, what should it look like?	If Alberta's Cancer Control were to develop a provincial cancer-specific exercise program, what should it look like?
What do you think the benefits of participating in an exercise program would be?	What were the benefits of participating in the ACE pilot exercise program? Probe: Where there any benefits that you did not anticipate?
What do you feel are the main issues that might prevent you from taking part in an exercise program?	What do you feel are the main issues or barriers that might prevent you or others from taking part in the ACE program in the future? Probe: What could be done to overcome these issues? Probe: What were the negative aspects or drawbacks of participating in ACE?
If you were to participate in an exercise program, what types of exercise would you be most interested in doing?	If you were to participate in the ACE program again, what types of exercises would you be most interested in doing?
What aspects of an exercise program would be required for you to participate to comply with the program?	What components of the ACE program would motivate you to want to attend?
What elements would you like included in an exercise program that would motivate you to want to attend?	What aspects of the ACE program would be important to help you continue with an exercise program over the long-term? The grant funding will provide support to the ACE program for 4 years this includes resources to facilitate recruitment to the program, screening, exercise testing, referral, and exercise programming. How do you think the program should be funded over the long-term (beyond the grant funding period)?

Figure 3-1. Study Schema

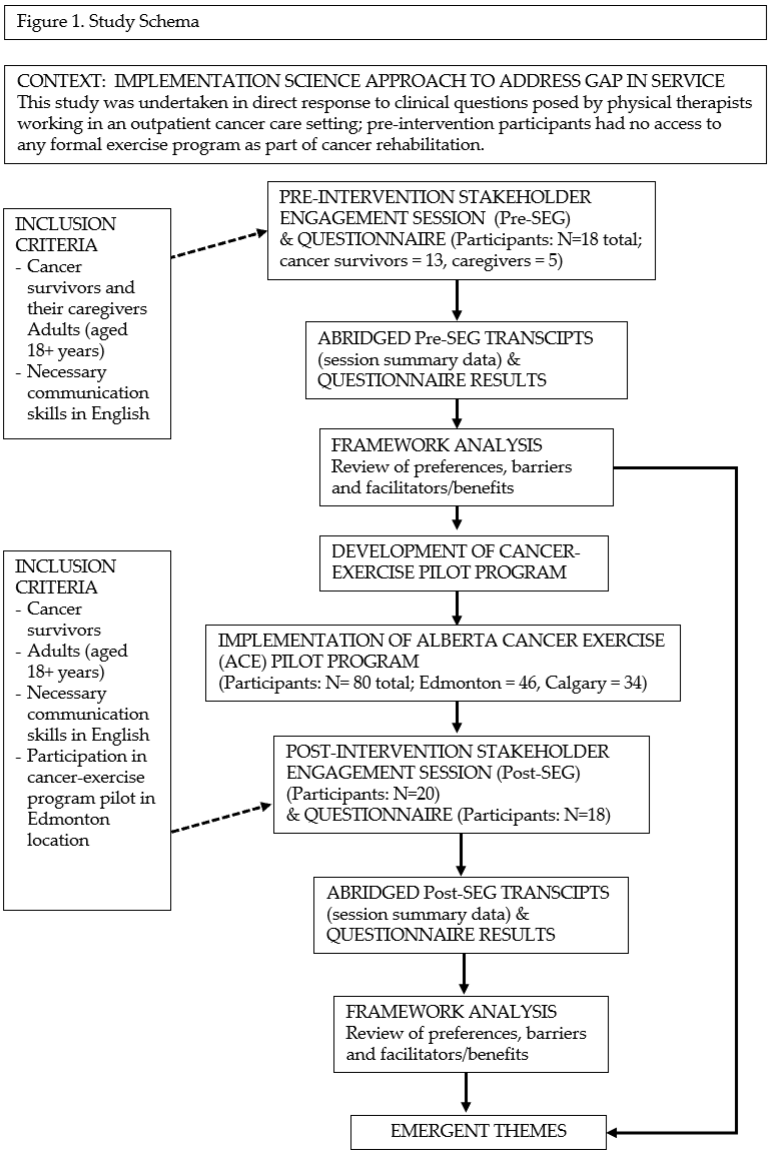
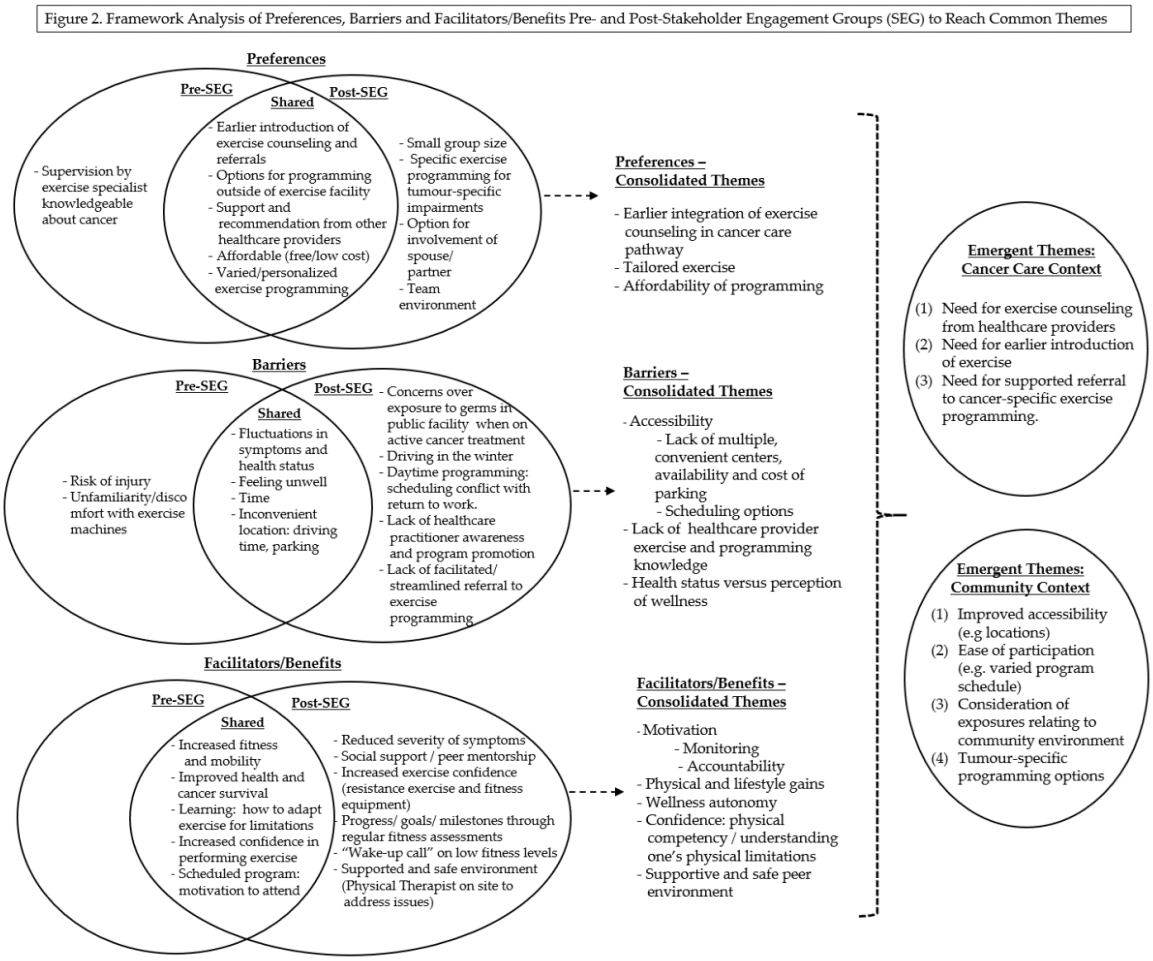


Figure 3-2. Framework Analysis of Preferences, Barrier and Facilitators/Benefits Pre- and Post-Stakeholder Engagement Groups (SEG) to Reach Common Themes



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Chapter 4

Virtual or In-Person:

A Mixed Methods Survey to Determine Exercise Programming Preferences During COVID-19

Suderman K, Skene T, Sellar C, Dolgoy N, Pituskin E, Joy AA, Culos-Reed SN, McNeely ML. Virtual or In-Person: A mixed methods survey to determine exercise programming preferences during COVID-19. *Current Oncology*. 2022; 29(10):6735-6748. doi:10.3390/curroncol29100529

4.1. Abstract

Background. A survey was conducted to identify barriers and facilitators to engaging in virtual and in-person cancer-specific exercise during Coronavirus Disease 19 (COVID-19). **Methods.** A theory-informed, multi-method, cross-sectional survey was electronically distributed to 192 individuals with cancer investigating preferences towards exercise programming during COVID-19. Respondents had previously participated in an exercise program and comprised two groups: those who had experience with virtual exercise programming ('Virtual') and those who had only taken part in in-person exercise ('In-Person'). Quantitative data were summarized descriptively. Qualitative data were thematically categorized using framework analysis and findings were mapped to an implementation model. **Results**. Survey completion response rate was 66% (N=127). All respondents identified barriers to attending in-person exercise programming during COVID-19 with concerns over increased risk of viral exposure. Virtual respondents (n=39) reported: (1) feeling confident in engaging in virtual exercise; and (2) enhanced motivation, accessibility, and effectiveness as facilitators to virtual exercise. In-Person respondents (n=88) identified: (1) technology as a barrier to virtual exercise; and (2) low motivation, accessibility and exercise effectiveness as barriers towards virtual exercise. Sixty-six percent (n=58) of In-Person respondents reported that technology support would increase their willingness to exercise virtually. **Conclusions.** With appropriately targeted support, perceived barriers to accessing virtual exercise—including motivation, accessibility and effectiveness—may become facilitators. Availability of technology support may increase engagement of individuals with cancer towards virtual exercise programming.

Keywords: cancer, exercise, eHealth, implementation

Chapter 4

Virtual or In-Person: A mixed methods survey to determine exercise programming preferences during COVID-19

4.2. Introduction

The novel Coronavirus Disease-19 (COVID-19) pandemic significantly increased barriers and disrupted in-person access to healthcare services for immunocompromised populations. Barriers to healthcare delivery from COVID-19 have led to a fundamental shift of patient-clinician interactions from primarily 'in-person', to options that include virtual care, telehealth, telemedicine, or 'eHealth' (1-3). While eHealth platforms have the potential to provide multidisciplinary care to vulnerable chronic disease populations and overcome remote/ rural settings (4), research is still novel and emerging around successful telehealth implementation (5).

The disruption to service access negatively impacted individuals with cancer, who are at increased risk for severe complications from COVID-19 due to immunocompromised side-effects of cancer therapies, comorbidities, and advanced age (6,7). With the population of individuals diagnosed and living with cancer continuing to rapidly grow worldwide (8,9), there is a widening gap of supportive care services to address the many acute and chronic side effects from cancer and cancer-related treatments (10-12). Supportive care refers to services designed to meet the physical, emotional, social, and practical needs of individuals across the cancer spectrum (13). An extensive body of evidence, including 16 published guidelines from major medical or health-oriented organizations globally, recognize exercise as beneficial for individuals with cancer across the cancer spectrum (14). Regular exercise results in numerous physiological and psychosocial benefits for cancer survivors, including improved survival outcomes for common cancers, overall quality of life, cancer-related fatigue, cardiorespiratory fitness and muscular strength (14-16). Given the strength of evidence supporting the benefits of exercise for the cancer population, targeted efforts are needed to integrate cancer-specific exercise programming into standard patient care (17-20), now exacerbated due to increased barriers to exercise presented by COVID-19 (21,22).

With the rapid pivot to eHealth virtual platforms, COVID-19 has provided a unique environment to understand cancer survivors' perspectives to virtual delivery of exercise programming. Program accessibility is a known barrier identified by individuals with cancer towards engaging in exercise (i.e. transportation, parking, facility type and location, time of day) (23). While home-based exercise improves accessibility, home programs lack support from exercise professionals and peers, which survivors have identified as significant facilitators towards exercise (24). There is promise for use of virtual platforms to deliver accessible cancer-specific exercise programming remotely, while maintaining exercise professional and social supports (25,26). Continuing research during the pandemic has led to initiatives around large scale implementation of eHealth platforms focusing on parameters of engagement, such as feasibility, acceptability, and efficacy (27-29). Virtual service delivery may provide a means to avoid the unnecessary risks of viral transmission associated with in-person settings (30); however, the ability of eHealth to meet the exercise needs of people with and recovering from cancer is unclear. Moreover, with the rapid transition to eHealth platforms for cancer supportive care services, there is limited understanding of best practices for implementing and delivering cancer-specific virtual exercise programming (31).

4.2.1. Research Context of the Clinical Team

4.2.1.1. Alberta Cancer Exercise Hybrid-Effectiveness-Implementation (ACE) Study

The present study was part of the integrated knowledge translation (iKT) series (32) of sub studies from the Alberta Cancer Exercise Hybrid Effectiveness-Implementation (ACE) study. ACE is an implementation study that proposes a clinic-to-community model of care to support implementation of cancer-specific, community-based, exercise programming; protocol and findings are described elsewhere (33-35). The study involves a 12-week exercise program for individuals diagnosed with any cancer. The ACE study pivoted to providing virtual exercise programming during the lockdowns associated with COVID-19.

4.2.2. Objective

This study aimed to understand the facilitators/preferences and barriers towards exercise during COVID-19 to inform ongoing cancer-specific exercise programming. Specific objectives included an understanding of the perspectives of individuals who had previously participated in

standardized exercise towards (1) in-person and virtual exercise, and (2) the use of technology to access virtual exercise programming. Findings were intended to inform ACE maintenance programming in Northern Alberta during the pandemic and support future clinical implementation of virtual exercise programming in the cancer setting.

4.3. Materials and Methods

4.3.1. Study Design

A cross-sectional survey was administered to individuals with cancer who had previously participated in ACE programming at Northern Alberta sites (Edmonton, Grande Prairie, Fort McMurray and Red Deer) either in-person prior to the pandemic, or virtually during the pandemic. A multi-method approach using both quantitative and qualitative data was utilized to provide a more inclusive understanding of the participants' perspectives towards in-person and virtual exercise during COVID-19, as well as the use of technology to access virtual exercise programming. Survey questions were theory informed and designed based on implementation theory from the Capability, Opportunity, Motivation - Behaviour (COM-B) Model (36). Survey questions were mapped from each of the three model domains/constructs: (1) *capability*- an individual's psychological (knowledge) and physical capacity (skills) to perform behaviours or activities; (2) *opportunity*- physical (environment) or social factors (interpersonal influences) external to an individual that influence the behaviour; and (3) *motivation*- brain processes that direct behaviour (optimism, habitual and emotional responses, and analytical decision-making) (40). Survey questions included both multiple choice and short answers to comprehensively capture each COM-B Model construct. For question mapping and survey questions see Supplementary Material Table S1. Demographic and medical information were previously collected through the ACE study (33). Ethics approval for this sub-study was granted by the Health Research Board of Alberta: Cancer Committee (HREBA.16-0905) and the intervention component was prospectively registered (NTC02984163). For consent forms refer to Appendix 8. For ethics approval refer to Appendix 9.

4.3.2. Data Collection

Participants were eligible to participate in the survey if: (1) they had enrolled in either Fall 2019 or Winter 2020 (both in-person), or Spring 2020 (virtual) of the ACE 12-week cancer-specific

exercise program through sites in Edmonton, Fort McMurray, Red Deer or Grande Prairie; (2) had consented to future contact from the ACE research team; (3) had an active email address; and (4) had completed 12-week and, if applicable, 24-week post program ACE questionnaires.

'In-Person' are respondents who participated in ACE community-based classes prior to COVID-19 (Fall 2019, Winter 2020). 'Virtual' are those who participated virtually (live supervised online classes) during COVID-19 (either ACE Spring 2020, or independently).

Inclusion criteria for the ACE study required participants to: (1) have a diagnosis of cancer of any type; (2) be over the age of 18 years; (3) be able to participate in mild levels of activity at minimum; (4) be pretreatment or receiving active cancer treatment (e.g., surgery, systemic therapy and/or radiation therapy), or have received cancer treatment within the past 3 years or have existing long-term, or have late presenting effects of their cancer treatment (e.g., radiation fibrosis syndrome, lymphoedema, communication deficits related to cancer treatment or incontinence); and (5) be able to provide informed written consent in English. ACE classes involved a combination of aerobic, resistance, balance and flexibility exercises delivered in a standardized circuit-type class setting twice weekly for a minimum of 60 minutes per session for a 12-week period (approximately 3-4 metabolic equivalent units per session). For intervention description refer to Table 1. The ACE study protocol has been previously reported in detail elsewhere (33).

The ACE study pivoted to providing virtual exercise programming during COVID-19. Virtual exercise programming classes were live, supervised and conducted over zoom within the context of the following parameters: (1) participants were provided with technology support in setting up and using their device in preparation for virtual programming that involved orientation to the virtual platform, evaluating connectivity and troubleshooting any issues related to the virtual environment (i.e. location of device and alignment with the computer camera for facilitating monitoring of exercise performance); (2) all exercise sessions were conducted live over a consistent virtual platform (Zoom); (3) three intensity levels of each exercise (light, moderate, vigorous), were continuously demonstrated for participants by designated exercise professionals; (4) participants were directed to follow appropriate intensity levels and pin the instructor demonstrating the preferred level; (5) exercises were chosen that

could be completed in home environments, focused on body weight exercises with consideration of limited space and equipment; (6) each virtual session was monitored by a qualified exercise professional who was responsible for monitoring performance, correcting exercise form, and helping troubleshoot any technology issues etc.; (7) exercise resistance bands were provided for participants.

The survey was active from August 2020 - September 2020, to coincide with, and inform Northern Alberta Fall 2020 and Winter 2021 ACE exercise programming. The survey was administered electronically through Research Electronic Data Capture (REDCap), a secure, web-based application designed for research study data collection, provided by Women and Children's Health Research Institute (37), hosted on a secure server in the University of Alberta's Faculty of Medicine and Dentistry's data centre. Eligible participants were emailed a secure survey link through REDCap. For survey questions refer to Appendix 10.

4.3.2. Data Analysis

Data from the survey included both continuous and categorical variables. Basic descriptive statistics were generated by REDCap including frequencies, percentages and counts of responses to quantitative questions. Qualitative data from short answer and open-ended questions were analyzed using framework analysis, a form of content analysis to identify patterns in qualitative data, with a defining feature involving matrix outputs of rows and columns of summarized data (38). Framework analysis provides a practical lens to answer specific questions with actionable outcomes, lending itself well to inform clinical and implementation practices (39). Three researchers independently coded written responses (KS, MM, ND) into framework tables. After initial coding, researchers collaborated to amend and refine codes, and develop framework tables in relation to patterns of barriers, facilitators and/or preferences towards exercise and technology. Themes were then mapped to respective domains of the COM-B Model to inform implementation strategies for local Fall 2020 ACE exercise programming and future clinical practice (40).

4.4. Results

4.4.1. Demographics

A total of 127 cancer survivors responded (66% response rate), with 69% (n=63) aged 55 and older, and 25% (n=32) 40-55 years of age. The average age of respondents was 59 years (SD = 11.4). The most common cancer diagnosis was breast (44%, n=56), followed by digestive cancer (17%, n=22), and head and neck cancer (11%, n=14). The majority of respondents were female (71%, n=90), and 46% (n=58) of all respondents were actively receiving treatment for cancer. Respondents mainly resided in an urban centre (n=93, 73%), or within 15-30 kms of an urban centre (n=28, 22%). The average commute to In-Person exercise programming was 14.3 km. Respondent demographics can be viewed in Table 2.

As all survey recipients had previously participated in exercise programming through ACE, we were able to explore the characteristics of non-respondents compared to respondents. Non-respondents were slightly younger with an average age of 57 years of age (SD 11.1) compared to respondents (59 years, SD 11.4). A larger proportion of non-respondents were males (n=29, 45%) compared to respondents (n=37, 29%). Further details on non-respondent demographics can be viewed in Table 2.

4.4.2. Cancer Survivor Exercise Behaviors and Preferences During COVID-19

In response to the question "Would you have concerns about taking part in an exercise class delivered in-person this Fall?" 56% (n=71 of 127) of all respondents indicated "yes" (Fig. 1a). The majority of respondents who identified concern over in-person exercise, rated their level of concern for joining in-person exercise programming (Fall 2020) from 'Quite a bit' to 'Very Much' (61%, n =43 of 71) (Fig. 1b). All respondents identified barriers to attending in-person exercise programming related to personal safety and concerns over increased risk of COVID-19 exposure and transmission with an in-person exercise setting. The identified risks included: environmental exposure; space and cleaning procedures (e.g., cleaning of equipment, physical distancing, ventilation, sharing of equipment, type of exercise); the burden of masking while exercising; and health-specific risks due to an immunocompromised status from cancer treatments, and pre-existing comorbidities.

In response to the question, "How much of a priority is exercise currently for you given COVID-19?", responses were mixed with 45% (n= 57) reporting 'Not at all' or 'Somewhat', and 55% (n=70) reporting 'Quite a bit' or 'Very Much' (Fig. 1c). The reported exercise frequency was: 1-2 times per week for 32% of respondents (n=41); 3-4 times per week also for 32% (n=41); greater than 5 times a week for 24% (n=30) and 'Not at all' for 12% (n=15). Current exercise environments were identified as: 'self-exercise alone' 71% (n=90); followed by 'self-directed exercise with others' (socially distanced walking, running, biking) at 29% (n=37). The three main types of exercise engaged in were reported as: (1) aerobic exercise at 78% (n=99); (2) resistance exercise at 43% (n=54); (3) and flexibility and stretching at 26% (n=33). Thirteen percent (n=17) of respondents were partaking in virtual exercise classes (live or pre-recorded). Only 17% (n=21) of respondents reported healthcare provider (HCP) initiated counselling regarding exercise during COVID-19 (Fig. 1a).

We explored differences in rating barriers and facilitators between those who prioritized exercise (n=70) compared to those who did not prioritize exercise (n=57) during COVID-19. The only notable difference was those who did not prioritize exercise were more confident (self-identified as fairly to completely confident) using their electronic device (n=40 of 57, 71%) compared to those who prioritized exercise (n=36 of 70, 51%).

4.4.3. ACE In-Person Participants and Virtual Exercise Programming

For In-Person participants (n=88), 73% (n=64) indicated that they were 'Not at all' to at most, 'Somewhat' confident participating in a virtual exercise program (Fig. 1c). Communication applications such as Facetime, Skype and Zoom were identified by 20% (n=18) of In-Person respondents to be used at least once a day. The majority, 61% (n=54), 'Agreed' or 'Strongly Agreed' that the provision of technological support would increase their comfort in taking part in a virtual exercise program (Fig. 2a). Responses to the statement, "Would knowing you have access to [technology] support change your willingness to take part in a virtual exercise program?" can be divided into four categories (Fig. 2b): (1) 42% (n=37) responded "Yes, I WAS willing to take part in virtual programming before, and now I am even MORE willing to take part"; (2) 24% (n=21) indicated "Yes, I was NOT willing to take part in virtual programming before, but now I am MORE willing to take part; (3) 13% (n=11) indicated, "No, a

technical support staff has no effect on my choice to take part"; (4) 22% (n=19) responded "NO - I was NOT willing to take part in virtual programming before, and I am still NOT willing to take part." Of the respondents who indicated technical support staff had no impact on their participation, 68% (n=13 of 19) stated they were already comfortable with technology and did not need assistance (Fig. 2c). Of all In-Person respondents, only 6% (n=5) indicated they would not participate virtually regardless of technology support. Only one respondent indicated they did not have access to the technology needed to participate in exercise virtually. Preferences for virtual exercise program features were identified by In-Person respondents, in order of highest to least priority: (1) access to recordings of classes; (2) exercise descriptions provided prior to the class; (3) convenient class timing; (4) having an engaging instructor; and (5) support for set up (including online platform, computer and set up of exercise space at home) (Fig. 2d).

4.4.4. ACE Virtual Participants and Virtual Exercise Programming Experience

ACE Spring 2020 online participants who took part in the survey (n=19) responded to the statement "I experienced unique benefits taking part in the ACE virtual exercise program during the pandemic", with 89% (n=17) 'Agreeing' or 'Strongly Agreeing'. These participants were provided with technology support in setting up and using their device to virtually participate in exercise programming, which 63% (n=12) 'agreed' or 'strongly agreed' technology support was beneficial. ACE online respondents did not identify any concerns regarding the virtual exercise program itself. Seventy-nine percent (n=15 of 19) of respondents reported they had no difficulties accessing the virtual exercise program. Identified barriers to the virtual exercise programming were reported as poor internet connection (16%, n=3) and lack of home exercise equipment (11%, n=2). One respondent reported a lack of comfort using technology and a separate respondent reported their screen was too small to properly follow the virtual program.

4.4.5. Thematic Findings and Implementation Mapping to COM-B Model

For the purposes of exploratory and qualitative analyses, participants were divided into two main groups: (1) respondents with in-person exercise experience alone ("In-person", n=88); and (2) respondents with experience exercising in a virtual environment ("Virtual", n=39) which

included 19 respondents from the spring 2020 session as well as 20 respondents who had participated in-person in the Fall 2019 and Winter 2020 ACE study sessions as well.

4.4.5.1. In-Person

Individuals with experience with in-person exercise alone identified three main perceived thematic barriers to attending virtual exercise classes: (1) accessibility: lack of technology competency and limited space and exercise equipment at home; (2) effectiveness: virtual exercise programming viewed as less effective than in-person without personalized hands-on cuing, monitoring and corrections from the exercise instructor(s); less effective in managing safety and treatment side effects; and (3) motivation: a perceived lack of accountability with no face-to-face interactions; a lack of social support/ community; perceived invasion of privacy (home setting being seen on screen); and a loss of routine. For thematic findings refer to Fig. 3A.

Mapping of themes to the COM-B Model corresponded with the following model components: (1) accessibility mapped to Capability: participant identified lack of knowledge and skills towards engaging with technology; (2) effectiveness mapped to Opportunity: a lack of physically present social influences (instructors and other participants) and barriers of the local environmental context and resources; and (3) motivation mapped to Motivation: lack of optimism towards virtual exercise encounters. For thematic mapping to COM-B, refer to Fig. 4.

4.4.5.2. Virtual

Individuals with experience exercising in the virtual environment identified three main thematic benefits to virtual exercise: (1) accessibility: pandemic-related safety; exercise comfort as no masking needed; (2) effectiveness: self-reported physical and mental health benefits including better coping with stress and cancer-related symptom burden reduction; an individualized approach maintained with exercise options in the group class; support for setting up home exercise space and home equipment (resistance bands provided); and (3) motivation: virtual exercise provided sense of community, support and encouragement. For thematic findings refer to Fig. 3B.

Mapping of themes to the COM-B corresponded with the following model domains: (1) accessibility mapped to Capability: virtual platform alleviated pandemic related safety and

masking concerns for participants to engage in exercise (2) effectiveness mapped to Opportunity: the virtual class structure facilitated a conducive environment with appropriate resources and social support for participants to engage and exercise safely; and (3) motivation mapped to Motivation: virtual community environment facilitated optimism, and intrinsic goal setting and intentions towards virtual exercise encounters. For thematic mapping to COM-B, refer to Fig. 4.

4.5. Discussion

Survey findings showed that a majority of individuals with cancer who had taken part in the ACE program had limited experience engaging with virtual exercise — at a time when they were also uncomfortable attending in-person exercise due to COVID-19. This finding highlights the need for consideration of alternative modes of exercise programming delivery. Home-based exercise programs have been previously reported to lack community and peer support, leading to reduced adherence and effectiveness in individuals with cancer (41). Virtual group exercise offers the promise of group support while maintaining social distancing, allowing the convenience of home (no travel time or costs), and increasing accessibility to individuals residing outside of urban centres (29, 31). A study examining the effectiveness of a virtual exercise oncology program involving 491 cancer participants undergoing antineoplastic therapy between March and June 2020, reported significant benefit for psychological outcomes of improved feelings of support (58.7% increase, $P < 0.05$), and a significant decrease in loneliness (54% decrease, $P < 0.05$) (26).

A primary finding of this survey was that perceived barriers to virtual exercise programming by individuals without virtual exercise experience were identified as facilitators by those who had virtual experience. Virtual programming may be enhanced by considering accessibility and capability options and underlying motivation to facilitate greater engagement. Our survey findings highlight that successful transition from in-person to virtual programming involves more than just offering virtual classes. A recent survey of 593 cancer respondents found strong predictors of cancer survivors' virtual engagement with HCPs to be access to, and past experiences with interactive technologies for health-related purposes (42). Successful transitioning to telehealth for exercise programming was found to be largely influenced by patients' willingness (motivation), and capability to use technology.

The success of in-person programming for individuals with cancer may not necessarily correlate to successful virtual programs. Implementation efforts may need to specifically address the nuance of virtual versus in-person exercise programming. Specifically, time and resources may need to be allocated for the upskilling of technological competency and confidence, as well as program support (i.e., dedicated staff monitoring virtual exercise participant performance) to preserve service quality in a virtual setting. Exercise professionals may need to adjust their approaches to match the limitations of virtual engagement and allot time to support the setup of an appropriate home virtual exercise environment.

The availability of technology training support for participants could help increase willingness and comfort, and thus optimize motivation. A survey of 377 cancer participants from the Macmillan Move More Northern Ireland (MMNI) exercise program investigated the impact of COVID-19 on the physical activity patterns and attitudes towards digitally supported exercise in individuals with cancer (43). MMNI pandemic programming offered 'live' virtual exercise sessions and a recorded exercise library available on YouTube. Sixty-two percent of respondents (n=233 of 377) reported participating in exercise virtually. Of the 38% of MMNI respondents (n=144) who did not engage with virtual technology, 43% (n=62 of 144) responded they were interested, with participants identifying a lack of technological proficiency/ support as a barrier to participation. Given the older age of individuals with cancer at diagnosis (8), it is likely that many individuals have less experience and comfort with virtual environments. Lower computer literacy in combination with age has been reported as a barrier to virtual exercise engagement for individuals with cancer (44). Thus, an aging cancer population with limited exposure to virtual platforms may warrant additional technology support for effective transition to virtual exercise programming.

A growing body of evidence supports that successful telehealth implementation involves identifying user technology competencies to facilitate participation (45,46). Providing a standardized technological proficiency assessment tool for initial screening could pre-emptively identify participants who require further technology support (4). A recent scoping review examining best practices in implementation of telehealth-based cancer supportive care included 19 review papers and 23 telehealth guidance documents (28). Findings concluded that factors

related to both the user (cancer population) and the provider (healthcare/supportive care providers) influence the acceptability and effectiveness of telehealth services. The findings suggest that for successful telehealth, providers need to focus on technology competency, device adequacy, participant confidence in utilizing or providing services, and mitigation of impact on service quality. For clinically actionable items to support virtual exercise implementation see Figure 4.

Strengths of this study included a novel comparison of the perspectives of individuals with cancer towards engaging in-person and virtual exercise during a pandemic, after previous exercise participation. The online survey format allowed for greater reach of participants (n=127) and aligned with current COVID-19 related policies for avoiding in-person contact. Consistent with percentages from the overall ACE population, the majority of respondents were female (71%, n=90) and diagnosed with breast cancer (44%, n=56), limiting generalizability to males, and other tumor groups. The average age of respondents was 59 years, limiting generalizability to older cancer survivors; however, the average age is similar to the average age of participants (~58 years) in the overall ACE program (N=2270). Non-respondents were slightly younger with a higher proportion of males, with a potential bias in those motivated to respond. All respondents had used an electronic format for patient-reported outcomes during their respective ACE programming (both in person and virtual), so there may be bias in terms of familiarity with the online response format. Additionally, fewer individuals had experience exercising virtually compared to in-person, which offers potential of skewed responses.

The findings of this survey provide perspective in understanding how cancer-specific exercise programming delivery can be facilitated to meet the needs of individuals with cancer during a pandemic. The identified differences between In-Person versus Virtual programming highlight the need to create and deliver content matched to both the virtual platforms and to the participants' levels of capability and confidence in technology. These survey findings indicate potential benefit in providing dedicated technology support to increase willingness to participate and engage with novel virtual exercise services.

Table 4-1. Intervention description using the template for description and replication checklist (TIDieR)

Intervention	Alberta Cancer Exercise (ACE) Hybrid Effectiveness Implementation Study[1]
Why	Exercise improves aerobic fitness, muscular strength and cancer-related symptoms
What: Materials	Exercise studio for circuit classes: bands, free weights, mats, bender balls, bosu; Community fitness centre or cancer-specific clinic for group personal training: treadmill, stationary bike, exercise machines (chest press, bicep curl, leg curl/extension, seated row, pullies) free weights and mats
What: Procedures	
Providers	Oversight: exercise physiologist or physical therapist. Instructor: qualified exercise professional
How	Supervised sessions of either standardized circuit-type class setting or group personal training
Where	Community-based exercise facilities and cancer-specific exercise clinics
Type	Aerobic, resistance, balance and flexibility exercises
Intensity	3-4 metabolic equivalent (MET) units per session (360–480 MET-minutes/ week) Progression of intensity to 4–5 METs over the 12-week duration (480–600 MET-minutes/week 2-4 (light to somewhat heavy) on the 11-point Borg Rating of Perceived Exertion Scale
Frequency	Twice weekly
Session time	60 minutes per session
Overall duration	12-weeks
Tailoring	Adaptations to address cancer-related symptoms, muscular stiffness and dizziness, and prevent adverse events
Trial fidelity	Staff with training and experience in exercise oncology Exercise supervision Attendance tracked for number of completed sessions Monitoring of symptoms (e.g. fatigue, muscle soreness) Recording of minor and serious adverse events

[1] McNeely ML, Sellar C, Williamson T, Shea-Budgell M, Joy AA, Lau HY, et al. Community-based exercise for health promotion and secondary cancer prevention in Canada: protocol for a hybrid effectiveness-implementation study. *BMJ Open*. 2019;9:e029975

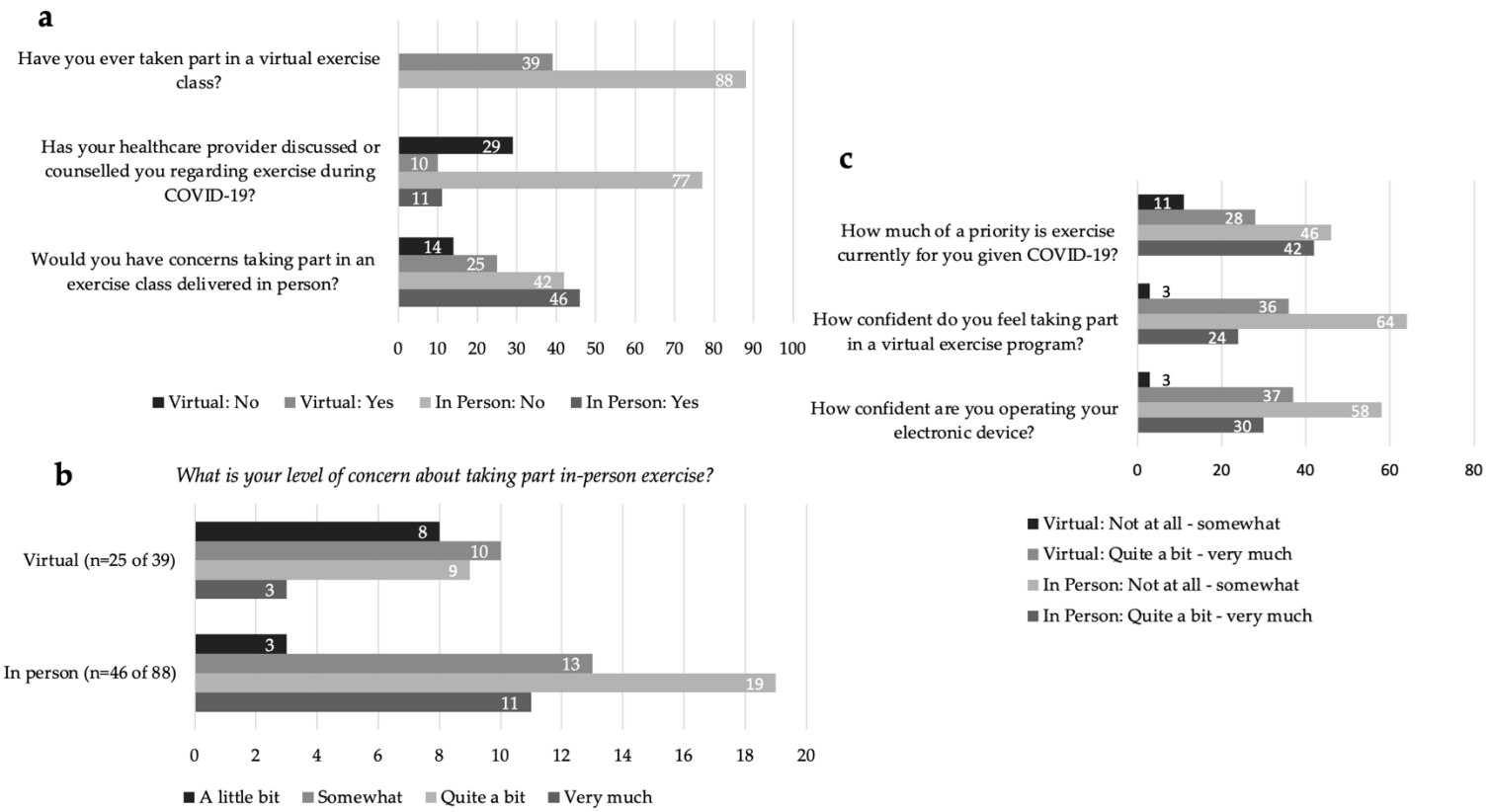
Table 4-2. Baseline Demographic and Medical Data

Respondent Characteristics	In-Person Exercise (Spring 2019-Winter 2020)	Virtual Exercise (Spring 2020)	Total Respondents	Non-Respondents
	N= 88, No. (%)	N=39, No. (%)	N=127, No. (%)	N=65, No. (%)
		Sex		
Male	29 (33.0)	8 (20.5)	37 (29.1)	29 (44.6)
Female	59 (67.0)	31 (79.5)	90 (70.9)	36 (55.4)
		Age		
26-39	7 (7.8)	1 (2.6)	8 (6.3)	5 (7.7)
40-54	18 (20.5)	14 (35.9)	32 (25.2)	22 (33.8)
55-69	47 (53.4)	16 (41.0)	63 (49.6)	30 (46.2)
>70	16 (18.2)	8 (20.5)	24 (18.9)	8 (12.3)
Average Age (Years, Standard deviation)	58.7 (11.5)	59.0 (11.3)	59.0 (11.4)	56.7 (11.1)
		Tumor Type		
Blood	12 (11.1)	1 (5.3)	13 (10.2)	3 (4.6)
Breast	35 (39.8)	21 (53.8)	56 (44.1)	17 (26.2)
Gastrointestinal	16 (18.2)	6 (15.4)	22 (17.3)	7 (10.8)
Genitourinary	3 (3.4)	2 (5.1)	5 (3.9)	1 (1.5)
Gynecological	2 (2.3)	2 (5.1)	4 (3.1)	5 (7.7)
Head and neck	11 (12.5)	3 (7.7)	14 (11.0)	7 (10.8)
Lung	1 (1.1)	1 (2.6)	2 (1.6)	2 (3.1)
Neurological	6 (6.8)	1 (2.6)	7 (5.5)	6 (9.2)
Skin	1 (0.9)	0 (0.0)	1 (0.8)	3 (4.6)
Other	1 (0.9)	2 (10.5)	3 (2.4)	2 (3.1)
		Currently receiving treatment (while in exercise program)		
Yes	39 (44.3)	19 (48.7)	58 (45.7)	31 (47.7)
No	49 (55.7)	20 (51.3)	69 (54.3)	34 (52.3)
		Cancer Treatment (received while in exercise program)		
Chemotherapy	17 (19.3)	7 (17.9)	24 (18.9)	10 (15.4)
Radiation	7 (6.5)	0 (0.0)	7 (5.5)	4 (6.2)
Hormone Therapy	10 (11.3)	11 (28.2)	21 (16.5)	10 (15.4)
Biological Therapy	0 (0.0)	1 (2.6)	1 (0.8)	4 (6.2)
Other	12 (13.6)	2 (5.1)	14 (11.0)	6 (9.2)
		Cancer Treatment (completed)		
Chemotherapy	57 (64.8)	18 (46.1)	75 (59.1)	40 (61.5)
Radiation	47 (53.4)	25 (64.1)	72 (56.7)	34 (52.3)
Hormone Therapy	6 (6.8)	2 (5.1)	8 (6.3)	3 (4.6)
Biological Therapy	0 (0.0)	0 (0.0)	0 (0.0)	2 (3.1)
Surgery	58 (65.9)	30 (76.9)	88 (69.3)	47 (72.3)
Other	12 (13.6)	2 (5.1)	14 (11.0)	6 (9.2)
		Location of Residence		
Edmonton (urban)	62 (70.5)	31 (79.5)	93 (73.2)	53 (81.5)
Catchment area 15-30 kms	24 (27.3)	4 (10.3)	28 (22.0)	6 (9.2)
Catchment area 30-100 kms	2 (2.3)	3 (7.7)	5 (3.9)	5 (7.7)
Rural > 100 kms	0 (0.0)	1 (2.6)	1 (0.8)	1 (1.5)
Average km Commute	14.3 km	N/A	N/A	19.0 km

Table 4-3. Supplementary Table S1. Capability, Opportunity, Motivation-Behaviour (COM-B) Model Survey Question Mapping

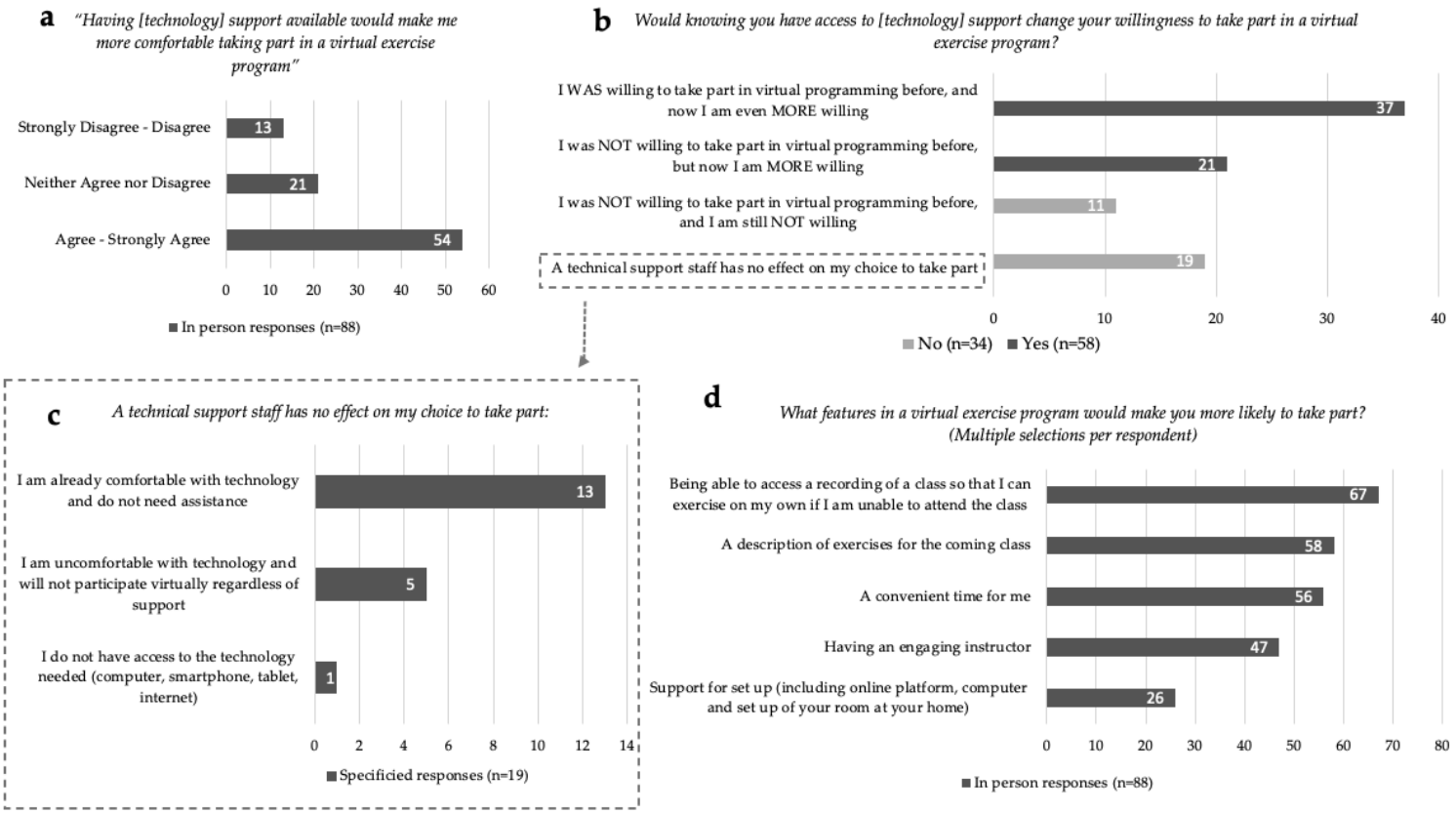
<table>
<tr><td colspan="3">Table S1. Capability, Opportunity, Motivation-Behaviour (COM-B) Model[1] Survey Question Mapping</td></tr>
<tr><td>COM-B[1] Components and domains</td><td colspan="2">Responses by Group: In-Person[2] and Virtual[3]</td></tr>
<tr><td rowspan="3">Component:
<u>Capability</u>
Domains:
Knowledge
Skills (Physical, Psychological)
Memory, Attention and Decision Processes</td><td>In-Person and Virtual</td><td>In-Person Only</td></tr>
<tr><td>• How are you currently exercising?
• What type(s) of exercise are you currently taking part in?
• How confident are you in operating your electronic device?
• How often do you use programs such as FaceTime, Skype, and Zoom to connect with others?
• What do you use for your virtual communications?</td><td>• How confident do you feel about taking part in a virtual exercise program?
• What device(s) would you use if you took part in a virtual program?
Virtual Only
• How confident do you feel about taking part in a virtual program again?</td></tr>
<tr><td colspan="2"></td></tr>
<tr><td rowspan="3">Component:
<u>Opportunity:</u>
Domains:
Social Influences
Environmental Context and Resources</td><td>In-Person and Virtual</td><td>In-Person Only</td></tr>
<tr><td>• Have you ever taken part in a virtual exercise class?
• Has your healthcare provider discussed or counselled you regarding exercise during COVID-19?
• What exercise equipment do you have access to?
• Would you have concerns about taking part in an exercise class delivered in-person this fall?
• What is your level of concern about taking part in in-person exercise?
• What are your concerns about in-person exercise classes?
• Would you have concerns about taking part in a virtual exercise class this fall?
• What is your level of concern about taking part in virtual exercise?
• What are your concerns about virtual exercise classes?
• What type(s) of exercise programming would you be open to taking part in this fall?
• If you were asked to complete fitness testing, how would you prefer to complete these tests?
• Have you ever taken part in a virtual exercise class?
• Would your family or friends be supportive of you engaging in virtual/in-person exercise programming?</td><td>• ACE[4] staff can provide support to help you get familiar with using the virtual programming, and to ensure you are set up at home. Please indicate your agreement with the following statement: "Having support available would make me more comfortable taking part in a virtual exercise program."
• Would knowing you have access to support change your willingness to take part in a virtual exercise program?
• Having support staff to assist you would not change your choice to take part in virtual exercise because…
• Would someone be available to assist you with technology if you were participating in a virtual exercise program?
• What features in a virtual exercise program would make you more likely to take part? Please select all that apply. Please specify what other feature(s) would make you more likely to participate.
• What difficulties would you anticipate if you were to take part in a virtual exercise program?
• Would you have another person at home during the virtual exercise classes who could assist you if required (with non-technology issues)?</td></tr>
<tr><td colspan="2">Virtual Only</td></tr>
<tr><td colspan="2">• If you were to participate in a virtual exercise program again, would you use the same device to connect to the class?
• What different device(s) would you use? Please select all that apply.
• Did you find having support available in setting up and using your device to participate in the class beneficial?
• Please rate the following statement: “I experienced unique benefits taking part in the ACE Spring virtual exercise program during the COVID-19 pandemic.” Please let us know what the unique benefits were that you experienced.
• Did you experience any of the following difficulties during the virtual exercise program? Please select all that apply.
• Are there any features of the ACE virtual exercise program that you would change?</td></tr>
<tr><td rowspan="3">Component:
<u>Motivation:</u>
Domains:
Intentions
Goals
Beliefs about capabilities
Optimism</td><td colspan="2">In-Person and Virtual</td></tr>
<tr><td colspan="2">• How much of a priority is exercise currently for you given COVID-19?
• On average, how many times per week did you exercise in the last month? (Please only count days where you exercised for at least 10 minutes at a moderate intensity level)
• On average, how many minutes per week did you exercise (at a moderate or vigorous intensity) in the last month?
• To meet Alberta Health Services guidelines and accommodate all participants, a likely program option for the fall will be having one class a week of virtual exercise, and the other as in-person exercise OR only virtual exercise classes. How willing would you be to participate in a combined exercise program where you attended one day in-person and the second day virtually?</td></tr>
<tr><td colspan="2"></td></tr>
<tr><td colspan="3">[1]COM-B: Capability, Opportunity, Motivation-Behaviour Model from Michie, S., Atkins, L., & West, R. (2014). The Behaviour Change Wheel Book - A Guide to Designing Interventions. Great Britain: Silverback Publishing.
[2]In-Person: previous in-person exercise experience alone (n=88)
[3]Virtual: experience exercising in a virtual environment (n=39)
[4]ACE: Alberta Cancer Exercise Hybrid Effectiveness- Implementation Study</td></tr>
</table>

Figure 4-1. Virtual and In-Person Responses



a Virtual and In-Person exercise preferences and reported exercise counsel by a healthcare professional. **b** Virtual and In-Person level of concern regarding in-person exercise in COVID-19. **c** priority of exercise during COVID-19 and confidence ratings accessing virtual exercise and using electronic devices.

Figure 4-2. In-Person virtual exercise and technology responses



a willingness to take part in an exercise program with technology support available. **b** technology support staff specified responses for unchanged willingness. **c** programming facilitators for virtual exercise engagement. **d** comfort ratings with available technology support staff towards virtual exercise programming.

Figure 4-3. Perceived Barriers and Identified Facilitators towards Virtual Exercise Programming.

A: Perceived Barriers to Virtual Exercise; B: Identified Facilitators to Virtual Exercise

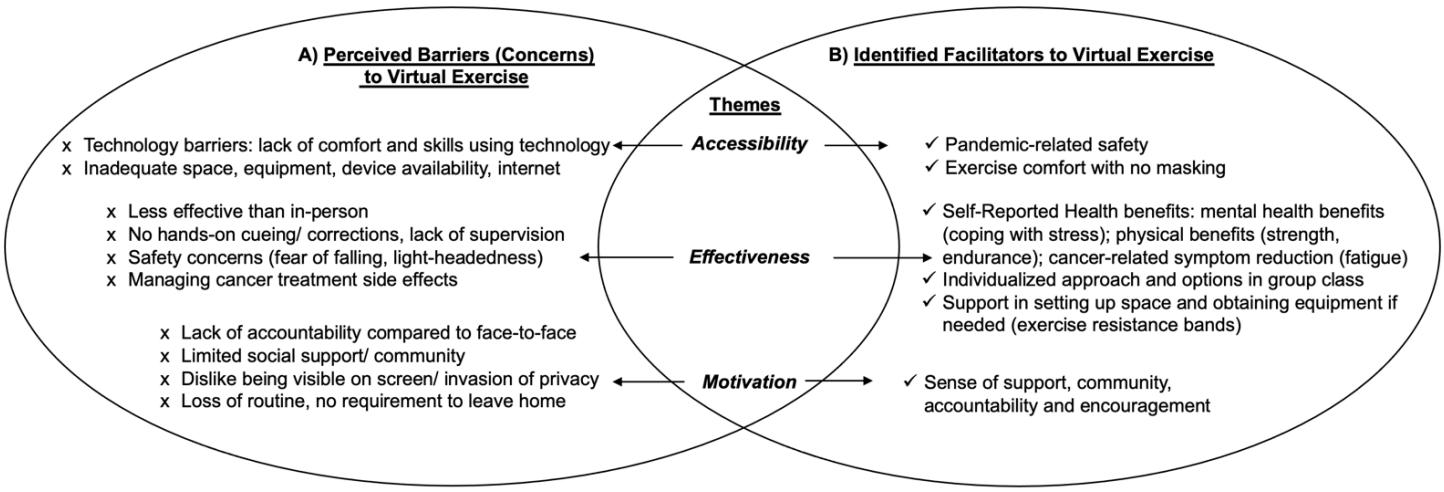
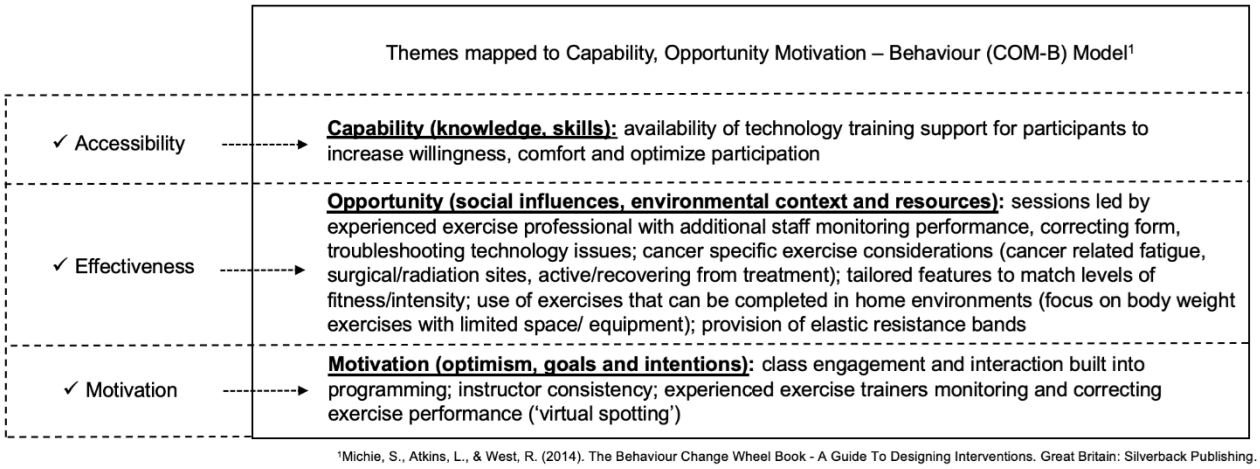


Figure 4-4. Thematic Findings Mapped to COM-B Model with Clinically Actionable Items to Support Virtual Exercise Implementation



[1]Michie, S., Atkins, L., & West, R. (2014). The Behaviour Change Wheel Book - A Guide To Designing Interventions. Great Britain: Silverback Publishing.

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Chapter 5

Predictors of Technology Training Time for Cancer, Lung Disease and Lung and Liver Transplant Patients Accessing a 12-Week Virtual Exercise and Nutrition Program: Heal-Me TeCH

Kirsten Suderman, Graeme Purdy, Tara Skene, Naomi Dolgoy, Sunita Ghosh, Edith Pituskin, S. Nicole Culos-Reed, Puneeta Tandon, Margaret L. McNeely. In preparation for submission to Digital Health.

5.1. Abstract

Background: Understanding the factors that influence technology training time (TTT) needs of individuals with chronic disease accessing virtual care is necessary to overcome the barrier of technology and develop effective supports**.** Participants with cancer, lung disease and lung and liver transplant were randomized to a 12-week study to determine the acceptability and efficacy of a virtual nutrition and exercise program using a novel eHealth application: Healthy Eating, Active Living and Mindful Energy (Heal-Me). **Purpose:** The Heal-Me **Te**chnology **C**ounselling for e**H**ealth (TeCH) study examined the predictors of TTT required for the study participants to become oriented to the Heal-Me Application. **Methods:** Demographic, technology proficiency, fitness and medical data from N=157 participants in the intervention groups were collected through virtual physical fitness assessment, self-report and medical records. Participants were also asked prior to the start of the TTT session to self-rate their technology proficiency on a scale from 0-5 with a score of zero being 'Not at all proficient or confident with technology' and a score of five being a 'Technology Expert'. **Results:** The average TTT was 46.2 minutes. Findings in the univariate analysis showed that age ($r = 0.42$, $P < 0.001$), self-rated technological proficiency ($t = 5.10$, $P < 0.001$), quality of life ($r = 0.24$, $P = 0.002$), energy/vitality ($r = 0.17$, $p = 0.04$), ethnicity ($F = 1.97$, $P = 0.09$) and number of comorbidities ($r = 0.26$, $P < 0.001$), were positively associated with TTT; whereas higher technological proficiency scores ($r = -0.28$, $P < 0.001$) and biological sex ($t = -1.70$, $P = 0.09$) were negatively associated with TTT. In the subsequent multivariable analysis, age ($\beta = 0.26$, $P = 0.004$), self-rated technological proficiency ($\beta = -0.23$, $P = 0.005$), ethnicity ($\beta = 0.20$, $P = 0.006$) and biological sex ($\beta = 0.15$, $P = 0.04$) added significantly to the predicted TTT. Higher age, lower self-rated technology proficiency scores, non-White ethnicity and male sex were associated with higher TTT. **Conclusions:** Older adults, with lower rated technology proficiency may take longer to become oriented to virtual care applications. Ethnicity and biological sex may play a role in the time needed for orientation to eHealth applications. Considering the technology training support needs of individuals with chronic disease may increase accessibility to eHealth applications.

Chapter 5

Predictors of Technology Training Time for Cancer, Lung Disease and Lung and Liver Transplant Patients Accessing a 12-Week Virtual Exercise and Nutrition Program: Heal-Me TeCH

5.2. Introduction

Vulnerable individuals who are immunocompromised, including those with serious chronic medical conditions such as cancer, organ failure (i.e., cirrhosis and chronic lung disease) and transplantation, have encountered barriers to accessing care both during and post the coronavirus disease (COVID-19) pandemic (1-3). Virtual care, telemedicine, telehealth, or 'eHealth' offers a promising bridge to access multidisciplinary supports and programming, essential in maintaining quality of life and avoiding hospital stays (4). Previous virtual nutrition and physical activity services and programming have demonstrated improved clinical outcomes, quality of life and reduced healthcare utilization (5, 6). eHealth offers accessibility for chronic disease populations whose benefits extend beyond COVID-19 (7). However, there is limited evidence regarding successful virtual service implementation or virtual accessibility and acceptability for these chronic disease populations (8).

To provide effective virtual care beyond the COVID-19 crisis, fundamental changes in eHealth training, technological accessibility and healthcare policy are necessary (9). Evidence-based strategies are needed to inform implementation of effective and sustainable virtual programming. Healthcare providers and allied health/supportive care programs currently have limited direction to effectively and sustainably provide virtual services, supports and eHealth interventions to vulnerable populations (10). Patients in turn need to have access to and awareness of technology and receive education on the use of eHealth before it is widely adopted across patient populations (11). Our team recently conducted a survey of 127 participants taking part in our exercise oncology implementation study to understand their experiences towards virtual and in-person exercise during the pandemic (12- 13). Findings from the survey identified a lack of experience and confidence among individuals with cancer accessing technology and participating in virtual exercise programming (13). The survey

findings also indicated the need for providing technology support to increase participant willingness to engage with novel virtual services (13).

Furthermore, inequities in access to virtual care have contributed to a 'digital divide' (14, 15). Significant barriers to accessing virtual care identified in the literature include older age, presence of chronic disease, low technological proficiency, of ethnic minority or groups that have been historically marginalized and low socioeconomic status (16, 17). Recent literature regarding the digital divide encompasses the concept of eHealth literacy, described as "the ability to seek, find, understand and appraise health information from electronic sources and apply knowledge gained to addressing or solving a health problem" (18). Beyond having the ability to access technology, eHealth literacy encompasses an individual's technology competency, such as patterns of access, usage and online skills (19). eHealth literacy has been reportedly lower in individuals with chronic disease (20). These findings are reflected in a growing body of evidence on the need for eHealth training and screening of patients' potential technological proficiency (14). Technology and eHealth platform tutorials have been proposed as a bridge to accessing eHealth for chronic disease populations (17).

5.2.1. Research Context of Clinical Team

5.2.1.1. Healthy Eating, Active Living, Mindful Energy Application (Heal-Me)

eHealth has also gained increasing popularity through smartphone apps, commonly termed mobile health or 'm-Health' (21). The novel Healthy Eating and Active Living, Mindful Energy application (Heal-Me app), was initiated pre-pandemic to provide virtual access to multidisciplinary healthcare and programming (22). The Heal-Me app was designed to be adapted for and used by a diverse range of chronic disease populations. Heal-Me content is evidence-based and theory informed, co-developed by a team involving patient advisors, behavior change experts, physicians and allied health specialists in physical activity, physiotherapy, nutrition and disease self-management education (22).

5.2.1.2. Heal-Me Personalized Online Nutrition and Exercise Routines (Heal-Me PiONEer)

The Heal-Me Personalized Online Nutrition and Exercise Routines (Heal-Me PiONEer) study delivered virtual care using the Heal-Me app, whose study methods have been reported elsewhere (22). Briefly, Heal-Me PiONEer was a mixed-methods, 12-week, RCT of individuals

with either chronic lung disease, cancer, or solid organ transplant (liver, lung). The trial compared virtual nutrition and physical activity care at three levels of support intensity: (i) standard care; (ii) virtual group-based support through Heal-Me; and (iii) virtual group based and personalized one-to-one support through Heal-Me (22). Heal-Me PiONEer outcomes included impacts on clinical outcomes, acceptability, and cost. However, to access virtual care and navigate the online Heal-Me app, participants were required to possess basic technology proficiencies. For PiONEer study schema refer to Figure 1.

5.2.2. Objectives

The purpose of this sub-study, Heal-Me **Te**chnology **C**ounselling for e-**H**ealth (Heal-Me Tech), was to explore and evaluate the delivery of standardized technology counselling support for chronic disease populations accessing virtual multidisciplinary care. Specifically, objectives were to examine demographic, clinical (i.e. medical, physical fitness), and technological proficiency variables that may predict needed technology training time (TTT). Given the lack of research into factors that predict TTT (and virtual program technology counselling overall), an exploratory approach was taken that included a range of potential predictors.

5.3. Methods

5.3.1. Study Design

A multimethod exploratory descriptive design was utilized to explore the virtual needs and technology proficiency of chronic disease groups accessing virtual multidisciplinary care through Heal-Me PiONEer. Both quantitative and qualitative data were collected to provide a more comprehensive understanding of virtual technology counselling for chronic disease groups.

Standardized virtual technology counselling sessions (TCS) were conducted after randomization of participants to one of the two intervention arms of the Heal-Me PiONEer trial: (1) personnel-light and (2) personnel intensive. For study schema refer to Figure 1. The 'personnel-light' approach to virtual care involved support through *group-based interactions* with the Trainers and other participants during live group exercise and nutrition classes (~3/week). The 'personnel-intensive' approach, in addition to the 'personnel-light' features, involved *one-to-one sessions* to review progress and goals and make any necessary modifications to

programming (up to seven one-to-one consultations with an exercise specialist, and three one-to-one consultations with a dietitian). The increased virtual multidisciplinary support of 'personnel-intensive' was reflected in the Heal-Me app and TCS with an additional messaging feature enabled between participants' and their assigned trainers to facilitate one-to-one program tailoring. Control participants had the option to crossover to the personnel-light intervention after the post-intervention follow-up was complete (Fig. 1).

TCS were led by Heal-Me research staff who underwent Heal-Me app training and had previous experience assisting with Heal-Me app counselling sessions of populations with chronic disease. Research staff followed a detailed standardized script to navigate participants through a list of competencies for navigating each section of the Heal-Me app. The script was developed by Heal-Me research staff (KS, GP, TS), and refined through feedback from technology counselling of individuals with multiple myeloma in an ongoing virtual study involving the Heal-Me app (23). For a list of Heal-Me app competencies covered in TCS refer to Table 1. TCS involved the enrolled Heal-Me participant, with an option for a family member to observe. Ethics approval was granted by the University of Alberta Health Research Ethics Board, Pro00103715 23-Sept-2020. For consent forms refer to Appendix 11. For ethics approval refer to Appendix 12.

Inclusion Criteria: adults (≥18 years of age); one of three chronic disease groups: 1) cancer (survivors who have completed an initial course of chemo/radiotherapy and may be on maintenance therapy); 2) chronic lung disease; and 3) status post-transplant (liver or lung); previous enrollment in exercise rehabilitation program offered by local disease or condition-specific hospital or community-based exercise programs; have access to an Internet connected device; and the ability to communicate in English (22).

Exclusion criteria*:* (1) palliative cancer; (2) individuals receiving compassionate care; (3) individuals deemed unsafe to participate in a virtual exercise program by their specialist, primary care physician, or exercise physiologist; and (4) unable to provide informed consent (22).

5.3.2. Data Collection

Once eligible participants provided informed consent, they were emailed an online link to fill out data collection forms within REDCap. REDCap is a secure research data management system, designed for research study data collection provided by the Women and Children's Health Research Institute (24). TCS took place from November 2020 to September 2021, over Zoom, using a password protected University of Alberta proxy account. TCS occurred after baseline exercise testing and PiONEer randomization (Fig. 1). Sessions were interactive, with participants invited to ask questions and give comments or feedback at any point. Sessions were scheduled for approximately an hour and were timed. Session timing was paused, to the best of the researcher's ability, if questions or discussions deviated from the technology counselling script, or if external issues arose, such as internet connectivity. At the end of each section (i.e. exercise, nutrition, tracking) participants were asked if they had any further questions, which were then clarified before continuing. The TCS were ended after the competency checklist was complete (Table 1), and the participant had no further questions.

Field notes were completed at the end of each session by the research staff and included: overall impressions of the TCS; comments regarding general participant technology competency (i.e. if skills demonstrated were reflective of technology proficiency scoring, app sections/concepts that caused confusion); technological related issues (device and connectivity issues); and any participant feedback, comments or concerns.

5.3.2. Predictor Variables

Participants' self-perceived *technological proficiency* was assessed at baseline prior to the TCS by both a questionnaire and a self-rating. First, previously validated questionnaires were used to measure technological proficiency. Participants completed either the Mobile Device Proficiency Questionnaire (MDPQ) (25) or Computer Proficiency Questionnaire short form (CPQ-12) (26), depending on the participants' preferred device. As an additional step at the beginning of TCS, participants were asked to verbally rate their self-perceived technology proficiency level. The technology proficiency self-rating involved asking participants to rate, on a scale of 0-5, how proficient or confident they perceived themselves to be at using technology such as a computer, tablet, or smartphone. Participants were given standardized cuing: "A zero would mean you are not at all proficient or confident with technology; a five would mean you

would consider yourself as a technology expert." A visual scale was shared on the screen while standardized cuing was given (Fig. 2). This scale was designed based on components of the Technology Proficiency Self-Rating Scale and adapted for the specific needs of an implementation study with a broad population pool (27).

Demographic characteristics included age, biological sex, education level, marital-status, self-identified ethnicity and socioeconomic status. *Clinical characteristics* included disease type (cancer, chronic lung disease, post solid-organ transplantation of liver or lung), and comorbidities as calculated by the Charlson Comorbidity Index (28). Quality of life (QoL) was measured using the World Health Organization-5 Well-Being (WHO WB) questionnaire (29). Vitality was measured using the RAND Short-Form Survey 36-items (SF-36), Vitality subsection (30). Fitness was determined by using the 30 second sit-to-stand results score (number of sit-to-stands in 30 seconds) from the baseline exercise testing (31).

The participants' data related to demographic and clinical data and technology proficiency MDPQ/CPQ-12 questionnaires were collected through the REDCap database. Participant self-rated technology proficiency scores and TCS field notes were entered into REDCap by Heal-Me research staff.

5.4. Data Analysis

5.4.1. Quantitative Analysis

The main outcome variable was the TTT required for orientation to the Heal-Me application, expressed in minutes. MDPQ/CPQ-12 scores were expressed as a percentage. Data related to the Charlson Comorbidity Index, WHO WB, SF-36 and 30 second sit-to-stand score and age were all continuous variables. The following ordinal variables were dichotomized: highest level of education (less than university degree or, university degree or higher), marital status (partner or no partner), ethnicity (majority or minority), technology self-rating (≤ 3, at most 'moderately confident with technology', or, 4-5 'highly confident/ technology expert'), disease type (categorized as cancer or, chronic lung disease or organ transplant) and socioeconomic status ($\leq$ \$79,999 or $\geq$ \$80,000).

Data were imported into the Statistical Package for the Social Sciences (SPSS) for descriptive and variate analysis (V28, IBM Corp). Prior to data analysis an examination of test

assumptions was performed (32). Subsequent analyses were conducted in three phases. First, univariate analysis was conducted to examine associations between the predictors and TTT using one-way ANOVA, *t*-tests, and Pearson's correlations where appropriate. Second, variables that had statistical significance ($P < 0.1$) were retained for the multivariable analysis to determine the independent predictors of TTT. Third, a multiple linear regression model was used to model scores reflecting the dependent variable, TTT, as a function of all predictor variables included in the multivariable model. Values for partial eta squared (PES) were calculated to determine the effect sizes of the individual variables. A power analysis indicated that 129 study participants would provide sufficient statistical power to detect a medium effect size between the independent and dependent variables within a multiple linear regression model using 13 predictors. Thus, the current sample size of 157 was deemed to have sufficient statistical power.

5.4.2. Qualitative Analysis

Field notes taken during the technology training session by research staff and were analyzed using framework analysis (33). Two researchers (KS, ND) coded field notes into framework tables in relation to: (1) participants who identified as lower technology competency (technology self-rating of ≤3); and (2) participants who identified as higher technology competency (technology self-rating of ≥4). Research staff flagged participants who struggled to complete the competencies for navigating each section of the Heal-Me app. Flagged participants were included in the lower technology competency thematic analysis. After initial coding, researchers met to discuss and refine codes into barriers and facilitators towards TCS and consolidate themes. The Capability, Opportunity, Motivation-Behavior (COM-B) Model was developed to understand behaviour change (i.e. successful engagement with virtual technology counselling) and used to inform thematic analysis (34). The COM-B Model was used as a guide to map thematic findings to the three main inter-related factors of the model: (1) capability: an individual's psychological and physical capacity to perform behaviours or activities; (2) opportunity: physical (environment) or social factors (interpersonal influences) external to an individual that influence the behaviour; and (3) motivation: brain processes that direct behaviour (habitual and emotional responses, and analytical decision-making) (34). Identified

domains of the COM-B Model were then used to inform actionable implementation strategies to inform future TCS for the Heal-Me app.

5.5. Results

A total of 163 participants underwent TCS. Of the total Heal-Me Tech participants (N=163), n=66 participants were randomized to Group 2 'Personnel Light'; n=65 randomized to Group 3, 'Personnel Intensive' and n=32 were Group 1 control crossovers (Fig. 1)**.** Participants ranged in age from 20 to 82 years, with an average of 61 years of age (SD= 11.1). The majority of participants were those with a cancer diagnosis (n=106, 68%) followed by those with chronic lung disease (n=28, 18%) and those who had received a lung or liver transplant (n=23, 15%). Females represented 63% of participants (n=99). Most participants self-identified as White (n=136, 87%), had a university degree or higher (n=107, 68%) and were married or common law (n=111, 71%). A total of n=58 participants rated themselves ≤3 on technology self-rating (lower technology proficiency), and n=99 ≥4 (higher technology proficiency). The average age of participants who self-rated lower technology proficiency was 61.5 (SD = 10.1) and higher technology proficiency was 61.0 (SD = 11.1). For demographic characteristics, refer to Table 2.

The average TTT was 46.2 minutes (SD 10.6), ranging from 25 to 83 minutes. Examination of test assumptions indicated that TTT data were not normally distributed. Data were subsequently log transformed after extreme outliers were removed (3 high scores and 3 low scores). Thus, N=157 participants were included in the final analysis. Although variables were highly correlated, data indicated that multicollinearity did not present a significant problem.

The results of the univariate analysis are presented in Table 3. Factors that were positively associated with TTT are as follows: age ($r = 0.42$, $P < 0.001$), self-rated technological proficiency ($t = 5.10$, $P < 0.001$), quality of life ($r = 0.24$, $P=0.002$), energy/vitality ($r = 0.17$, $p=0.04$), ethnicity ($F = 1.97$, $P =0.09$) and number of comorbidities ($r = 0.26$, $P < 0.001$), were positively associated with TTT; whereas higher technological proficiency scores ($r = -0.28$, $P < 0.001$) and biological sex ($t = -1.70$, $P = 0.092$) were negatively associated with TTT. The results of the multiple regression showed that a model using the above demographic and clinical variables was a significant predictor of TTT ($p < 0.001$). The model explained 33% of the variance in TTT.

In the subsequent multivariable analysis, age (β=0.26, P= 0.004), self-rated technological proficiency (β=-0.23, P= 0.005), ethnicity (β = 0.20, P= 0.006) and biological sex, (β= 0.145, P= 0.043) added significantly to the predicted TTT.

Age was the strongest predictor with a medium effect on TTT (PES: 0.059); self-rated technological proficiency (PES: 0.054) and ethnicity (PES: 0.052) showed small to medium effects; and biological sex (PES: 0.027) showed a small effect on TTT (Figure 3). Older age was associated with longer TTT, while higher self-rated technology proficiency scores were associated with shorter TTT (Figure 4). Men took slightly longer than women for TTT, by approximately three minutes. White participants were associated with lower TTT, on average 46 minutes, while participants self-identifying as Asian, Latino, Indigenous, and Arab took on average 51 minutes for TCS.

5.5.1. Technology Counselling Staff Field Note Thematic Findings

Overall thematic analysis identified a theme of 'virtual connectedness'. All participants, regardless of technology proficiency, expressed they were motivated to participate in TCS as a means to connect virtually with other patients and healthcare staff. Thematic findings identified three main barriers experienced during sessions by participants with lower technology self-rating: (1) virtual navigation: participants had trouble conceptualizing the virtual layout of the Heal-Me app (homepage, sections, subsections) and became disoriented; (2) distinguishing between live and pre-recorded sessions: participants had difficulty differentiating between live, interactive sessions (date and time specific) and pre-recorded sessions (independent, accessible any time, pre-recorded videos), i.e. live exercise classes and pre-recorded independent exercise sessions; (3) overestimated technology proficiency: participants overestimated their self-rated technology proficiency, displaying a lack of exposure to, and understanding of the digital skill set associated with use of an eHealth application.

5.5.1.1. Characteristics of Lower Compared to Higher Technology Proficiency Participants

A total of n=27 participants were flagged by research staff as struggling to complete the competencies for navigating the Heal-Me app during the TCS. Common characteristics of flagged participants included repeated questioning over the same concepts, disorientation when navigating different sections of app, requiring repeated demonstrations before

comprehending tasks and lack of familiarity with basic technology proficiency tasks such as microphone unmuting, adjusting device volume, opening or refreshing a web browser and searching a personal inbox. These characteristics were more common for participants who reported rarely using applications and were older aged, reflected in longer TTTs. In contrast, participants with higher technology proficiency reported they had experience using web-based or mobile applications, were more likely to report using their respective device for work and were often of younger age. These participants asked fewer questions and required less reminders and repetitions of demonstrations during TCS. Qualitative thematic findings in relation to the COM-B Model factors are summarized in Figure 5.

5.6. Discussion

The findings of this study provide a novel perspective to facilitating virtual orientation of healthcare applications for chronic disease populations. A primary finding was age independently predicted TTT, with older aged participants taking longer to learn how to use the Heal-Me App (Fig. 4). Older age has been previously reported in the literature as a barrier to accessing virtual healthcare, largely due to lack of exposure and training in newer technologies (11, 17). A recent 2020 systematic review of barriers to implementing telehealth in an aging population found a lack of technical literacy as the most commonly cited barrier in the elderly (35). Other barriers were reported as a lack of motivation/feeling overwhelmed learning new technology skills, cost and lack of technical support (35).

While barriers to using telehealth can affect the accessibility of health services to older adults, elderly populations have much to gain from virtual access to healthcare and supportive programming. Research supports positive medical outcomes with the use of telehealth interventions including decreased psychological distress, increased autonomy, increased cognitive ability and increased quality of life (35). Furthermore, older individuals who use the Internet and related technologies to seek health-related information have improved outcomes in health communication with medical professionals, decision making about their health issues and proper use of health services (16). In individuals with chronic disease, factors of higher age along with lower income, lower education, living alone or in rural areas were found to be associated with lower eHealth use, suggesting eHealth may be least used by individuals who

need it most (17). Goyal et al. found that once older persons adapt to an application, they adhere longer than younger people, who download applications more frequently but lose interest more often (36). Older aged individuals may require additional time to facilitate and solidify learning during virtual orientations, but stand to benefit greatly from increased technological competency and enhanced access to virtual care.

Another finding of this study was a 5-point technology proficiency self-rating scale (Fig. 2) independently predicted TTT, where higher self-rated technology proficiency scores were associated with shorter TTT (Figure 4). Technology barriers and low technology literacy have been cited as major issues that may reinforce disparities in health access in telehealth and eHealth interventions (11). A meta-analysis of individuals with cancer reported low technology literacy and apprehension to using technology as barriers to eHealth (37). Standardized screening of an individual's technological proficiency provides a potentially clinically feasible, simple step to inform and potentially address digital barriers (38). Interestingly, the MDPQ/CPQ-12 as an assessment of technological device proficiency, while significant in univariate analysis, was not found to be significant in the subsequent multivariable analysis for predicting TTT. MDPQ/CPQ-12 questions are based primarily on respective device tasks and do not probe into experience or skills using applications, which may impact the applicability to app orientation and findings.

Ethnicity was found to be an independent predictor of TTT. This finding is consistent with literature surrounding digital divide sociodemographic characteristics: low use of digital technologies has been reported for health purposes among individuals from ethnic and racial minority groups (17,39,40). A recent publication of 17,704 older adults found minority status (African American, Latino and Asian) reduced the odds of using the internet for health information (16). Furthermore, minority status combined with lower socioeconomic status substantially reduced the odds of internet usage for health information (16). Needs of ethnic minoritized populations should be considered in design and implementation of eHealth exercise programming to avoid perpetuating disparities (40,41).

Biological sex was found to be an independent predictor of TTT. Results regarding the influence of biological sex in accessing eHealth among individuals with chronic disease are

inconsistent in the literature. In a 2019 review of sociodemographic factors influencing the use of eHealth in people with chronic diseases, only five of 22 studies showed biological sex as a factor influencing the use of eHealth (17): in three studies, women were found to be more engaged and satisfied with eHealth applications (36,42,43); in contrast two studies showed men were more likely to accept telemonitoring than women (44,45).

While many obstacles are present for hospitals, healthcare providers and researchers to establish telehealth and eHealth services (46), addressing barriers to patient access is a key step to increasing engagement (7). Addressing patient barriers through tailored delivery of eHealth may help increase the prevalence of use (11,17). Literature on successful virtual education emphasizes the importance of recognizing learners' needs and adopting a 'learner-centered' or patient-centered approach for an effective learning experience (47). Considering the learner's previous technology exposures, such as work or other related experience with technology may better inform proficiency capabilities during the TCS, improve accessibility for chronic disease populations and optimize acceptability and effectiveness (37). While other measures for assessing technology proficiency are available (25,26), a simple 5-point rating may be a potential tool for informing TTT during virtual eHealth app orientations.

Thematic barriers may be addressed with virtual education and design strategies from the literature (Figure 5). Difficulty navigating an application could be addressed by ensuring good platform aesthetics. Confusion with virtual concepts such as distinguishing between live and pre-recorded sessions and required technology proficiency skills may benefit from incorporating experiential learning such as engaging features like reminders/prompts, games and videos (37). The involvement of older individuals in the development of m-Health interventions may also help address these virtual barriers (17). However, consideration for design feedback should be given to older individuals' previous technology exposure and use of applications, as more technology proficient individuals may bias design features (i.e. targeting older individuals with less technology experience or exposure to applications may yield more useful feedback).

Strengths of this paper included a novel analysis of predictors for TTT for three chronic disease populations virtually accessing care through a multidisciplinary healthcare application.

The virtual format aligned with COVID-19 policies for social distancing and allowed a greater reach of participants. This study was strengthened by a multimethod analysis of a range of potential factors that might influence TTT, as well as a thematic exploration of virtual orientation sessions from the perspective of research staff educators.

A limitation of this study was a lack of a required skill test by participants following TCS to show successful competency using the app. Future virtual orientations to applications may want to consider incorporating experiential learning and interactive elements such as skill checks as an objective measurement of participant understanding. The self-rated technological proficiency scale was developed by the authors for use in the Heal-Me TeCH study and has not been validated in the literature. The self-rated scale was used to expand on the findings of validated technology proficiency questionnaires, the MDPQ/CPQ-12 (25,26). The majority of participants were female (n=99, 63%), had a cancer diagnosis (n=106, 68%) and self-identified as White (n=136, 87%), limiting generalizability.

The findings of this study provide novel findings related to technology support of individuals with chronic diseases using an eHealth application. While eHealth applications are a promising means to deliver care and programming, barriers to technology use should be considered, as factors such as age and technology proficiency levels, ethnicity and biological sex may lead to healthcare disparities. Technology counselling sessions may help address barriers towards eHealth. Further research is needed to understand barriers to use and explore novel instructional methods for supporting individuals with chronic disease in the use of eHealth applications.

Table 5-1. Heal-Me App Technology Proficiency Skills

Heal-Me App Sections	Skills	Learning Goal
Login	Open internet browser Enter Heal-Me website address Enter login information Use of 'remember me' and 'forgot your password'	Heal-Me is a web-based online app, not downloadable from app store
General Overview Layout	Recognize 'home' page Appropriately navigate to icons/labels to access different areas of the app Navigate back to home screen Access profile icon to logout and reset password	Virtual Navigation Logging out if not on a secure device
Calendar and Live Sessions	View calendar of upcoming classes Connect to live group exercise and nutrition sessions by clicking on secure links Add/cancel class registration	Live vs. recorded material -Live group sessions are scheduled and virtually attended at a specific date and time Virtual Navigation within app subsection
Exercise	Access 'My Exercise Routines' for recorded exercise program created by the study exercise trainer Exercise remotely: select appropriate exercise routine (low or normal energy options); view additional information on exercises (demonstration video, written description); start and pause workout Follow prompts to log exertion level at conclusion of session Interpret 'weekly goals' tracking box and 'target exertion level' Access 'Additional Exercise Minutes' to enter exercise minutes outside of study into text boxes	Areas of app (i.e. progress icons, target exertion level) automatically update Live vs. recorded material -Recorded sessions can be accessed at any time Virtual Navigation within app subsection
Nutrition	Access 'Tracking my nutrition' to enter intake into text boxes Interpret 'nutrition goals' box (i.e. calorie range, number of meals and snacks) set by the study dietitian Access and navigate recipe resource section (breakfast, lunch, dinner)	Understanding study requires only the tracking of protein Virtual Navigation within app subsection Areas of app (i.e. progress icons, nutrition goals) automatically update
Resources	Access study resources (exercise and nutrition) Access app tutorial videos (all steps covered in app training)	Recognize resource section as source to answer app questions and for further study information Virtual Navigation within app subsection
Achievements	Access to see point accumulation based off achieving weekly study requirements through app	This area of app automatically updates Virtual Navigation within app subsection

Table 5-2. Demographic Characteristics

Table 2. Demographic Characteristics N=157			
Age, years, mean (SD)	61 (11.1)	**Disease Group, No. (%)**	
Biological Sex, No. (%)		Cancer	106 (68)
Female	99 (63)	Lung Disease	28 (18)
Male	58 (37)	Lung Transplant	11 (7.0)
Education, No. (%)		Liver Transplant	12 (7.6)
Some/Completed High School	24 (15)	**Ethnic Origin, No. (%)**	
Some University/College	26 (16)	European Origins	136 (87)
Completed University/College	76 (48)	Asian Origins	8 (5.1)
Some/Completed Graduate School	31 (20)	Latin/Central/ South American origins	4 (2.5)
Annual Income, No. (%) n=140		Indigenous/First Nation Origins	2 (1.3)
< $20 000	7 (5)	Arab	1 (1.0)
Between $20 000 - $39 000	20 (14)	Not Disclosed	6 (3.8)
Between $40 000 - $59 000	20 (14)	**Marital Status, No. (%)**	
Between $60 000 - $79 999	20 (14)	Never Married	18 (11)
Between $80 000 - $99 999	24 (17)	Married/Common Law	111 (71)
> $100 000	49 (35)	Divorced/Separated/ Widowed	28 (18)
Not Reported	17 (12)	**Charlson's comorbidity index, mean (SD)**	4.6 (2.0)

Table 5-3. Univariate Analysis of Associations with Technology Training Time

N=157	**Demographic and Clinical Characteristic associations with TTT**		
	n	***r***	***P***
Age	157	0.42	***<.001**
Comorbidities	157	0.26	***<.001**
	n	***t***	***P***
Biological Sex	157	-1.70	***0.092**
Marital-Status	157	0.71	0.48
	n	***F***	***P***
Income	139	1.38	0.24
Disease Type	157	2.06	0.13
Education Level	157	0.66	0.66
Ethnicity	151	1.97	***0.086**
	Behaviour, psychosocial and fitness associations with TTT		
	n	***r***	***P***
WHO WB	157	0.24	***0.002**
SF-36 Energy/Vitality	157	0.17	***0.038**
30 Second Sit to Stand	157	0.40	0.618
Score MDPQ/CPQ-12	157	-0.28	***<.001**
	n	***t***	***P***
Technology Self-Rating	157	5.10	***<0.001**

TTT= Technology Training Time
WHO WB = World Health Organization Well-Being Questionnaire
SF-36 = Short Form Survey 36 Item Energy/ Vitality Section
MDPQ= Mobile Device Proficiency Questionnaire
CPQ-12= Computer Device Proficiency Questionnaire
*denotes statistical significance

Figure 5-1. Study Schema

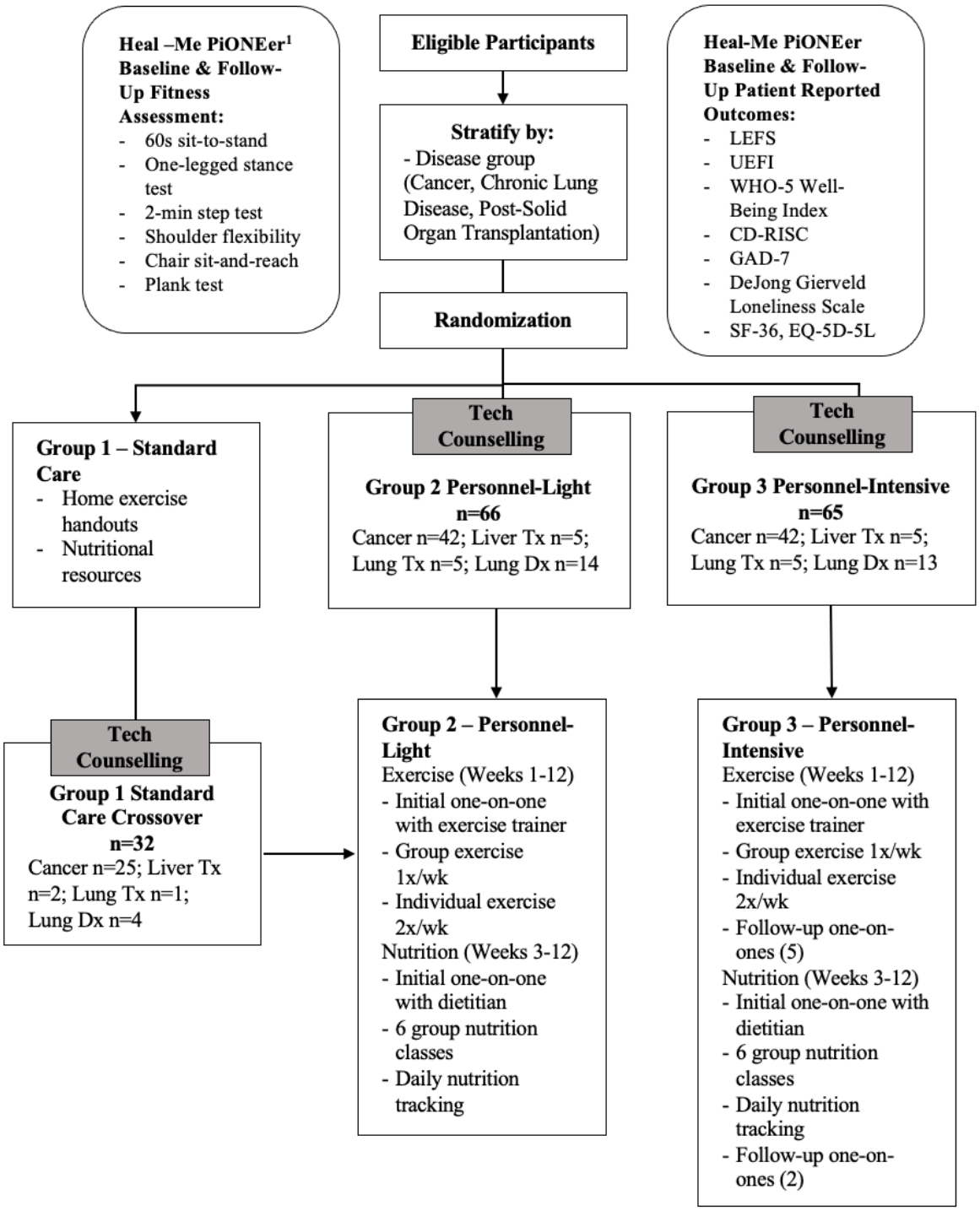


Figure 2. Study Schema. LEFS: Lower Extremity Functional Scale; UEFI: Upper Extremity Functional Index; CD-RISC: Connor Davidson Resilience Scale; GAD-7: Generalized Anxiety Disorder Screener; SF-36: Short-Form Survey; EQ-5D-5L: EuroQol 5 Dimension, 5 Level

[1]Tandon, P. et al. (2022). Heal-me PiONEer (personalized online nutrition and exercise): An RCT assessing 2 levels of app-based programming in individuals with chronic disease.

Figure 5-2. Technology Proficiency Self-Rating Scale

Technology Proficiency Scale	
0	**Not proficient and/or confident with technology (i.e., computers, tablets, smartphones)** E.g.: Uncomfortable with turning on a device like a computer screen
1	**A little proficient and/or confident with technology** You can interact somewhat with technology, but use devices very minimally *(e.g., only make phone calls on a cell phone)*
2	**Sort of proficient and/or confident with technology** You can do some tasks you want or need to using your devices *(e.g., send emails and/or texts)* BUT there are still a lot of areas you are uncomfortable with
3	**Moderately proficient and/or confident with technology** You can do on average most tasks you want or need to using technology/your devices BUT find it challenging if you have to figure something out beyond your comfort level
4	**Highly proficient and/or confident with technology** You can do almost everything you want or need to using technology/your devices Can usually figure out new tasks
5	**Technology "Expert"** You can do everything you want or need to using technology/your devices AND if you don't know how, you can figure it out/ successfully troubleshoot

Figure 1. Technology Proficiency Self-Rating Scale

Figure 5-3. Multivariable Analysis Results

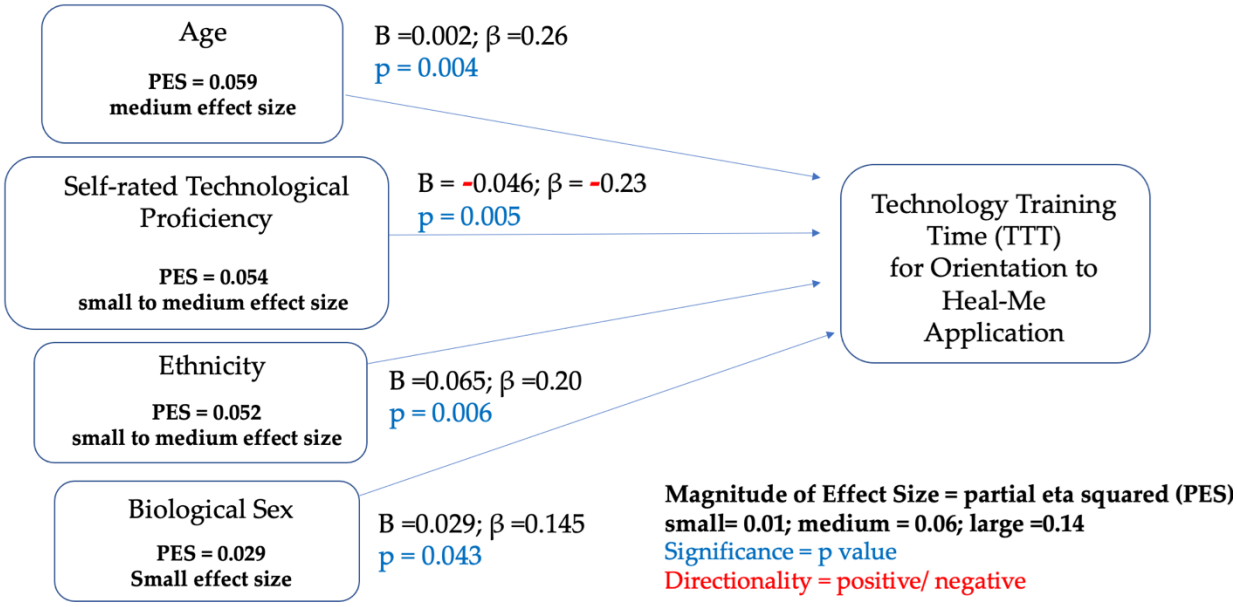


Figure 5-4. Technology Training Time by Age and Self-Rated Technology Proficiency

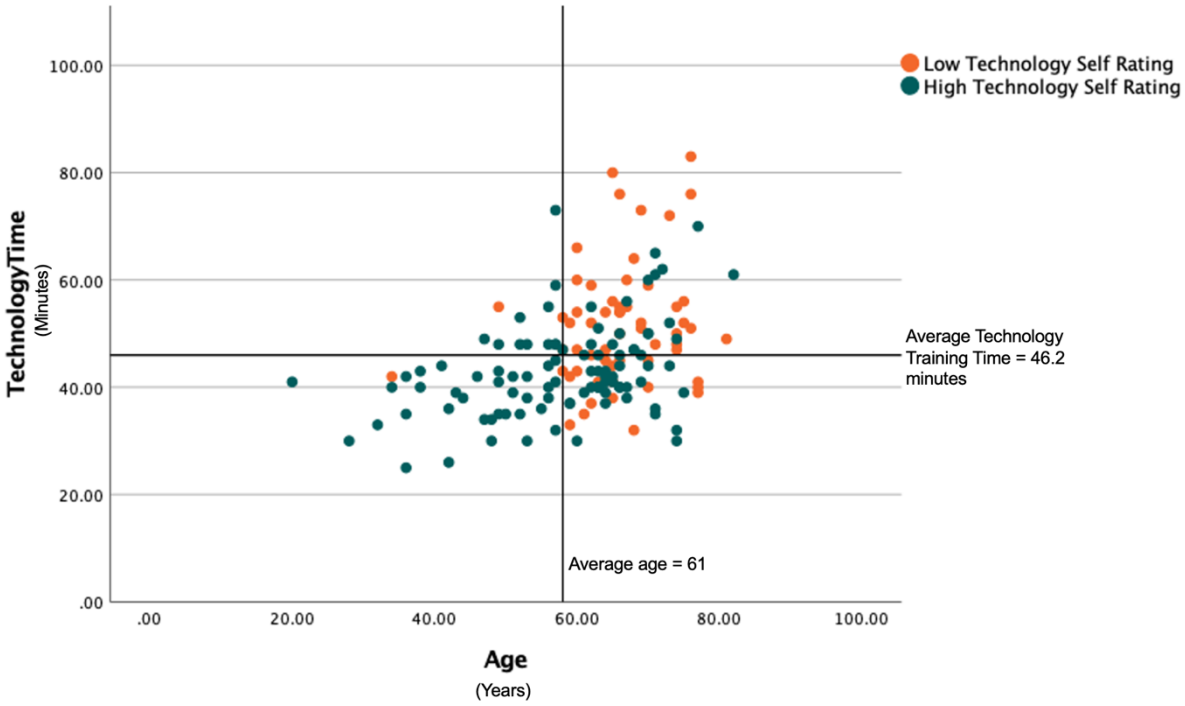
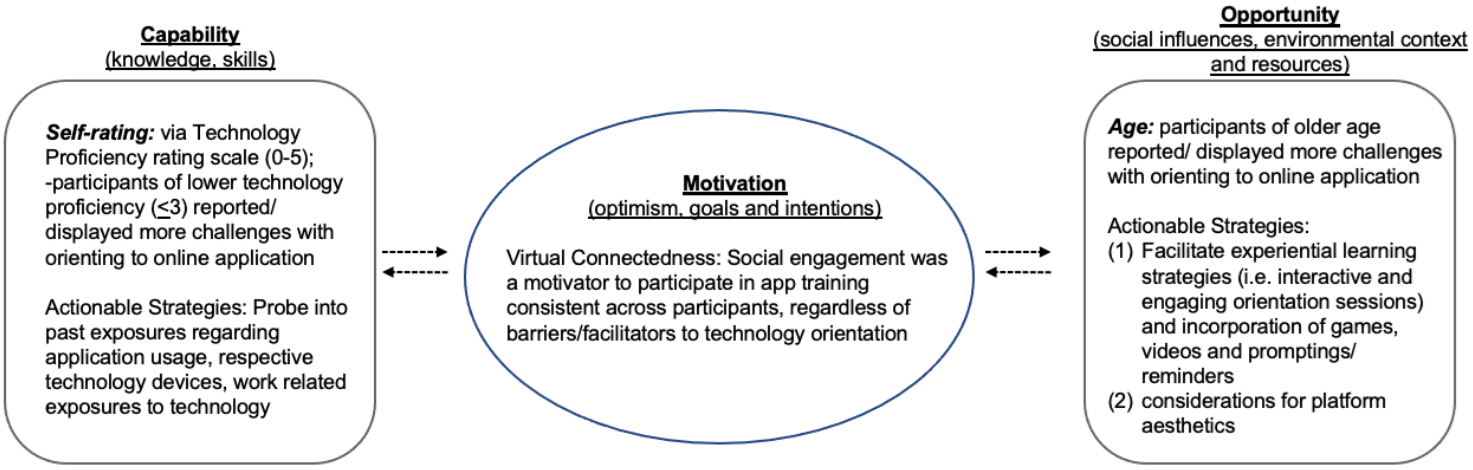


Figure 5-5. Qualitative Thematic Findings[1]



[1]Adapted from Michie S, Atkins L, West R. (2014). The Behaviour Change Wheel Book – A Guide to Designing Interventions. Great Britain: Silverback Publishing.

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Chapter 6

Discussion

Chapter 6

Discussion

6.1. Introduction

Advancements in cancer screening treatments and technologies have led to improved survival rates and a growing population of individuals living with cancer-related treatment effects (1). A robust body of literature demonstrates the benefits of exercise in addressing the needs of the growing population living with or beyond cancer, including emerging research on decreased rates of recurrence, cancer-specific mortality and all-cause mortality (2,3). Having established benefits of exercise for individuals with cancer, focus is now shifting from efficacy (randomized controlled trials) to effectiveness (pragmatic trials and implementation studies) — namely closing the knowledge-to-practice gap by examining how best to implement and integrate exercise counselling, referral and programming into oncology patient care. The purpose of this dissertation was to identify and address specific knowledge-to-practice gaps related to barriers towards implementation of evidence-based exercise oncology practice. A further objective of this dissertation was to support the implementation of cancer-specific exercise programming by using strategies to adapt and integrate evidence-based interventions within specific targeted practice settings. A commentary on study objectives, findings and overall conclusions of this dissertation is provided below.

6.2. Study 1 Objectives

'Implementing Cancer Exercise Rehabilitation: An Update on Recommendations for Clinical Practice'

To provide an update on: (1a) the state of the evidence supporting exercise for survivors of cancer

The primary updates of the 2019 review on the state of the evidence supporting exercise for survivors of cancer was that individuals with cancer participating in higher levels of exercise were found to have fewer treatment-related adverse effects when compared to survivors who performed less/no exercise. A two-part systematic review and meta-analysis by Cormie et al. was summarized (4). Part one involved 36 articles (68,285 participants) and examined the benefit of exercise for outcomes of cancer mortality and recurrence, as well as all-cause mortality. Participating in higher levels of exercise after diagnosis of cancer resulted in

significantly reduced relative risk of cancer mortality (28-44%), cancer-recurrence (21-35%) and all-cause mortality (25-48%) when compared to survivors participating in less/no exercise (4). Part two reviewed 23 RCTs (3,735 participants) and 40 meta-analyses (9,126 patients, including 257 reported studies) examining the effect of exercise on adverse effects of cancer and cancer treatments. The most compelling evidence supported benefits of exercise for psychosocial outcomes of distress, anxiety and depression, as well as symptoms of fatigue during and after cancer treatments across cancer tumour types (4).

Notable literature since the time of this review has continued in the study of exercise benefits toward cancer recurrence and mortality (3). A 2020 physical activity and cancer survival summary by Friedenreich et al. assessed the strength of associations between pre and post diagnosis on all cause or cancer-specific mortality outcomes by cancer site from 145 epidemiologic studies and follow-ups from randomized controlled exercise intervention trials (5). The findings reported highest versus lowest levels of physical activity among individuals with cancer were associated with statistically significant decreases of >20% in cancer-specific or all-cause mortality outcomes in studies that assessed all cancer sites combined and ten other tumor sites (breast, colorectal, female reproductive, glioma, hematologic, kidney, liver, lung, prostate, and stomach cancers). The strongest evidence was observed for all cancer sites combined and breast, colorectal, and prostate cancers with data supporting an effect for all associations examined (i.e., pre- and post-diagnosis physical activity and cancer-specific and all-cause mortality) (5).

Another area of study that has also expanded is exercise for those with advanced chronic cancer, who are not yet palliative or appropriate for end-of-life care. Maintaining function and symptom management is important for this population to maintain quality of life for as long as possible. The unique needs of individuals with advanced cancer (i.e. cancer-related fatigue, dyspnea, bone metastases, nausea, venous thromboembolism) require consideration in terms of exercise screening, testing, and training from those with curative cancers (6). Exercise-related challenges facing both the patient and exercise specialist can be complex and may impact exercise risk and tolerance, requiring adaptations and capacity re-assessments. Timely rehabilitation and exercise, at appropriate volumes, shows promise as a

strategy to optimize physical functioning, symptom management, independence, and quality of life (QoL) (6,7). Further research is needed to determine exercise prescriptions, dosage and safety considerations in this growing population.

To provide an update on: (1b) guidelines for integrating exercise programming in the cancer clinical setting

Given the strength of the evidence supporting exercise, efforts towards implementation of exercise programming into clinical cancer care are warranted. At the time of this review, preliminary community-based efforts towards implementation of cancer-specific programming had begun to emerge in the literature. First, we summarized the findings from three large-scale community-based implementation programs: Livestrong at the YMCA (8), a community-based exercise program carried out in Texas called Fit STEPS for Life (9), and a cancer-specific exercise program called Life Now based out of Western Australia (10). In summary, there was limited availability of community-based, cancer-specific exercise programming. Published implementation programs reported high program attrition, suggesting the need for further exploration on the extent and nature (random or nonrandom) of program adoption, retention and dropouts. Moreover, the overall uptake of community-based exercise programming by cancer survivors relative to the larger population of survivors was low. Finally, there was limited data supporting the benefit of programs for objective physical fitness outcomes, quality of life, cost-effectiveness, as well as longer term general health and cancer outcomes. Further work utilizing implementation methodologies was found to be needed to better understand the critical factors affecting implementation uptake and long-term adoption of exercise.

Since the time of the review, multiple international publications have called for exercise to become a standard of care in oncology (2,11-15), necessitating large scale implementation of cancer-specific exercise programming in clinical and community-based settings. Of note, the American College of Sports Medicine's (ACSM) initiative 'Moving Through Cancer' has issued a call for clinicians and key stakeholders to create an infrastructure within healthcare to make exercise standard practice in oncology by 2029 (16). While international guidelines and calls to action are crucial, they are not meaningful if appropriate exercise counselling is not received by individuals with cancer and exercise programs are not available or accessible. Bridging the gap

of knowledge-to-practice in exercise oncology entails an examination of context-specific barriers and alignment of strategies to address these barriers to support exercise implementation (17,18).

Second to this objective, our review identified barriers towards exercise among individuals with cancer as follows: (1) physical: related to cancer and treatment side effects, fatigue and co-morbidities; (2) psychological: lack of motivation, fear/concerns about safety, desire for cancer specific exercise support; (3) contextual and environmental barriers (i.e. lack of time, cost, return to work, proximity/access to facilities); (4) changing needs over the cancer and survivorship trajectory. Moreover, the literature reported a lack of knowledge among Canadian healthcare professionals (HCPs), as well as exercise specialists in the community regarding appropriate exercise prescription, and limited availability of cancer-specific exercise programs (19). Efforts to address barriers to exercise, particularly those related to adverse effects of cancer, are a key step for individuals with cancer accessing exercise and success of exercise programming implementation.

Finally, we proposed an interdisciplinary model of care for integrating exercise programming into clinical care, including guidelines for medical and pre-exercise screening, exercise testing and programming considerations (Figure 2-2.). Integrating oncologist and HCP exercise counseling and promotion into routine clinical care is seen as critical to increase survivor exercise adoption and promote long-term exercise behaviour change. Subsequent models have been proposed, involving HCPs and exercise specialists in various capacities to establish exercise in oncology patient care (14,20,21). However, a large notable barrier comes from a lack of evidence on successful and feasible implemented cancer-specific exercise programming for HCPs refer to (22).

Since the review, multiple publications have notably addressed implementation barriers, which are complex and at multiple healthcare levels. Santa Mina et al. highlight challenges in implementing exercise guidelines and propose a pathway model to support the transition from HCP to exercise oncology programming (23). The pathway encourages a variety of approaches to exercise oncology implementation in Canada and provides a starting point to create a systematic approach to bridge the knowledge-to-practice gap. Of note is the proposed integration of a qualified exercise professional (i.e. certified exercise physiologist or

kinesiologist) into the oncology clinical team as an additional facilitator for oncology exercise counselling and referral by providing screening and assessment for exercise safety before individuals with cancer initiate exercise programming (23). Adsul et al. examined three oncology exercise implementation studies to describe pragmatic strategies and barriers and facilitators when implementing exercise oncology evidence-based interventions in non-research settings (22). Findings concluded implementation efforts were iterative and nonlinear, requiring different strategies and adaptations to target ongoing identified barriers. A recent scoping review from Purdy et al. evaluating implementation and pragmatism of cancer-specific exercise programs found limited reported information regarding program fidelity, adaptations, and maintenance/sustainability (24). The review identified the need for implementation of pragmatic exercise programs (i.e. interventions in real-world settings) that are both scalable and sustainable.

Notably, a recent comprehensive systematic scoping review analyzed implementation barriers in real-world exercise oncology settings, synthesizing 243 reported barriers towards implementation of exercise into oncology care from 50 original research studies (18). Three main exercise oncology implementation issues were reported: (1) inter-related barriers exist at every level of healthcare to impede exercise implementation into routine cancer care (innovation, individual professional, patient, social context, organization context, economic and political context); (2) the greatest number of barriers were found at the organizational level of healthcare (i.e. structures and resources are not in place to support oncology exercise counselling, prescription or referral); and (3) exercise oncology implementation is complex, requiring input from multiple stakeholders across every level of healthcare (18).

In summary, since the published review, there has been further evidence highlighting the benefits of exercise for individuals with cancer, and an emerging need to investigate how to best translate exercise oncology research into clinical and community-based practice to ensure individuals are receiving evidence-based care.

6.3. Study 2 Objectives

The Alberta Cancer Exercise pilot cross-sectional survey and focus group, 'A practical approach to Informing a Community-Based Exercise Study'

(1) To share the findings related to survivor reported exercise preferences, barriers, and facilitators before and after participation in the Alberta Cancer Exercise (ACE) pilot trial

The aim of this paper was to understand local cancer survivor needs (barriers, preferences/facilitators) prior to and following the Alberta Cancer Exercise (ACE) pilot randomized controlled trial as a means to inform implementation of the ACE province-wide cancer-specific, community-based exercise study (25). The primary findings from the ACE pilot participants are summarized by three identified barriers: (1) a lack of exercise counseling from HCPs, with only 7% indicating referral to exercise from HCPs; (2) the need for earlier introduction of oncology exercise counselling in the cancer care pathway; and (3) a lack of supported referral to oncology exercise programming during and following cancer treatment. These findings are consistent with the growing body of literature regarding the state of HCP oncology exercise counselling and referral (26-28). Moreover, HCP exercise counselling and referral practices are limited and face barriers at multiple levels, notably, a lack of available and accessible cancer-specific exercise programming (18).

While oncology HCPs have been shown to influence a patients' exercise participation by giving effective and timely exercise education (27,29-31), exercise counselling and referral rates have remained consistently low and relatively unchanged in the last decade (18). A 2005 Canadian study found oncologists reported recommending exercise to 28% of their patients (32). Despite growing evidence supporting the benefit of exercise, a 2015 Canadian study reported that less than 20% of individuals with cancer had received education on the importance of exercise from any HCP at any point in the course of their cancer treatment (19). Studies outside Canada show similar findings, with only 9% of oncology nurses and less than 25% of oncology physicians referring survivors to exercise programming (27,31). Furthermore, a survey of 120 Canadian oncologists found that 80% were unaware of exercise guidelines for individuals with cancer, lacking knowledge on screening and identification of appropriate individuals for exercise referral (28). HCPs cite a primary barrier of time in clinic (33), along

with a lack of role definition in the responsibility for exercise education, uncertainty on optimal timing to initiate such a discussion and perceiving a negative attitude towards exercise from individuals with cancer (34,35).

In summary, HCP exercise oncology counselling and referral are critical to provide individuals evidence-based information and guidance. However, larger organizational barriers such as healthcare structures, systems for oncology exercise referral and the current lack of available and accessible exercise programming need to be simultaneously addressed (18).

(2) To describe how the findings informed the design of the current five-year ACE Hybrid-Effectiveness Implementation Study.

To our knowledge, this was the first study using a multi-method integrated knowledge translation (iKT) approach to inform future implementation of cancer-specific exercise programming in a community-based setting. As a formal methodological approach does not yet exist for iKT (36), we chose a multi-method approach including both quantitative and qualitative data collection. We found an iKT method effective in identifying patient-reported actionable outcomes to address needs related to exercise in clinical cancer and community-based contexts. The multi-method design led to the identification of key actionable strategies by enabling a richer understanding of determinants that may influence successful implementation of the exercise program. We were able to provide a more in-depth participant perspective of local exercise preferences, barriers and facilitators. This study also utilized *The Knowledge-To-Action (KTA) model* as a process model to facilitate and provide orientation for actionable steps involved in the implementation process for the pilot trial and the larger ACE province-wide implementation study (37). The ACE pilot study aligned with KTA phases associated with (1) adapting knowledge to the local context and (2) assessing barriers and facilitators to cancer-specific exercise programming in our local context (37). The KTA stepwise approach guided the interpretation findings to inform phase (3) 'select, tailor and implement interventions' (37).

Findings were used to inform acceptable ACE program implementation and optimize survivor program satisfaction. Of note, at the time of publication, ACE programming was still in person, prior to coronavirus disease 19 (COVID-19). Study results, at the time, suggested a supported exercise program involving both a cancer-specific trained exercise specialist and

physiotherapist could potentially prove beneficial for addressing both physical fitness and cancer-related impairments simultaneously. Physiotherapists have since been identified in ACSM's 'Moving Through Cancer' as principal HCPs in prescribing and supporting patients to access appropriate exercise programs (16). However, the initiative acknowledges needing increased oncology education and organizational restructuring to adequately address this role (16). Other key actionable study initiative findings were identified as: (1) ensuring easily accessible community locations; and (2) addressing concerns with exposure to bacteria and viruses in a public facility. Potential actionable options included supported home-based exercise, flexible programming options and/or entry into community-based exercise programs in the post-treatment period of the cancer trajectory.

In summary, given the patient-identified gap in oncology exercise education and support for individuals with cancer, further research exploring the perspective of HCPs on exercise counselling and referral practices was identified as the next critical step to inform integration of exercise into cancer care.

6.4. Study 3 Objectives

Virtual or In-Person: A Mixed Methods Survey to Determine Exercise Programming Preferences During COVID-19

(1) To understand the perspectives of individuals who had previously participated in standardized exercise towards (i) in-person and virtual exercise, and (ii) the use of technology to access virtual exercise programming.

The global COVID-19 pandemic significantly increased barriers and disrupted in-person access to healthcare services for immunocompromised populations. The disruption to access of needed supportive care/allied health services negatively impacted individuals with cancer — individuals who are at increased risk for severe complications from COVID-19 due to immunocompromised side effects of cancer therapies, comorbidities and advanced age (38,39). In light of COVID-19, cancer-specific exercise programming needed to be recontextualized to a virtual delivery environment.

An iKT multi-method approach was again utilized, involving both quantitative and qualitative data, to better understand participants' perspectives. Pre-COVID-19, we conducted a survey and subsequent focus group for local oncology HCPs (33) and piloted HCP oncology exercise counselling, screening and referral tools (40). Through this work, we utilized the implementation theory from the Capability, Opportunity, Motivation—Behaviour (COM-B) Model developed by Michie et al. (41). The COVID-19 survey, and focus group questions were theory informed, mapped from the COMB-B Model constructs and domains (41). Qualitative data were thematically categorized using framework analysis (42), based on our previously described HCP pre-COVID research, and findings were mapped back to the COM-B Model to inform exercise programming implementation.

Primary findings from this study were that a majority of individuals with cancer had limited experience engaging with virtual exercise—at a time when they were also uncomfortable attending in-person exercise due to COVID-19. This highlighted the need for the consideration of alternative modes of exercise programming delivery and implementation strategies. Secondly, technology was identified as a barrier to participating in virtual programming by respondents who reported only having experience exercising in-person. The availability of technology training support for participants was identified as a means to increase willingness and comfort. Sixty-six percent (n = 58 of 88) of respondents who only had experience exercising in-person, reported that technology support would increase their willingness to exercise virtually.

A growing body of evidence supports that successful telehealth implementation involves identifying user technology competencies to facilitate participation (43,44). Providing a standardized technological proficiency assessment tool for initial screening could preemptively identify participants who require further technology support (45). A 2021 scoping review examining best practices in the implementation of telehealth-based cancer multidisciplinary care included 19 review papers and 23 telehealth guidance documents (46). The review findings suggested that for successful telehealth, focus should be on technology competency, device adequacy, participant confidence in utilizing or providing services, and mitigation of the impact on service quality. Lower computer literacy in combination with age has been reported as a

barrier to virtual exercise engagement for individuals with cancer (47). Thus, an aging cancer population with limited exposure to virtual platforms may warrant additional technology support for effective transition to virtual exercise programming. These findings highlighted the need to create and deliver educational content that is matched to both the respective virtual platform and to the participants' levels of capability and confidence in technology.

(2) To understand the facilitators/preferences and barriers towards exercise during COVID-19 to inform ongoing cancer-specific exercise programming.

Thematic findings were mapped to respective domains of the COM-B Model to inform implementation strategies. Primary findings showed that perceived barriers to virtual exercise programming by individuals without virtual exercise experience were identified as facilitators by those who had virtual experience. With appropriately targeted support, perceived virtual exercise barriers—including motivation, accessibility and effectiveness—were identified as facilitators (Fig. 4-3.). Successful transitioning to telehealth for exercise programming was found to be largely influenced by patients' willingness (motivation) and capability to use technology. These findings highlight that successful pivoting from in-person to virtual programming involves a supported transition and more so than just offering virtual programming. Virtual programming may be enhanced by considering accessibility and capability options (i.e. technology and internet availability, competency and skills) and underlying motivation to facilitate greater engagement.

6.5. Study 4 Objectives

'Predictors of Technology Training Time for Cancer, Lung Disease and Lung and Liver Transplant Patients Accessing a 12-Week Virtual Exercise and Nutrition Program: Heal-Me TeCH Study'

(1) To evaluate the implementation of a standardized technology counselling support process for individuals with chronic disease (cancer, lung and liver disease) accessing virtual multidisciplinary care

The rapid upscaling of virtual delivery during COVID-19 presented new contextual barriers and facilitators to exercise implementation for individuals with cancer, along with other vulnerable disease groups such as those with organ failure (i.e., cirrhosis and chronic lung

disease) and following solid organ transplant. While the focus of this dissertation was on cancer implementation, those with chronic lung disease and lung and liver transplant recipients were included in this specific trial. Given the lack of research in technology orientation/counselling to access virtual multidisciplinary programming (exercise and nutrition), a larger sample size allowed for more robust conclusions and generalizability of findings. All trial participants were required to have experience with in-person exercise rehabilitative programming for their respective disease. Participants accessed both virtual exercise and nutrition programming through the Heal-Me application. As exercise implementation is the focus of this dissertation, the technology counselling session involved a thorough orientation to the virtual exercise delivery section of the application. Comprehensive education on protein tracking for the nutrition section was covered in a separate session by the designated study dietician.

An iKT approach was utilized, with previous survey findings used to inform virtual implementation strategies. Standardized virtual technology counselling sessions were implemented for the Heal-Me PiONEer study to specifically address the previously identified barrier of technology and identified facilitator of provision of technology support in accessing virtual exercise programming. A mixed methods exploratory descriptive design was undertaken to explore the virtual needs of chronic disease groups (cancer, chronic lung, post solid organ liver and lung transplant) accessing virtual multidisciplinary care through Heal-Me Pioneer (45). The COM-B Model was again used as a guide to map thematic findings and inform actionable virtual implementation (41). Given the lack of research into factors that predict technology training time (TTT) (and virtual program technology counseling overall), an exploratory approach was taken that included a range of potential demographic, clinical and technology proficiency predictors.

Virtual technology counselling sessions were deemed effective, with only six participants (of N=163) requiring a follow up counselling session to complete the Heal-Me App skills orientation.

(2) To explore the factors influencing technology training time among individuals with chronic disease accessing exercise and nutrition services through the Heal-Me application during COVID-19

A primary finding was age independently predicted TTT, with older aged participants taking longer to learn how to use the Heal-Me App (partial eta squared= 0.059, medium effect size). Older age has been previously reported in the literature as a barrier to accessing virtual healthcare, largely due to lack of exposure to, and training in newer technologies (48,49). In individuals with chronic disease, factors of higher age along with lower socioeconomic status, lower education, living alone and in rural areas have been found to be associated with lower eHealth use, indicating eHealth is potentially least used by individuals who stand to greatly benefit from eHealth use (49).

The second primary finding of this study was that a 5-point technology proficiency self-rating scale independently predicted TTT, in which higher self-rated technology proficiency scores were associated with shorter TTT (partial eta squared= 0.054, small to medium effect size). Considering the learner's needs, such as an individual's technology proficiency prior to a technology counselling session, may improve accessibility for chronic disease populations and optimize acceptability and effectiveness (49,50). Interestingly the MDPQ/CPQ-12 as an assessment of technological device proficiency was significant in the univariate analysis, but not in the subsequent multivariable analysis for predicting TTT. MDPQ/CPQ-12 questions are based primarily on respective device tasks and do not probe into experience or skills using specific web-based or mobile applications, which may impact their value in application-specific technology training needs.

Participants of ethnic minority were associated with higher TTT, with a small to medium effect size (partial eta squared = 0.052). Interestingly, ethnic origin was found to be an independent predictor of TTT despite 90% of study participants identifying as White (n=136 of 151 participants who disclosed their ethnic origin). Study minorities included Asian (n=8, 5%), Latin/Central/South American (n=4, 3%), Indigenous (n=2, 1%), and Arab (n=1, 0.7%). Ethnic minority groups have been reported to use eHealth less, however differences between specific minority groups are unclear (49,51,52). Of note, the combination of minority status and low socioeconomic status substantially reduces the odds of using technology for healthcare purposes (51). Ethnicity may play a role in the time needed for orientation to eHealth applications, however further investigation is required.

Males took slightly longer on average than females in technology orientation, however the implications of this finding are unclear in the literature (partial eta effect size= 0.027, small effect size). Further investigation into potential sex and gender differences in technology training needs is warranted.

Elderly populations with chronic disease have potential to benefit from virtual access to healthcare and supportive programming. Research supports positive medical outcomes with the use of telehealth interventions including decreased psychological distress, increased autonomy, increased cognitive ability and increased quality of life (43). Older individuals who use the Internet and related technologies to seek health-related information have improved outcomes in health communication with medical professionals, decision making about their health issues and proper use of health services (51).

In summary, age and a simple measure of self-rated technology proficiency may aid in determining the TTT needs of individuals accessing multidisciplinary eHealth applications. The role of ethnicity and biological sex may play a role in the time needed for orientation to eHealth applications, but further research is warranted.

6.6. Dissertation Strengths and Limitations

Strengths of this dissertation involve the use of an iKT approach and theoretically informed implementation methodology (41). A criticism of implementation practice centres around unclear or vague methodology and strategies, lacking contextualization and appropriate strategies to address local barriers before implementation commences. Thus, the iKT approach (53) used in this thesis work focused on the perspective of individuals with cancer throughout all KTA process model steps (37). The theoretical framework identified behaviour change domains to aid in understanding and interpreting the qualitative results and guide future implementation strategies. Using models and frameworks allowed for more clarity and transparency in study methodology around implementation.

A limitation of the dissertation was the impact of COVID-19 preventing research work to implement the HCP exercise-oncology counselling and referral strategies in a larger scale study. In respect to patient demographics, patients were predominately individuals with breast

cancer, Caucasian, female and with higher levels of education, limiting generalizability of results. Both surveys were conducted electronically, requiring individuals to have access to technological devices to participate and biasing results towards those with access and potentially higher socioeconomic status. The self-rated technological proficiency scale was developed by the authors for use in the Heal-Me TeCH study and has not been validated in the literature. The self-rated scale was used to expand on the validated technology proficiency questionnaires, the MDPQ/CPQ-12 (54,55). The MDPQ/CPQ-12 focused on device tasks (i.e. using a mouse/ keyboard, sending an email, watching videos, transferring information between a computer and mobile device) and did not capture an individual's confidence towards using technology.

6.7. Recommendations for Clinical Practice

Utilizing appropriate implementation science frameworks or theories may aid in standardizing future approaches to evidence-based exercise oncology implementation, while still allowing for flexibility to address context specific barriers. While there is no optimal methodological framework that has been developed for exercise oncology implementation, an integrated knowledge translation (iKT) approach (53) guided by the KTA process model (37) and implementation theory (41) proved effective in identifying contextual barriers and informing local strategies for exercise oncology implementation. Regardless of implementation strategies used, identified preferences of individuals with cancer towards oncology exercise programming should be considered for successful implementation such as accessibility, supervision by exercise specialists knowledgeable about cancer and tailoring exercise for cancer-related side-effects (i.e. cancer-related fatigue) (56,57).

In regard to oncology exercise counselling and referral, evidence suggests that increased effort should be placed on addressing barriers experienced by individuals with cancer, rather than solely emphasizing education on exercise benefits (58). From the perspective of individuals with cancer, the complexity of barriers to exercise may outweigh any potential benefits. To potentially improve exercise uptake, consideration should be given to address specific barriers relevant to individual with cancer and their phase in the cancer care continuum (pre-treatment,

treatment, post-treatment, survivorship, living with advanced cancer, palliation) and respective tailored exercise goals (Figure 2-1.).

The COVID-19 pandemic has led to the need for restructuring of in-person focused exercise oncology programming and implementation for individuals with cancer. Solely offering in-person clinic and community-based exercise programs may be an outdated approach, with virtual delivery of care evidence vastly expanded in the last two years and showing promise. However, the success and effectiveness of in-person programming for individuals with cancer may not necessarily translate to successful access to virtual programs. Implementation efforts may need to specifically address the nuance of virtual versus in-person exercise programming. Specifically, time and resources may need to be allocated for the upskilling of technological competency and confidence, as well as program support (i.e., dedicated staff monitoring virtual exercise participant performance) to preserve service quality in a virtual setting. Exercise professionals may need to adjust their approaches to match the limitations of virtual engagement and allot time to support the setup of an appropriate home-based virtual exercise environment.

The differences in virtual programming highlight the need to create and deliver content matched to both the virtual platforms and to the participants' levels of capability and technology proficiency. Practical virtual exercise considerations may include: (1) providing participants with technology support in setting up and using their device in preparation for virtual programming, evaluating Internet connectivity and troubleshooting any issues related to the virtual environment (i.e., location of device and alignment of the computer camera for facilitating monitoring of exercise performance); (2) offering various intensity levels of each exercise (light, moderate, vigorous) and demonstrating of the various intensity levels by designated exercise professionals; (4) choosing exercises that can be completed in home environments such as body weight exercises and that consider limitations due to home space and availability of exercise equipment; (5) having each virtual session monitored by a qualified exercise professional who is responsible for monitoring participant performance, correcting exercise form and helping troubleshoot technology issues that occur; (6) consider remote

exercise safety and adapt emergency procedures for virtual functionality (i.e. medically stable, family member present, emergency contacts provided) (59).

The need to educate skills required for use of eHealth applications and web-based platforms is of great importance (60). The provision of virtual training and education to patients and involved oncology exercise professionals and HCPs with virtual implementation is a key factor for success (60,61). Older age and lower technology proficiency ratings may be an indicator of increased resources (time allotment) to facilitate successful virtual comprehension. Those identifying as ethnic minorities, as well as males, may take longer for virtual orientation. However, further investigation into potential ethnic minorities and sex and gender differences in technology training needs is warranted.

6.8. Future Directions for Research

While research is promising, there is a need for continued investigation into associations between physical activity and cancer survival in adequately powered, randomized controlled trials, as well as a need for evidence to support trial design, implementation, and evaluation. Additional large scale randomized controlled trials are still necessary to determine specific effects on understudied tumour groups (aside from breast, prostate and colorectal cancers) and ethnic minority populations, as well as advanced cancer populations. Furthermore, clarification is still needed on the optimal exercise prescription parameters (frequency, intensity, modality and volume) and type of exercise over the continuum of prehabilitation, treatment and into survivorship, those living with advanced cancer and palliative care.

Exercise oncology implementation in real-world settings is not well understood. Basen-Enguist and Parker propose three action areas that succinctly summarize the current exercise oncology implementation need: (1) to expand availability of evidence-based physical activity programs for survivors; (2) provide patient-centered screening and referral of cancer survivors to exercise services/programs; (3) expand dissemination and implementation research to test service delivery models for evidence-based exercise interventions (62).

Thus, further research is needed exploring large scale implementation efforts to establish oncology exercise counselling referral, while simultaneously implementing sustainable clinic

and community-based exercise programming to refer to. Contextualizing barriers and adapting exercise oncology implementation to address context-specific barriers at all levels of healthcare is critical in creating sustainable and effective programming (62). The integration of a qualified exercise professional (i.e. certified exercise physiologist or kinesiologist) into the oncology clinical team has been proposed for enhancing exercise uptake, providing screening and assessment for exercise safety to appropriate oncology exercise programming (23). Oncology exercise professionals have the potential to support HCP-identified exercise counselling and referral barriers such as lack of time and knowledge and should be considered in future implementation efforts (23).

Virtual oncology exercise and chronic disease programming is a rapidly emerging area that needs further evidence-based implementation studies from oncology HCP, exercise professional and patient perspectives. More implementation research is needed specifically addressing virtual programming barriers and facilitating technology counselling training for exercise professionals and immunocompromised populations. As individuals from minoritized populations are less likely to access eHealth (52,63), needs of ethnic minoritized populations should be considered in design and implementation of eHealth exercise programming to avoid perpetuating disparities (63). Future efforts should consider diverse ethnic, cultural and economic contexts in eHealth technology design for ensured inclusivity of all intended audiences accessing virtual care (63,64). Further evidence is needed to inform development of mHealth solutions and to understand key elements of designing, implementing, and evaluating successful mHealth applications for managing chronic disease populations (65,66).

6.9. Summary

The purpose of this dissertation was to identify and address gaps in exercise oncology evidence-based care for individuals with cancer. A further objective of this dissertation was to provide research evidence to guide the implementation of cancer-specific exercise programming. The purpose of the update on recommendations for clinical practice was to summarize the state of the evidence supporting exercise for individuals with cancer and guidelines for integration of exercise programming in the cancer clinical setting. An integrated

knowledge translation (iKT) approach was utilized for all studies (53), with methodology informed by implementation theory that proved effective in identifying barriers and developing strategies towards local exercise oncology implementation. Dissertation studies involving surveys and focus groups pre-COVID-19 and surveys mid-COVID-19 were conducted to understand the barriers and facilitators/preferences of individuals with cancer towards exercise participation and inform ongoing cancer-specific exercise programming. Findings provided valuable information to inform implementation strategies for in-person and virtual oncology exercise programming. The implementation of standardized technology counselling support for individuals with chronic disease (cancer, lung and liver disease) accessing virtual multidisciplinary care identified predictors influencing technology training time. Older aged participants required longer training sessions to become proficient, while higher self-rated technology proficiency scores were associated with shorter technology training times.

The dissertation has examined the research evidence regarding exercise oncology programming and the current scope of cancer-specific exercise implementation. Important questions remain to be answered regarding implementation methodology and theoretical foundations (implementation science), the scope of barriers at all healthcare levels and feasibility, sustainability and cost effectiveness of exercise programming in oncology clinical and community-based settings.

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APPENDICES

APPENDIX 1 ABSTRACT – HEALTHCARE PROVIDER SURVEY

Preferences and barriers of health care providers in cancer clinical care practices regarding exercise counseling and referral

Accepted Abstract for Canadian Physiotherapy Congress, November 2018, Montreal, QC, Canada.

Suderman, K, Culos-Reed, S.N., Pituskin, E. McNeely, M.L.

Background/Rationale: Exercise has been shown to have significant benefits for cancer survivors during the course of their treatment and disease into survivorship. Health care providers (HCPs) are in an optimal position to provide exercise counselling and positively impact exercise behavior. Cancer survivors, however, report a lack of counselling on exercise options and available programs.
Purpose: To determine HCP preferences, barriers and facilitators towards exercise counseling and referral of cancer survivors to community-based exercise.
Relevance: As physical therapists (PTs) are the primary discipline involved in provision of exercise in the clinical setting, understanding the issues facing HCPs can inform PT's role in facilitating exercise among cancer survivors.
Methods: An evidence-based theory informed cross sectional questionnaire was conducted on a sample of HCPs (N=47) at the Cross Cancer Institute, Edmonton. Questionnaire responses were analyzed quantitatively. Responses were then mapped to a behavior change model inform potential future implementation strategies.
Results: Across all HCP disciplines: 92% recommended exercise counseling to be performed at multiple time points; 72% reported being, at most, 'somewhat' confident towards exercise counseling; and 17% reported performing daily exercise counseling with patients. The most common HCP identified barrier to exercise counseling was time, followed by a lack of knowledge regarding appropriate exercise. The most common facilitator was the 'interdisciplinary team', including access to physical therapy services.
Conclusion: This study has identified current exercise counseling practice and preliminary barriers and facilitators to exercise counseling of cancer survivors from the HCPs' perspective to inform future implementation strategies and improve current practice.

APPENDIX 2 ABSTRACT – EXERCISE SCREENING AND REFERRAL IMPLEMENTATION

Integrated Knowledge Translation to Inform Implementation of Exercise Counselling and Referral of Cancer Survivors

Accepted Abstract for American College of Sport Medicine's 67th Annual Meeting. May 2020. San Francisco, CA, United States.

Suderman, K, Culos-Reed, S.N., Pituskin, E. McNeely, M.L.

BACKGROUND: There is limited evidence supporting successful implementation of exercise-programming for cancer survivors into cancer clinical care pathways. We designed and launched a five-year hybrid effectiveness and implementation study to evaluate the relative benefit from an Alberta wide clinic-to-community-based cancer and exercise model of care – the Alberta Cancer Exercise (ACE) program, and to evaluate the implementation ACE into clinical cancer care.
PURPOSE: To determine HCP preferences, barriers and facilitators towards exercise counselling and referral of survivors to ACE at the Cross Cancer Institute (CCI) in Edmonton, Alberta, and to test the feasibility of in-clinic, HCP-informed implementation tools.
METHODS: Stage I: A theory-informed electronic questionnaire was distributed to HCPs at the CCI, of which N=47 responded (Aug – Oct 2017). A subsequent focus group N= 7 (May 2018) of CCI HCPs was held to probe into questionnaire findings and to determine potential actionable strategies. **Stage II:** Responses were mapped to the COM-B and tools were developed to specifically target the needs of HCPs in the head and neck cancer (HNC) tumor group. Educational packages were distributed to HCPs (N=9) for in-clinic use for 4 weeks, corresponding to ACE recruitment for Spring programming (March – April 2019). Referral of HNC survivors to local ACE programming was tracked.
RESULTS: Stage I: Across all disciplines, only 17% of HCPs reported performing exercise counseling with survivors. The most common HCP identified barrier to exercise counseling was time, followed by a lack of knowledge regarding appropriate exercise. The most common facilitator was the 'interdisciplinary team', including access to physical therapy services. **Stage II:** Tool-based implementation strategies were developed and involved an educational package and exercise screening algorithm that was distributed to HCPs. A total of 14 new HNC survivors were referred to ACE Spring programming, representing more than double the average number of previous HNC referrals (n =6) per session. HCPs reported the implementation tools to be 'somewhat' to 'very helpful'.
CONCLUSION: HCP-identified implementation tools can enhance exercise-counseling and referral practices and improve referral to community-based exercise programming.

APPENDIX 3 – GRANT OF PERMISSION FOR REPUBLICATION

Grant of Permission **October 4, 2022**

Dear Dr. Suderman,

Thank you for your interest in our copyrighted material, and for requesting permission for its use.

Permission is granted for the following subject to the conditions outlined below:

Licensed Content: Suderman K, McIntyre C, Sellar C, McNeely ML. Implementing cancer exercise rehabilitation: an update on recommendations for clinical practice. Current Cancer Therapy Reviews. 2019 Aug 1;15(2):100-9.

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Sincerely,

AMBREEN IRSHAD

Senior Editor

Partnering to Develop an Alberta Cancer Exercise (ACE) Program: Evaluation of Impact Indicators

(A study to evaluate outcomes from a community-based exercise program for survivors of cancer)

CONSENT FORM

This form is part of the process of informed consent. It is designed to explain this research study and what will happen to you if you choose to be in this study. If you would like to know more about something mentioned in this consent form, or have any questions at anytime regarding this research study, please be sure to ask your doctor, nurse or physical therapist. Read this consent form carefully to make sure you understand all the information it provides. You will get a copy of this consent form to keep. You do not have to take part in this study and your care does not depend on whether or not you take part. This study is being conducted by researchers at the University of Alberta, University of Calgary, Cross Cancer Institute and Tom Baker Cancer Centre. This study will take place in Edmonton and Calgary, and the Cross Cancer Institute is one of the centres. The study is funded through a grant from the MSI Foundation.

Your doctor has referred you to the study. You are being asked to participate in this study because you have indicated that you are interesting in participating in a community-based exercise program for survivors of cancer.

Your participation in this study is entirely voluntary. Please take your time to make your decision. It is recommended that you discuss with your friends and/or family about whether to participate in this study.

"WHY IS THIS STUDY BEING DONE?"

You are being asked to take part in this study because you have received treatment for your cancer and you have expressed an interest in taking part in a community-based exercise program that is specifically designed to address the needs of survivors of cancer.

"WHAT DO WE HOPE TO LEARN?"

We hope to learn more about the outcomes from offering a community-based exercise program for survivors of cancer. We want to see whether survivors are

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We hope to learn more about the outcomes from offering a community-based exercise program for survivors of cancer. We want to see whether survivors are interested and able to take part in the program and if outcomes are similar to those seen in supervised clinic and hospital based programs. If the program is acceptable to survivors and shows benefit for physical fitness and quality of life outcomes, we plan to expand the program to other community-based exercise facilities in Alberta.

"WHAT IS INVOLVED IN THIS STUDY?"

In this study, you will receive one of two treatments. You will be "randomized" into one of two groups. Randomization means the treatment to which you are assigned is determined by chance. It is like flipping a coin. You will have an equal chance of being assigned to group 1 or 2. You will be told which treatment you will be receiving.

Group 1

Standard Care Group. If you assigned to this group, you will be asked to continue with your usual physical activities for a 16-week period. You will receive education on the importance of physical activity after a cancer diagnosis and how to become more active after cancer treatment. After the 16 weeks, you will have the option to take part in the 8-week supervised exercise program at the Don Wheaton YMCA.

Group 2

ACE Exercise Group. If you are assigned to this group, you will take part in the 8-week supervised exercise program at the Don Wheaton YMCA. The exercise program will be tailored to your fitness level, and will be designed to address your personal fitness or lifestyle goals. After the 8-week program, you will have the option to continue with an 8-week maintenance program at the YMCA.

All participants will have measurements taken at the start of the study, at 8 weeks, 16 weeks, and 24 weeks to see the effect of the exercise on their physical fitness, symptoms and quality of life.

"HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?"

About 80 people will take part in this study in Alberta.

"WHAT WILL MY PARTICIPATION INVOLVE?"

If you want to take part in this study you will be required to sign the consent form. We will collect your relevant medical history and demographic information.

You will have the following tests and procedures:

1. Body composition measurement: We will measure your height and body weight. As well, we will take a measurement of your waist size with tape measure. These measurements take between 2 and 3 minutes to complete.

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2. Aerobic fitness measurement: We will have you do one of the following fitness tests to determine your fitness level: 1) a submaximal test on a stationary bike; or 2) a submaximal walking test on a treadmill at a progressive incline; or 3) a 6-minute walk test in a hallway on a flat surface. The choice of which test to use will be decide based on your health and preference. All three tests are submaximal tests, meaning that you will exercise at a moderate level to a specific heart rate (i.e., bike or treadmill test) or for a specific time period (i.e., 6-minute walk test). The aerobic fitness testing takes between 10 and 15 minutes to complete.

3. Musculoskeletal fitness measurement: we will measure your grip strength, perform a submaximal strength test for your arms (bench press) and your legs (leg press), and assess your flexibility using a sit-and-reach test and shoulder elevation measure. We will also assess your balance using a one-legged stance balance test. These tests take around 30 minutes to complete.

4. Cancer-related symptoms: We will assess symptoms associated with your cancer treatments using the Memorial Symptom Assessment Scale. This 24-item scale asks you about any symptoms you may be experiencing as a result of your cancer treatment, how often you are experiencing the symptoms and the severity of the symptom. This questionnaire takes 5-10 minutes to complete.

5. Health-related Quality of Life: We will assess your quality of life using the Functional Assessment of Cancer Therapy-General scale. This 27-item questionnaire asks specific questions about your physical wellbeing, social/family wellbeing, emotional wellbeing and functional wellbeing. This questionnaire takes around 10 minutes to complete.

"HOW LONG WILL I BE INVOLVED IN THE STUDY?"

You may be in this study for approximately 24 weeks. Each testing session will take around an hour and a half (90 minutes) to complete.

"WHAT ARE THE SIDE EFFECTS?"

The main side effect from exercise testing and training is secondary muscle soreness. You may notice that your muscles are sore for a couple of days after the testing session and during the first week or so of the exercise program. We expect that these symptoms will get better as you get used to exercise. As well, the exercise program will be personalized to you to minimize excessive soreness and modified as needed if you experience any excessive muscle soreness or fatigue from your exercise sessions.

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Every medical treatment including the standard treatment has side effects, which your doctor will explain to you. It is important that you know and understand the possible side effects of the treatments given in this study. The main risk associated with exercise is musculoskeletal injury (injury to the muscles, tendons, joints or bones). Your exercise sessions will be supervised and your program designed to minimize this risk by slowly increasing the amount and intensity of your exercise over time.

There is also a very small risk of heart issues (such as chest pain, irregular heart rate, heart attack) should you exercise too intensively. To avoid any risks associated with exercise, you will be screened to ensure it is safe and appropriate for you to take part in the exercise program. All exercise will be of a low to moderate intensity level to minimize the stress on the heart and body. As well, we will monitor your vital signs (e.g., heart rate, blood pressure) during the exercise testing and if needed, when you exercise at the YMCA. If any concerns are identified at any time, you will be referred back to your doctor for further evaluation. If any issues develop during the study period, your exercise sessions may be held or discontinued.

If you have any side effects, you should call the study coordinator/ physical therapist in charge of the study. The telephone numbers are on the last page of this form.

"WHAT ARE MY RESPONSIBILITIES?"

You must be willing to attend all scheduled study visits, undergo all of the testing described above and complete the questionnaires. It is very important that you inform the study research coordinator of any injuries, side effects or health problems that you may be experiencing as well as any medications (prescribed or holistic) that you are taking while on this study.

"WHAT ARE MY ALTERNATIVES?"

You may choose not to participate in this study. Your healthcare provider will discuss lifestyle issues for survivors with you. Right now, the usual treatment at the Cross Cancer Institute is to receive counseling on the value of physical activity and healthy living after completion of cancer treatments.

"ARE THERE ANY BENEFITS TO PARTICIPATING IN THIS STUDY?"

Participation in this study may or may not be of personal benefit to you. However, based on the results of this study, it is hoped that patient care can be improved in the long-term.

"CAN I WITHDRAW FROM THIS STUDY?"

In discussion with you, your doctor at the Cross Cancer Institute, either at his/her own initiative or at the request of the sponsor of this study, may withdraw you from the study at any time if it is in your best interests. Taking part in this study is voluntary; you may withdraw from the study at any time if you wish to do so. If you

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decide to stop participating in the study, we encourage you to talk to your doctor first. The researchers may stop your treatments for reasons such as:

- You are unable to tolerate the exercise.
- You sustain an injury as a result of participation.
- You experience an adverse effect during or after exercising.
- Your doctor no longer feels this is the best treatment for you.

No matter which group you are randomized to, even if you stop treatment early, we would like to keep track of you and your health for the 24-week study period to look at the long-term effects of the study treatments. Should you decide to withdraw from the study at any time, information collected on you up until that point would still be provided to researchers.

"ARE THERE COSTS TO ME FOR TAKING PART IN THIS STUDY?"

You will not have to pay for the treatment you receive in this study. We will provide $6.00 per visit to cover your parking costs at the University of Alberta when you come for any tests or procedures associated with the study. Costs associated with attending the 8-week exercise program at the YMCA will be covered. There may be additional costs to you for taking part in this study such as:

- transportation
- parking costs at the YMCA
- meals
- babysitting, etc.

"WHAT ARE MY RIGHTS AS A PARTICIPANT?"

If you suffer an injury or become ill as a result of participating in this research, you will receive all medical treatments (or services) recommended by your doctors. No compensation will be provided beyond this point. However, it is important to note that nothing said in this consent form alters your legal rights to recover damages (e.g. legal action). If new information becomes available or there are changes to the study that may affect your health or willingness to continue in the study, you will be told in a timely manner.

"WILL MY PERSONAL INFORMATION BE KEPT CONFIDENTIAL?"

Identifiable health information will be collected from you and from your medical record at the Cross Cancer Institute during this study. This information may be used by the researchers who are carrying out this study, and may be disclosed to others as described below. Any research proposal to use information that identifies you for a purpose other than this study must be approved in advance by the Health Research Ethics Board of Alberta-Cancer Committee. Direct access to your identifiable health information collected for this study will be restricted to the researchers who are directly involved in this study except in the following circumstances: Your identifiable health information may need to be inspected or copied from time to time for quality assurance (to make sure the information being

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used in the study is accurate) and for data analysis (to do statistical analysis that will not identify you). The following organizations may do this inspection:

- Health Research Ethics Board of Alberta-Cancer Committee, the institutional review board at this centre
- Members of the Regulatory/Audit team at the Cross Cancer Institute, for quality assurance purposes
- Health Canada

Any disclosure of your identifiable health information will be in accordance with the Alberta Health Information Act. As well, any person from the organizations listed above looking at your records on-site at the Cross Cancer Institute will follow the relevant Alberta Health Services and the relevant Alberta Innovates-Health Solutions Health Research Ethics Board of Alberta-Cancer Committee policies and procedures that control these actions. Any disclosure of your identifiable health information to another individual or organization not listed here will need the approval of the Health Research Ethics Board of Alberta-Cancer Committee. Your identifiable health information collected as part of this study, which includes records of your progress, your responses to the questionnaires and your diaries will be kept confidential in a secure AHS facility.

The researchers who are directly involved in your study may share information about you with other researchers, but you will not be identified in that shared information except by a number. The key that indicates what number you have been assigned will be kept secure by the researchers directly involved with your study and will not be released.

Although absolute confidentiality can never be guaranteed, Alberta Health Services will make every effort to keep your identifiable health information confidential, and to follow the ethical and legal rules about collecting, using and disclosing this information in accordance with the Alberta Health Information Act and other regulatory requirements. The information collected during this study will be used in analyses and will be published and/or presented to the scientific community at meetings and in journals, but your identity will remain confidential. It is expected that the study results will be published as soon as possible after completion.

A description of this clinical trial will be available on http://www.ClinicalTrials.gov, as required by U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

This study's registration ID number to use on this web page is: NCT02330575

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"WHO DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?"

For information about your disease and/or research related injury/illness, you may contact the Principal Investigator, Margie McNeely at 780-432-8716 or 780-248-1531 or page her through the Cross Cancer Institute Switchboard at 780-432-8771 to answer any questions you have about this study. If your doctor or physical therapist has not been able to answer or resolve your questions and/or concerns about this study, or if you feel at any time that you have not been informed to your satisfaction about the risks, benefits, or alternatives to this study, or that you have been encouraged to continue in this study after you wanted to withdraw, you can call the Alberta Health Services Patient Concerns Department at 780- 432-8585 or toll free at 1-877-753-2170.

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UNDERSTANDING OF PARTICIPANTS

I can refuse to take part or withdraw from this study at any time without jeopardizing my health care. If I continue to take part in the study, I will be kept informed of any important new developments and information learned after the time I gave my original consent. I also give consent for the Principal Investigator and Alberta Health Services (the Custodian) to disclose identifiable health information, as per the Alberta Health Information Act, to the organizations mentioned on the previous pages. I have read and understood all of the information in this consent form. I have asked questions, and received answers concerning areas I did not understand. I have had the opportunity to take this consent form home for review and discussion. My consent has not been forced or influenced in any way. I consent to participate in this research study. Upon signing this form I will receive a signed copy of the consent.

(PRINT NAMES CLEARLY)

_____	_____	_____
Name of Patient	Signature of Patient	Date
_____	_____	_____
Name of Person Obtaining Consent	Signature of Person Obtaining Consent	Date

Patient Study Number or Hospital Number: _____

Was the patient assisted during the consent process in one of the ways listed below?
□ Yes □ No

If yes, please check the relevant box and complete the signature space below:

□ The consent form was read to the patient, and the person signing below attests that the study was accurately explained to, and apparently understood by the patient.
□ The person signing below acted as a translator for the patient during the consent process.

_____	_____
Signature of person assisting in the Consent Discussion	Date

Please note: More information regarding the assistance provided during the consent process should be noted in the medical record for the patient if applicable.

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APPENDIX 5 HEALTH ETHICS APPROVAL – ALBERTA CANCER EXERCISE PILOT

HREBA Health Research Ethics Board of Alberta Cancer Committee

Health Research Ethics Board of Alberta
Cancer Committee
1500, 10104 - 103 Avenue NW
Edmonton, Alberta, T5J 4A7
Telephone: (780) 423-5727
Fax: (780) 429-3509
Email: cancer@hreba.ca

CERTIFICATION OF RESEARCH ETHICS REVIEW

This is to acknowledge that the following study has been reviewed and on behalf of the Health Research Ethics Board of Alberta (HREBA) – Cancer Committee (CC) I am granting approval to your participation in the research study.

Ethics ID:	HREBA.CC-14-0153_REN2
Principal Investigator:	Margaret McNeely
Co-Investigator(s):	Kerry Courneya S. Nicole Culos-Reed Jacob Easaw Anil Abraham Joy Harold Lau Albert Murtha Matthew Parliament Edith Pituskin
Student Co-Investigator(s):	There are no items to display
Study Title:	Partnering to Develop an Alberta Cancer Exercise Program: Evaluation of Impact Indicators
Sponsor (if applicable):	MSI Foundation

Effective: August 17, 2016 **Expires:** August 16, 2017

This Committee is constituted and operates in accordance with the Alberta Health and Information Act (HIA), the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2), Good Clinical Practice (GCP) Guidelines of the International Conference on Harmonization (ICH), Health Canada's Food and Drug Regulations (FDR), Part C, Division 5.

The deliberations of the Cancer Committee included all elements described in Section 50 of the HIA and found the study to be in compliance with all applicable requirements of the Act.

The membership of this Committee complies with the membership requirements for Research Ethics Boards defined in Part C, Division 5 of the Food and Drug Regulations. This Committee carries out its functions in a manner consistent with Good Clinical Practices and has reviewed and approved the clinical trial protocol and informed consent form for the trial which is to be conducted by the Qualified Investigator named above at the specified clinical trial site. This approval and the views of the Committee have been documented in writing.

Members of the Committee who are named as investigators or co-investigators in research studies do not participate in discussion(s) related to, nor vote on, such studies when they are presented to the Committee. It

is not our policy to release the names of the Committee membership, however, an outline of its composition can be provided.

Please refer to the accompanying letter for conditions of approval.

Approved on behalf of CC by,	**Date:**
Jackson Wu , HREBA-CC	August 22, 2016

APPENDIX 6 SURVEY -ALBERTA CANCER EXERCISE PILOT

ACE PILOT – post study focus group May 2016

DEMOGRAPHIC INFORMATION

I am a cancer survivor ☐ **I am a family member/ friend** ☐

1) What age range are you in?
   a) 18-25 years
   b) 26-39 years
   c) 40-54 years
   d) 55-69 years
   e) > 70 years

2) What is your current work status:
   a) Retired.
   b) Sick leave/disability.
   c) Part-time.
   d) Full-time.
   e) Homemaker/ work at home.

3) Marital status:
   a) Married.
   b) Single.
   c) Divorced.
   d) Widowed.

4) Treatment received (select all that apply):
   a) Surgery.
   b) Chemotherapy.
   c) Radiotherapy.
   d) Other.

5) How would you currently rate your general health?
   a) Excellent.
   b) Very Good.
   c) Good.
   d) Fair.
   e) Poor.

6) Where do you currently live?
   a) Edmonton
   b) Outside of Edmonton in _____

ACE PILOT – post study focus group May 2016

PHYSICAL ACTIVITY BACKGROUND

I am a cancer survivor ☐ **I am a family member/ support person** ☐

1) How often did you exercise PRIOR to your cancer diagnosis?
   a) Never – completely sedentary.
   b) Rarely.
   c) Sometimes (less than 150 minutes per week of moderate intensity exercise).
   d) Regularly (at least 150 minutes per week of moderate intensity exercise).
      - My job involved a lot of physical activity_____.

2) How often did you exercise DURING treatment for your cancer?
   e) Never – completely sedentary.
   f) Rarely.
   g) Sometimes.
   h) Regularly.

3) Before taking part in ACE how often did you exercise FOLLOWING completion of your cancer treatment?
   a) Never – completely sedentary.
   b) Rarely.
   c) Sometimes.
   d) Regularly.

4) How long did it take you to drive/ commute to the Don Wheaton Family YMCA?
   _____

5) Do you have a current membership at a fitness facility?
   - Yes.
   - No.

6) Did you continue your membership with the YMCA?
   a) Yes.
   b) No.

Family member/ support person start here… Survivor continue….

7) How often are you CURRENTLY exercising?
   a) Never – completely sedentary.
   b) Rarely.
   c) Sometimes (less than 150 mins per week of moderate intensity exercise).
   d) Regularly (at least 150 minutes per week of moderate intensity exercise).

8) What type(s) of exercise do you currently participate in? _____

9) What type(s) of exercise have you found most enjoyable in the past? _____

10) What is your favorite exercise during the winter? _____

11) What is your favorite exercise during the summer? _____

12) Do you have any exercise equipment at home? Yes ☐ No ☐
Yes, but collecting dust. ☐

13) If so, list any home exercise equipment you currently own:
_____
_____

ACE PILOT – post study focus group May 2016

EXERCISE COUNSELING (survivors)

1) Did you receive exercise counseling at any point from the time of your cancer diagnosis to treatment completion?
   a) Discussion initiated by oncologist or other health care professional.
   b) Discussion initiated by you.
   c) Not discussed.

   - If so, whom did you receive this counseling from?

   a) Oncologist.
   b) Nurse.
   c) Physical therapist.
   d) Exercise professional.
   e) Other_____

   - How did you hear about the ACE exercise program?

   a) Oncologist.
   b) Nurse.
   c) Physical therapist.
   d) Teaching or education session at the Cross Cancer Institute.
   e) Other_____

2) Would you have preferred to be counseled about exercise at some point after your cancer diagnosis?
   a) Yes.
   b) No.
   c) Maybe.

3) If you were to receive exercise counseling, when would you prefer this counseling?
   a) Before cancer treatment.
   b) During cancer treatment.
   c) Immediately after cancer treatment.
   d) 3 to 6 months following cancer treatment.
   e) At least 1 year after cancer treatment.

4) Where would you prefer this counseling to take place?
   a) Cancer Centre.
   b) Community fitness facility.
   c) Home.

5) Who do you think should deliver this counseling?
   a) Oncologist.
   b) Nurse.
   c) Exercise specialist/ Physical Therapist at Cancer Centre.
   d) Exercise specialist in Community.
   e) Another cancer survivor.
   f) Other.

6) If you were to receive exercise counseling, what would be your preferred method of exercise counseling?
   a) Face to face.
   b) Telephone.
   c) Videotape.
   d) Written materials (e.g. mail, brochure/pamphlet, book).
   e) Interactive workbook.
   f) Internet.
   g) No preference.

EXERCISE PROGRAM PREFERENCES & CHARACTERISTICS

As a participant who has taken part in the ACE program – please answer the following:

1) If you were to take part again, who do you think should be available as a support resource to you while completing the exercise program? (Please select all that apply).
   a) Oncologist.
   b) Nurse.
   c) Physical therapist.
   d) Exercise specialist.
   e) Cancer Survivor.
   f) Other.
   g) None of the above.

2) What intensity would you prefer the exercise to be?
   a) Light.
   b) Moderate.
   c) Vigorous.
   d) No preference.

3) When would you prefer to exercise?
   a) Early morning.
   b) Mid-morning.
   c) Afternoon.
   d) Evening.
   e) No preference.

4) What days of the week would you like to exercise?
   a) Weekdays.
   b) Weekend.
   c) Both weekdays and weekend.

5) What would be your preferred structure for the exercise program?
   a) Flexible.
   b) Scheduled.
   c) No preference.

6) Whom would you prefer to exercise with?
   a) Exercise alone.
   b) Exercise with friends or family member.
   c) Exercise with other cancer survivors
   d) No preference.

7) If you were to participate in the ACE program again, which of the following would you prefer?
   a) Exercise alone.
   b) Exercise with a trainer only (one-on-one).
   c) Exercise in a small group.
   d) Exercise in a large group.
   e) No preference.

8) Where would you most like to exercise?
   a) Outdoors.
   b) At home.
   c) At a community fitness facility.
   d) Cancer center.
   e) Other_____.
   f) No preference.

9) Would you like to perform exercise activities that are the:
   a) Same each time.
   b) Different each time.
   c) No preference.

10) In what type of setting would you prefer to perform the exercise program?
   a) Supervised.
   b) Unsupervised.
   c) No preference.

11) Would you like to perform exercise activities that are the:
   a) Competitive.
   b) Recreational.
   c) No preference.

12) How far would you be willing to travel to take part in an exercise program?
   _____(time) or _____ (distance)

APPENDIX 7 STAKEHOLDER ENGAGEMENT GROUP QUESTIONS – ALBERTA CANCER EXERCISE PILOT

ACE Pilot: post study focus group session May 2016

'Big Picture' of Alberta Cancer Exercise Program

Format: large flip chart page per person – 5 to 10 minutes to complete. Then circulate each sheet among the group.

Background:

The primary purpose of the ACE Pilot Study was to pilot test the operational strategies and processes, and preliminary efficacy of the planned provincial Alberta Cancer Exercise (ACE) program.

The processes involved include:

- operational issues: YMCA membership registration, payment methods, confidentiality
- recruitment feasibility,
- program adherence and completion rates,
- characteristics of participating survivors,
- efficacy of the intervention outcomes,
- program attrition,
- safety,
- preliminary cost effectiveness.

Question:

As a participant in the pilot study, please answer the following question based on your experience and perspective…

"If Alberta's Cancer Control were to develop a provincial cancer-specific exercise program, what should it look like?"

Small group Discussion Items:

Benefits and Barriers:

What were the benefits of participating in the ACE pilot exercise program?

Were there any benefits you did not anticipate?

What were the negative aspects or drawbacks of participating in ACE?

What do you feel are the main issues or barriers that might prevent you or others from taking part in the ACE program in the future?

Preferences:

If you were to participate in the ACE program again, what types of exercises would you be most interested in doing?

What components of the ACE program would motivate you to want to attend?

Sustainability:

1. **Long-term behavior change:**

What aspects of the ACE program would be important to help you continue with an exercise program over the long-term?

2. **Financial sustainability of the program:**

The grant funding will provide support to the ACE program for 4 years this includes resources to facilitate recruitment to the program, screening, exercise testing, referral, and exercise programming. How do you think the program should be funded over the long-term (beyond the grant funding period)?

APPENDIX 8 CONSENT FORM – ALBERTA CANCER EXERCISE STUDY

Informed Consent Form for Participation in a Research Study

The Alberta Cancer Exercise "ACE" Program for Cancer Survivors Supporting Community Based Exercise Participation for Health Promotion and Secondary Cancer Prevention

(A study to evaluate the benefit of a community-based exercise program for cancer survivors)

Protocol ID: *HREBA.CC-16-0905*

Principal Investigator: Dr. Margaret McNeely, PT, PhD
Department of Physical Therapy/ Department of Oncology
University of Alberta & Cancer Care Alberta
Phone: 780-248-1531

Co-Investigator: Dr. Nicole Culos-Reed, PhD
Faculty of Kinesiology
University of Calgary
Phone: 403-220-7540

Sponsor/Funder(s): Alberta Innovates Health Solutions and Alberta Cancer Foundation

Emergency Contact Number (24 hours / 7 days a week):
Cross Cancer Institute Telephone Triage Nurse:
780-432-8919 or 1-877-707-4848 (toll free)

You are being invited to participate in a research study because you have you have indicated that you are interested in participating in a community-based exercise program for survivors of cancer. This consent form provides detailed information about the study to assist you with making an informed decision. Please read this document carefully and ask any questions you may have. All questions should be answered to your satisfaction before you decide whether to participate.

The study staff will tell you about timelines for making your decision. You may find it helpful to discuss the study with family and friends so that you can make the best possible decision within the given timelines.

Taking part in this study is voluntary. You may choose not to take part or, if you choose to participate, you may leave the study at any time without giving a reason. Deciding not to take

part or deciding to leave the study will not result in any penalty or any loss of medical or health-related benefits to which you are entitled.

The principal investigator, who is one of the researchers, or the site research coordinator will discuss this study with you and will answer any questions you may have. If you do consent to participate in this study, you will need to sign and date this consent form. You will receive a copy of the signed form.

WHAT IS THE BACKGROUND INFORMATION FOR THIS STUDY?

The growing population of cancer survivors in Alberta has brought attention to the long term toll of cancer and its treatment on the body, mind and overall health of survivors. Exercise is an effective intervention that can optimize the health and wellbeing of cancer survivors and possibly reduce rates of cancer recurrence and secondary cancers. Currently standard care at Cancer Care Alberta sites across the province is to receive counseling on the value of physical activity and healthy living after the completion of cancer treatments.

The Health Research Ethics Board of Alberta – Cancer Committee (HREBA-CC), which oversees the ethical acceptability of research involving humans, has reviewed and granted ethics approval for this study.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to evaluate the benefit of a community-based exercise program for cancer survivors. The program is called the Alberta Cancer Exercise (ACE) Program. Our aim is to support persons who have been diagnosed with cancer to adopt an active lifestyle in order to improve their health outcomes. We want to see whether survivors are interested and able to take part in the program and if outcomes are similar to those seen in supervised research studies and hospital-based programs. We also plan to study how best to implement the program in the different community-based exercise facilities across Alberta.

WHAT ARE OTHER OPTIONS IF I DECIDE NOT TO PARTICIPATE IN THIS STUDY?

You do not have to take part in this study in order to receive continued medical care. You may choose not to participate in this study. Your healthcare provider will discuss lifestyle recommendations with you. Right now, the usual treatment at the Cross Cancer Institute is to receive counseling on the value of physical activity and healthy living after the completion of cancer treatments.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 2500 people across Alberta will take part in this study.

WHAT WILL HAPPEN DURING THIS STUDY?

STUDY INTERVENTION

If you agree to take part in this study, you will undergo screening and fitness testing and will be referred to a suitable exercise program. The exercise program will take place at selected sites including the Universities of Alberta and Calgary, Lethbridge College, as well as at municipal fitness centres, YMCAs and Wellspring locations across the province. You will take part in a twice weekly exercise program for a 12-week period (one session in-person and one session virtually) and will be followed for study outcomes for up to a year. The exercise program will be tailored to your fitness level and designed to address your personal fitness or lifestyle goals.

All participants will have measurements taken at the start of the study at 12-weeks, 24 weeks and at one year to see the effect of exercise on their physical activity levels and quality of life. Participants taking part in the study will have the option to receive follow-up questionnaires after completing the exercise program each year for up to 5 years (remaining length of the study).

STUDY PROCEDURES

Established Procedures

The following established procedures will be done as part of this study. All participants will have physical fitness measurements taken at the start of the study and at 12-weeks. Some of these procedures may be done as part of your standard care, in which case the results may be used. Some may be done more frequently than if you were not taking part in this study. Some of these procedures may be done solely for the purpose of the study. If the results show that you are not able to continue participating in the study, the principal investigator will let you know.

- Body composition measurement: We will measure your height and body weight. These measurements take between 1 and 2 minutes to complete.

- Aerobic endurance measurement (in-person program only): We will have you perform a 6-minute walk test in a hallway on a flat surface to determine your fitness level. This is a submaximal test, meaning that you will walk at a moderate pace for the 6-minute time period. The walk test takes around 10 minutes to complete.

- Musculoskeletal fitness measurement: we will measure your lower body endurance (30s Sit to Stand), and assess your flexibility using a sit-and-reach test and shoulder elevation measure. We will also assess your balance using a one-legged stance balance test. These tests take around 20 minutes to complete.

- Optional fitness tests: Depending on your interests and the location of your exercise program you may have the option to undergo additional fitness testing including the following: Grip strength (upper body strength); Plank test (core endurance); a submaximal/ maximal strength test for your arms (bench press) and your legs (leg press).

Questionnaires

You will be sent a link to an online questionnaire package through a secure REDCap website housed by the Faculty of Medicine and Dentistry at the University of Alberta. You will complete the questionnaire at the start of the study, at 12 weeks, at 24 weeks, and at one year. The purpose of the questionnaire is to understand how the program affects different aspects of your life.

- The revised Edmonton Symptom Assessment Scale : this questionnaire asks you to rate symptoms related to your cancer and cancer treatment. This questionnaire is usually administered as part of your standard care. This questionnaire takes about 5 minutes to complete.
- Stage of Change (at start of study only): This questionnaire asks about your readiness to take part in exercise. This questionnaire takes 1 minute to complete.
- Exercise preferences questionnaire (at the start of the study only): This questionnaire asks about your exercise goals and the type of exercises you would like to take part in. This questionnaire takes 1 minute to complete.
- Physical activity level: We will ask you about your physical activity level using the Godin Exercise Leisure-time Questionnaire. This 6-item questionnaire asks specific questions about the type, intensity, frequency and duration of your average weekly physical activity. This questionnaire takes around 2-3 minutes to complete.
- Function: We will assess your function using the Upper and Lower Extremity Functional scales. These questionnaires ask you to rate your difficulty performing daily tasks. These questionnaires will take about 5 minutes to complete.
- Cancer-related Quality of Life: We will assess your quality of life using the Functional Assessment of Cancer Therapy-Fatigue Scale. This 39-item questionnaire asks specific questions about the impact of your cancer and cancer treatment on your physical wellbeing, social/family wellbeing, emotional wellbeing, functional wellbeing and fatigue. This questionnaire takes around 10 minutes to complete.
- Cost effectiveness: We will assess the cost effectiveness of the program using the EQ-5D-5L. This 5-item questionnaire asks questions about your mobility, self care, usual activities, pain/discomfort and anxiety/depression. This questionnaire should take 2-3 minutes to complete.

Considerations given the Covid-19 Pandemic

In the event that in-person sessions need to be suspended due to the Covid-19 pandemic, the ACE program will be offered in a virtual format only. If needed, your follow-up assessments will also be done virtually and will replace the in-person tests.

Alternate tests to be completed if virtual exercise only (completed as possible):

i. Body composition: weight
ii. Two-minute step test: you will march in place for a two minute period. We will count the number of marching steps you are able to complete.
iii. Musculoskeletal fitness: timed sit-to-stand, shoulder flexion (flexibility), sit-and-reach test to assess flexibility and one-legged stance (balance);

The information you provide is for research purposes only and will remain strictly confidential. Some of the questions are personal; you may choose not to answer them.

Even though you may have provided information on a questionnaire, these responses will not be reviewed by individuals not involved in this study, e.g., your health care practitioner/team. If you would like them to know this information, please bring this to their attention.

WHAT ARE THE POTENTIAL SIDE EFFECTS FROM PARTICIPATING IN THIS STUDY?

You may experience side effects from participating in this study. Some side effects are known and are listed below, but there may be side effects that are not expected. You should discuss these with the principal investigator or research coordinator. The risks and side-effects of the standard or usual treatment will be explained to you as part of your standard care. These risks are not included in this consent form.

The main side effect from exercise testing and training is secondary muscle soreness. You may notice that your muscles are sore for a couple of days after the testing session and during the first week or so of the exercise program. We expect that these symptoms will get better as you get used to the exercise. As well, the exercise program will be personalized to you to minimize excessive soreness and modified as needed if you experience any excessive muscle soreness or fatigue from your exercise sessions.

It is important that you know and understand the possible risks of the treatments given in this study. The main risk associated with exercise is musculoskeletal injury (injury to the muscles, tendons, joints or bones). Your exercise sessions will be supervised and your program designed to minimize this risk by slowly increasing the amount and intensity of your exercise over time.

There is also a very small risk of heart issues (such as chest pain, irregular heart rate, heart attack) should you exercise too intensively. To avoid any risks associated with exercise, you will be screened to ensure it is safe and appropriate for you to take part in the exercise program. All exercise will be of a low to moderate intensity level to minimize the stress on the heart and body. If any concerns are identified at any time, you will be referred back to your doctor for further evaluation. If any issues develop during the study period, your exercise sessions may be held or discontinued.

If you have any side effects, you should call the principal investigator or study coordinator in charge of the study. The telephone numbers are on the last page of this form.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

Participation in this study may or may not be of personal benefit to you. Possible benefits include improved physical fitness and better energy. Based on the results of this study, it is hoped that in the long-term, patient care can be improved.

WHAT ARE MY RESPONSIBILITIES AS A STUDY PARTICIPANT?

If you choose to participate in this study, you will be expected to:

- Tell the study research coordinator about your current medical conditions;
- Tell the study research coordinator about all prescription and non-prescription medications and supplements, including vitamins and herbals, that you may be taking and check with the research coordinator before starting, stopping or changing any of these. This is for your safety as these may interact with the intervention you receive on this study;
- Tell the study research coordinator if you are thinking about participating in another research study;
- Attend all scheduled study visits, undergo all of the procedures described above and complete the questionnaires.
- Inform the study research coordinator of any injuries, side effects or health problems that you may be experiencing

HOW LONG WILL I BE PARTICIPATING IN THIS STUDY?

The study exercise program will last for about 12 weeks. Your initial fitness test will take part on the first day of the program and the follow-up testing session will occur on the last day of the program. Each testing session will take around an hour and a half (90 minutes) to complete.

WILL THERE BE ANY LONG-TERM FOLLOW-UP INVOLVED WITH THIS STUDY?

If you stop receiving the study intervention early, we would like to keep track of your health for up to the one year study period to look at the long term effects of the exercise intervention on your health. We would do this by having you come back to the Rehabilitation Clinic in Corbett Hall at the University of Alberta for the fitness assessments and/ or by completing the questionnaire.

In the event it is necessary to further evaluate the safety or efficacy of the community-based cancer exercise program it may be necessary to have access to additional information about your health status. The study team may attempt to obtain study-related information about your health from you or from other private sources, including your care physician. This may include contacting you again by phone or letter, but only if you have not withdrawn your consent for future contact. However, contacting you, your care physician or using other private sources of information, is optional, please indicate your decision using the check boxes below.

You give permission to the study research coordinator or member of the study team to attempt to obtain study-related information about your health status to further evaluate the safety or efficacy of the community-based cancer exercise program. This may include contacting your care physician, or by contacting you by phone or letter (i.e., future contact).

☐ Yes ☐ No Participant's Initials: _____

Name/phone number of care physician: _____

CAN I CHOOSE TO LEAVE THIS STUDY EARLY?

You can choose to end your participation in this research (called early withdrawal) at any time without having to provide a reason. If you choose to withdraw early from the study without finishing the intervention, procedure or follow-up, you are encouraged to contact the principal investigator or research coordinator. If you decide to stop participating in the study, we encourage you to talk to your doctor first. You may be asked questions about your experience with the study intervention.

You may withdraw your permission to use information that was collected about you for this study at any time by letting the research coordinator know. However, this would also mean that you withdraw from the study. Information that was recorded before you withdrew will be used by the researchers for the purposes of the study, but no additional information will be collected or sent to the sponsor after you withdraw your permission.

CAN MY PARTICIPATION IN THIS STUDY END EARLY?

In discussion with you, your doctor at the Cross Cancer Institute, either at his/her own initiative or at the request of the sponsor of this study, may withdraw you from the study at any time if it is in your best interests.The principal investigator may stop your participation in the study early, and without your consent, for reasons such as:

- You are unable to tolerate the exercise.
- You sustain an injury as a result of participation.
- You experience an adverse effect during or after exercising.
- Your doctor no longer feels this is the best treatment for you.
- The sponsor decides to stop the study;

If this happens, it may mean that you would not receive the study intervention for the full period described in this consent form. If you are removed from the study, the principal investigator will discuss the reasons with you and plans will be made for your continued care outside of the study.

HOW WILL MY PERSONAL INFORMATION BE KEPT CONFIDENTIAL?

If you decide to participate in this study, the principal investigator and study staff will only collect the information they need for this study.

Records identifying you, including information collect from your medical files/records, such as your Electronic Medical Records (EMR), Netcare, charts, etc., will be kept confidential to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document.

Authorized representatives of the following organizations may look at your identifiable medical/clinical study records at the site where these records are held for quality assurance

purposes and/or to verify that the information collected for the study is correct and follows proper laws and guidelines:

- The Health Research Ethics Board of Alberta – Cancer Committee, which oversees the ethical conduct of this study
- Members of the Regulatory/Audit team at the Cross Cancer Institute, for quality assurance purposes

Authorized representatives of the above organizations may **receive** information related to the study from your medical/clinical study records that will be kept confidential in a secure location and may be used in current or future relevant health research. Your name or other information that may identify you will not be provided (i.e., the information will be de-identified). The records received by these organizations will be coded with a number. The key that indicates what number you have been assigned will be kept secure by the researchers directly involved with your study and will not be released. To protect your identity, the information that will be on your assessment forms and questionnaires will be limited to your study ID and initials.

Any disclosure of your identifiable health information will be done in accordance with federal and provincial laws including the Alberta Health Information Act (HIA). The organizations listed above are required to have organizational policies and procedures to protect the information they see or receive about you, except where disclosure may be required by law. The principal investigator will ensure that any personal health information collected for this study is kept in a secure and confidential AHS facility as also required by law.

If the results of this study are published, your identity will remain confidential. It is expected that the information collected during the study will be used in analyses and will be published and/or presented to the scientific community at meetings and in journals, but your identity will remain confidential. It is expected that the study results will be published as soon as possible after completion. This information may also be used as part of a submission to regulatory authorities around the world to support the approval of this intervention.

Even though the likelihood that someone may identify you from the study data is very small, it can never be completely eliminated. Every effort will be made to keep your identifiable information confidential, and to follow the ethical and legal rules about collecting, using and disclosing this information.

Data collected will be entered into the secure RedCap server held at the University of Alberta and data will only be used for research purposes.

Studies involving humans sometimes collect information on race and ethnicity as well as other characteristics of individuals because these characteristics may influence how people respond to different interventions. Providing information on your race or ethnic origin is voluntary.

WILL MY HEALTHCARE PROVIDER(S) BE INFORMED OF MY PARTICIPATION IN THIS STUDY?

Your family doctor/health care provider will be informed that you are taking part in a study so that you can be provided with appropriate medical care. If you do not want your family doctor/health care provider to be informed, please discuss with your study team to find out your options.

WILL THERE BE ANY COSTS INVOLVED WITH PARTICIPATING IN THIS STUDY?

You will not have to pay for the exercise program you receive in this study. We will provide a parking pass to cover your parking costs at the University of Alberta when you come for any tests or procedures associated with the study. Costs associated with attending the 12-week exercise program in the community will be covered. You will have to pay if you wish to continue to take part after the 12-week program. The cost to continue in the program for a 12-week maintanence period will be subsidized; however, the cost may vary among facilities (fee for service). There may be additional costs to you for taking part in this study such as:

- transportation
- parking costs at the YMCA or municipal fitness centres
- meals
- babysitting, etc.

Possible Costs After the Study is Complete

You may not be able to receive the study intervention after your participation in the study is completed. There are several possible reasons for this, some of which are:

- Your caregivers may not feel it is the best option for you;
- You may decide it is too expensive and insurance coverage may not be available;
- The intervention may not be available free of charge.

The principal investigator will discuss these options with you.

WILL I BE COMPENSATED FOR PARTICIPATING IN THIS STUDY?

You will not be paid for taking part in this study. However in the case of research-related side effects or injury, as a direct result of participating in this research, you will receive all medical treatments or services recommended by your doctors.

Although no funds have been set aside to compensate you in the event of injury or illness related to the study treatment or procedures, you do not give up any of your legal rights for compensation by signing this form.

WHAT ARE MY RIGHTS AS A PARTICIPANT IN THIS STUDY?

You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study. You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of these results, please contact the principal investigator.

The results of this study will be available on a clinical registry; refer to the section titled "Where can I find online information about this study?". Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form you do not give up any of your legal rights against the hospital, investigators, sponsor, involved institutions for compensation or their agents, nor does this form relieve these parties from their legal and professional responsibilities.

IS THERE CONFLICT OF INTEREST RELATED TO THIS STUDY?

There are no conflicts of interest declared between the principal investigator and sponsor of this study.

WHAT IF RESEARCHERS DISCOVER SOMETHING ABOUT ME AS A RESEARCH PARTICIPANT?

During the study, the researchers may learn something about you that they didn't expect. For example, the researchers may find out that you have another medical condition.

If any clinically important information about your health is obtained as a result of your participation in this study, you will be given the opportunity at that time to decide whether you wish to be made aware of that information.

WHERE CAN I FIND ONLINE INFORMATION ABOUT THIS STUDY?

A description of this clinical trial will be available on http://www.clinicaltrials.gov, as required by U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

The study registration number to use this website is: NCT02984163

WHO DO I CONTACT FOR QUESTIONS?

If you have questions about taking part in this study, or if you suffer a research-related injury, you should talk to the project coordinatior or principal investigator. These person(s) are :

Dr. Christopher Sellar, PhD (Coordinator: Northern Alberta) 780-492-6007

Name	Telephone
Ms. Tanya Williamson, BKin (Coordinator: Southern Alberta)	403-210-8482
Name	Telephone

Dr. Margaret McNeely can also be contacted by calling 780-248-1531.

If you have questions about your rights as a participant or about ethical issues related to this study and you would like to talk to someone who is not involved in the conduct of the study, please contact the Office of the Health Research Ethics Board of Alberta – Cancer Committee at:

Telephone: 780-423-5727 Toll Free: 1-877-423-5727

SIGNATURES

Part 1 - to be completed by the potential participant.

	Yes	No
Do you understand that you have been asked to take part in a research study?	☐	☐
Do you understand why this study is being done?	☐	☐
Do you understand the potential benefits of taking part in this study?	☐	☐
Do you understand the risks of taking part in this study?	☐	☐
Do you understand what you will be asked to do should you decide to take part in this study?	☐	☐
Do you understand the alternatives to participating in this study?	☐	☐
Do you understand that you are free to leave the study at any time, without out having to give reason and without affecting your future health care?	☐	☐
Do you understand who will see your records, including health information that identifies you?	☐	☐
Do you understand that by signing this consent form you are giving us permission to access your health information if applicable?	☐	☐
Do you understand that by signing this consent form that you do not give up any of your legal rights?	☐	☐
Do you understand that your family doctor/health care provider will/may be informed of your participation in this study?	☐	☐
Have you had enough opportunity to ask questions and discuss this study?	☐	☐

By signing this form I agree, or *allow the person I am responsible for*, to participate in this study.

Signature of Participant /*Substitute Decision-Maker*	PRINTED NAME	Date

(As a Substitute Decision-Maker, you are being asked to provide informed consent on behalf of a person who is unable to provide consent for him/herself. If the participant gains the capacity to consent for him/herself, your consent for them will end.)

Part 2 - to be completed by the principal investigator or designee who conducted the informed consent discussion. Only compete this section if the potential participant has **agreed** to participate.

I believe that the person signing this form understands what is involved in the study and has freely decided to participate.

Signature of Person Conducting the Consent Discussion	PRINTED NAME	Date

Part 3 - to be completed only if the participant is unable to read or requires assistance of an oral translator/interpreter.

- The informed consent form was accurately explained to, and apparently understood by the participant*/substitute decision maker*.
- Informed consent was freely given by *or on behalf of* the participant.

Signature of Impartial Witness/Interpreter	PRINTED NAME	Date

You will be given a copy of this signed and dated consent form prior to participating in this study.

APPENDIX 9 ETHICS APPROVAL – ALBERTA CANCER EXERCISE STUDY

HREBA Health Research Ethics Board of Alberta Cancer Committee

Health Research Ethics Board of Alberta
Cancer Committee
1500, 10104 - 103 Avenue NW
Edmonton, Alberta, T5J 0H8
Telephone: (780) 423-5727
Fax: (780) 429-3509
Email: cancer@hreba.ca

Certification of Ethics Approval - Renewal

This is to acknowledge that the renewal to the research indicated below has been reviewed and on behalf of the Health Research Ethics Board of Alberta (HREBA) – Cancer Committee (CC), I am pleased to advise that approval has been granted.

Ethics ID:	HREBA.CC-16-0905_REN5
Principal Investigator:	Margaret McNeely
Co-Investigator(s):	Kerry Courneya Jacob Easaw Albert Murtha Marc Andrew Webster Anil Abraham Joy Raylene De Bruyn Edith Pituskin Jeff Vallance Nicole Culos-Reed Harold Lau Janice Yurick Matthew Parliament
Student Co-Investigator(s):	
Study Title:	The Alberta Cancer Exercise "ACE" Program for Cancer Survivors: Supporting Community-based Exercise Participation for Health Promotion and Secondary Cancer Prevention
Sponsor:	Alberta Cancer Foundation Alberta / Innovation and Science Alberta Cancer Foundation

Effective: 12-Oct-2021 **Expires:** 11-Oct-2022

Annual Progress Report reviewed at the HREBA-CC Full Committee Meeting on 12 October 2021.

This Committee is constituted and operates in accordance with the Alberta Health

Information Act (HIA), the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2), Good Clinical Practice (GCP) Guidelines of the International Conference on Harmonization (ICH), Health Canada's *Food and Drug Regulations* (FDR), Part C, Division 5 and is registered with the U.S. Department of Health and Human Services (HHS), Office for Human Research Protections (OHRP), IRB # 00009687.

Members of the HREBA-CC who are named as principal investigators or co-investigators in this research do not participate in discussions related to, nor vote on, such studies when they are presented to the Committee. The membership of this Committee is listed at www.hreba.ca.

This renewal is subject to the following conditions:

1. Approval is granted only for the research described in this application.
2. Any modification to the approved research must be submitted to the Committee for approval prior to implementation.
3. Reportable events (SAE's, new safety information, protocol deviations, audit findings, privacy breaches, and participant complaints) are to be submitted in accordance with the Committee's reporting requirements.
4. A request to renew this ethics certification must be submitted and reviewed by the Committee in advance of the expiry date indicated above.
5. A closure request must be submitted to the Committee when the research is complete or has been terminated.

Approved on behalf of CC by,	**Date:**
Dale Dewhurst, Chair , HREBA-CC	14-Oct-2021

Note: This correspondence includes an electronic signature (validation and approval via an online system).

APPENDIX 10 SURVEY – IN PERSON OR VIRTUAL ACE STUDY

We very much appreciate you taking the time to complete this optional survey.

Please read the information about this additioanl survey below, and begin the survey by answering the question at the bottom of this page.

Once you start the survey, it should take about 15 minutes of your time to complete.

You are allowed to stop the survey at any time and return to it later. However, in order to save your answers and to continue where you left off, you must scroll down to the end of the page and click the "Save and Return Later" button.

If you select this option, an email will automatically be sent to you. When you are ready to return, please open the email and click on the link provided to you. You will be asked to answer a personal question to access your questionnaire.

For any questions or concerns, please contact us at frmace@ualberta.ca.

Thank you!The ACE team

Determining the Impact of COVID-19 on Exercise in Participants in the Alberta Cancer Exercise (ACE) program

Purpose: Due to COVID-19 we are looking at the different ways we can safely offer our exercise programs, including virtual delivery and limited in-person sessions. Your feedback will be used to inform future programming for ACE cancer survivors.

This optional survey should take approximately 15 minutes of your time to complete.

In this survey, you will be asked questions about:

Your exercise and activity during COVID-19. How you would feel about participating in differernt types of exercise programs. Your opinions on virtual exercise programs.

The information you provide in this survey will be used in the planning of ACE exercise programming in Fall 2020 and beyond.

This survey is OPTIONAL, and your completion (or not) will in no way affect any continued participation in the ACE.

If you have any further questions about this survey, please contact us at:

email: frmace@ualberta.ca OR tel: (780) 492-6007

This research has been reviewed by and received approval from the Health Research Ethics Board of Alberta (HREBA) - Cancer Committee (CC).

Ethics ID: HREBA.CC-16-0905

If you have questions about your rights as a participant or about ethical issues related to this study and you would like to talk to someone who is not involved in the conduct of the study, please contact the Office of the Health Research Ethics Board of Alberta - Cancer Committee at:

Telephone: 780-423-5727

Toll Free: 1-877-423-5727

Part 1 (of 5): Exercising during Covid

How much of a priority is exercise currently for you given COVID-19?	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
On average, how many times per week did you exercise in the last month? (Please only count days where you exercised for at least 10 minutes at a moderate intensity level)	◯ Not at all ◯ 1-2 times / week ◯ 3-4 times / week ◯ 5-6 times / week ◯ everyday
On average, how many minutes per week did you exercise (at a moderate or vigorous intensity) in the last month?	◯ Not at all ◯ 30 minutes or less per week ◯ 31-60 minutes per week ◯ 61-90 minutes per week ◯ 91-150 minutes per week ◯ more than 150 minutes per week

How are you currently exercising? Please select all that apply.	☐ Self-directed exercise alone ☐ Self-directed exercise with others (eg. socially distanced walking, running, biking) ☐ Virtual exercise classes (live or prerecorded) ☐ In-person exercise classes ☐ Other
Please indicate how else you are currently exercising:	_____
What type(s) of exercise are you currently taking part in? Please select all that apply.	☐ Aerobic Exercise (e.g. walking, bicycling, aerobics class,...) ☐ Resistance Exercise (e.g. dumbbells, bands, weight machines...) ☐ Yoga ☐ Flexibility / Stretching ☐ Other
Please indicate the other type(s) of exercise you are currently doing.	_____
Has your healthcare provider discussed or counselled you in regards to exercise during COVID-19?	◯ Yes ◯ No
What exercise equipment do you have access to? Please select all that apply.	☐ I do not have any exercise equipment ☐ Dumbbells or other weights ☐ Resistance bands ☐ Yoga mat ☐ Cardio equipment (e.g. treadmill, elliptical, stationary bike,...) ☐ Other
Please indicate the other exercise equipment that you have access to:	_____

Part 2 (of 5): Fall 2020 and Winter 2021 Exercise Program Delivery Preferences

For the following questions, all program sites will strictly follow current Alberta Health Services (AHS) recommendations for social distancing, cleaning and sanitization, and the use of personal protective equipment (e.g. masks and gloves).

Class sizes will be reduced and steps to maintain social distancing will be in place.

The term "virtual exercise" for the purposes of this survey involves live, real-time streaming of exercise sessions with ACE instructors where you can follow along with using your own personal computer or device (eg. desktop, laptop, smartphone, tablet). The ACE instructors will be able to see you doing the exercises and can provide tips and coaching to ensure you are exercising properly.

Would you have concerns about taking part in an exercise class delivered in-person this Fall?	◯ Yes ◯ No
What is your level of concern about taking part in-person exercise?	◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
What are your concerns about in-person exercise classes?	_____
Would you have concerns about taking part in a virtual exercise class this Fall?	◯ Yes ◯ No
What is your level of concern about taking part in virtual exercise?	◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
What are your concerns about virtual exercise classes?	_____
What type(s) of exercise programming would you be open to taking part in this Fall? Please select all that apply.	☐ Virtual exercise (e.g. at your home using your computer or tablet) ☐ In-person exercise at the Cancer Rehabilitation Clinic (Corbett Hall at the U of A) or Wellspring Edmonton - personal training format using fitness equipment (2-3 participants at a time) ☐ In-person group exercise class at the YMCA (small class of 5 maximum) ☐ A combination of both virtual and in-person exercise options ☐ No preference ☐ I'm not interested in participating in a formal exercise program this Fall

In order to meet AHS guidelines and accommodate all participants, a likely program option for the Fall will be having one class a week of virtual exercise, and the other as in-person exercise OR only virtual exercise classes How willing would you be to participate in a combined exercise program where you attended one day in-person and the second day virtually?	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
If you were asked to complete your fitness testing again, how would you prefer to complete these tests? Please select all that apply.	◯ Virtual exercise testing ◯ In-person exercise testing (with social distancing, use of masks and gloves) ◯ No preference
You picked a preference for a virtual option above. Please indicate why you have this preference? Select all that apply.	☐ I prefer not having to commute. ☐ I am worried about COVID-19 based on my current health status and/or medical history. ☐ I have been advised by a health professional to self-isolate in order to avoid any risk of COVID-19 transmission. ☐ Other.
Please specify your other reason(s) for preferring the virtual option:	_____

Part 3 (of 5): Technology and Exercise	
What device(s) would you use if you took part in a virtual exercise program? Please select all that apply.	☐ Cell phone ☐ Laptop or Desktop computer ☐ Tablet ☐ Other
Please indicate the other device(s) that you would use.	_____
How confident are you in operating your electronic device?	◯ Completely confident ◯ Fairly confident ◯ Somewhat confident ◯ Not confident at all ◯ I do not operate an electronic device
How often do you use programs such as FaceTime, Skype, and Zoom to connect with others?	◯ Never ◯ Once / month ◯ Once / week ◯ Once / day ◯ 2-4 times / day ◯ Greater than 5 times / day
What do you use for your virtual communications? Please select all that apply.	☐ Facetime ☐ Skype ☐ Instagram Video Chat ☐ Facebook Messenger Chat ☐ Google meet ☐ Zoom ☐ Other
Please indicate the other app or program that you use:	_____
Have you ever taken part in a virtual exercise class?	◯ Yes ◯ No
How confident do you feel about taking part in a virtual exercise program?	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
ACE staff can provide support to help you get familiar with using the virtual programming, and to ensure you are set up at home. Please indicate your agreement with the following statement: "Having support available would make me more comfortable taking part in a virtual exercise program."	◯ Strongly disagree ◯ Disagree ◯ Neither Disagree/Agree ◯ Agree ◯ Strongly Agree

Would knowing you have access to support change your willingness to take part in a virtual exercise program?	◯ YES - I WAS willing to take part in virtual programming before, and now I am even MORE willing to take part. ◯ YES - I was NOT willing to take part in virtual programming before, but now I am MORE willing to take part. ◯ NO - I was NOT willing to take part in virtual programming before, and I am still NOT willing to take part. ◯ NO - A technical support staff has no effect on my choice to take part.
Having support staff to assist you would not change your choice to take part in virtual exercise because:	◯ I am already comfortable with technology and do not need assistance. ◯ I am uncomfortable with technology and will not participate virtually, regardless of support. ◯ I do not have access to the technology needed (computer, smartphone, tablet, internet) so cannot take part.
Would someone be available to assist you with technology if you were participating in a virtual exercise program?	◯ All the time ◯ Sometimes ◯ Maybe ◯ Never ◯ I would not require assistance

Part 4 (of 5): Exercise Preferences

Which of the following times are best for you to exercise? Please select all that apply.	☐ Weekday mornings ☐ Weekday afternoons ☐ Weekday evenings ☐ Saturday morning ☐ Other
Please specify what time(s) work best for you:	_____
What features in a virtual exercise program would make you more likely to take part? Please select all that apply.	☐ Support for set up (including program, computer and set up of room at your home) ☐ Having an engaging instructor ☐ A description of exercises for the upcoming class ☐ A convenient time for me ☐ Being able to access a recording of a class so that I can exercise on my own if I am unable to attend the class ☐ Other
Please specify what other feature(s) would make you more likely to participate:	_____
What difficulties would you anticipate if you were to take part in a virtual exercise program? Please select all that apply.	☐ Enough space to exercise ☐ Internet connection ☐ Safety concerns (e.g. fear of falling, lightheadedness, etc.) ☐ Managing my cancer related treatment side effects (e.g. fatigue, etc.) ☐ Availability of technology ☐ Comfort level in using technology ☐ Lack of supervision to assist with exercise technique ☐ Exercise equipment ☐ I do not anticipate any difficulties ☐ Other
Please specify the other difficulty(ies) that you would anticipate:	_____

Part 5 (of 5): Support for Engaging in Exercise	
Would your family or friends be supportive of you engaging in virtual exercise programming?	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much ◯ Unsure
Would you have another person at home during the virtual exercise classes who could assist you if required (with non-technology issues)?	◯ All the time ◯ Sometimes ◯ Maybe ◯ Never ◯ I do not anticipate requiring assistance

Please let us know of any final comments or concerns that you would like to share, and your preferences for further information and follow up.

Thank you very much for taking the time to complete this survey!

We hope to be able to continue to support your efforts to stay active during Covid 19. We have a number of new studies starting in Fall 2020 that you may be eligible for since you have completed the ACE exercise program. Would you like us to contact you with more information regarding these studies?	◯ Yes ◯ No
Since we were not able to offer you a 2nd "maintenance" exercise session last Spring, you are still eligible for this session. Unfortunately due to COVID-19 restrictions we most likely will not have the capacity to offer you an in-person program, but can offer you virtual exercise classes. Would you like us to contact you regarding the virtual exercise program?	◯ Yes ◯ No
Would you be willing to take part in a follow-up in-person interview or focus group session?	◯ Yes ◯ No
Please feel free to leave any additional comments to help inform our Fall ACE programming options.	_____

APPENDIX 11 CONSENT FORM – PIONEER STUDY

Puneeta Tandon, MD
Associate Professor of Medicine
Zeidler Ledcor Centre, 8540 112 Street NW
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PARTICIPANT CONSENT FORM
Information Sheet

Title of Study: HEAL-Me – PiONEeR study
Patient Participant

Principal Investigators: Dr. Puneeta Tandon and Dr. Margie McNeely
Phone Numbers: 780-492-9844 and 780-248-1531

WHY AM I BEING ASKED TO TAKE PART IN THIS RESEARCH STUDY?
You are being asked to take part in this study because:

- 1) You have indicated that you are interested in participating in an online supported exercise and nutrition program
- 2) You have taken part in an in-person exercise program before AND,
- 3) You have one of the chronic conditions that is eligible for participation in this study (chronic lung disease, cancer, post-liver transplant or post-lung transplant).

This form contains information about the study. Before you read it, a member of the study team will explain the study to you in detail. You are free to ask questions if there is anything you do not understand. You will be given a copy of this form for your records.

WHAT IS THE REASON FOR DOING THE STUDY?
Chronic conditions such as the ones listed above (chronic lung disease, cancer, post-liver transplant or post-lung transplant) can have a major impact on the body, mind and overall health. Exercise and Nutrition are effective interventions to optimize health and wellbeing. Online programs are a readily available alternative to provide exercise and nutrition support to people most in need of it, especially during COVID. As these kinds of online programs are still quite new, it is still not clear to clinicians how much support patients need while taking part in this kind of programming. We have received funding (Alberta Innovates) to evaluate 3 different kinds of online programs to help to answer this question. Our aim is to support persons who meet the study inclusion criteria to adopt an active lifestyle and a healthy diet to improve their health outcomes. We want to see whether the outcomes are similar across all 3 kinds of online programs.

WHAT WILL HAPPEN IN THE STUDY?
If you agree to take part in this study and meet the study criteria, you will be randomized to one of three study groups. This is like rolling a dice. You will have a 33% chance of being assigned to each one of the three groups. Two of the online programs will use an app our study team has developed called Heal-Me which stands for Healthy Eating and Active Living. One of the online programs will receive email Exercise and Nutrition content.

Importantly, we would prefer to carry out both Baseline and End-of-Study testing in-person. This allows us to get more accurate information. Please be assured that all COVID precautions will be followed during in-person contact. For the small group of people who are interested in participating in the study but who cannot come in for in-person testing, we will offer a purely online evaluation where all of the testing and study intervention take place from your home.

Depending upon which of the three groups you are randomized to, this is what you can expect:

1. **Baseline testing** *(time commitment ~1.5 hours in person, and ~ 1.5 hours at home for surveys):*

- You will be sent some survey questions to complete at home online. These surveys will contain questions about your medical history and will assess your quality of life, your ability to perform basic functional activities, your comfort with using digital technology and your nutritional intake). These surveys will take ~ 1.5 hour to complete at home.
- You will be given an appointment to come into the University of Alberta to carry out baseline testing (~1.5 hours). This includes:
    - A short (~40 minutes) baseline fitness test by an exercise specialist
    - A review of any surveys that still need to be completed (~15 min) and,
    - All participants will receive a Garmin watch for the 12-week duration of the study that will track their step counts. This watch will be returned at the end of the study.
- Additionally, if you are part of one of the two groups who receive the Heal-Me app:
    - In the first week you will also receive a virtual technology orientation to the app from your home (~1.5 hours, depending on your comfort with technology).
    - In the second week of the study, you will be asked to participate in a nutrition assessment by a dietitian. This will occur also virtually in your own home (~1 hour).

2. **During the 12-week study period** *(time commitment ~150 minutes per week for exercise sessions with additional time throughout the study for participants who have access to 1-1 counseling with a dietitian and an exercise specialist)**:***

- All participants will be asked to carry out exercise sessions 2-3 times a week (30-45 minutes each time). This will take place in the comfort of your own home.
- Participants randomized to the two study groups who receive the Heal-Me app will be asked to substitute one of the recorded sessions for an online live group exercise session once a week (45-60 minutes) and will also get access to online live group nutrition sessions occurring once every two weeks (30 minutes). All group sessions will take place with a group of 6-12 other study participants.
- Participants randomized to the study group who receives the Heal-Me app will get access to 1-1 counseling with a dietitian and an exercise specialist at selected times through the study.
- Participants randomized to the study group who do not receive the app, will be invited to participate in a study using the app after the first 12 weeks of the study are completed.

3. **End-of-study testing** *(time commitment ~1.5 hours):*

- You will be sent some survey questions to complete at home online. These surveys will assess your quality of life, your ability to perform basic functional activities, your comfort with using digital technology and your nutritional intake). These surveys will take ~ 1 hour to complete at home.
- You will be given an appointment to come into the University of Alberta to carry out end-of-study testing. This includes:
    - A short (~40 minutes) baseline fitness test by an exercise specialist and
    - A review of any surveys that still need to be completed (~15 min)
    - You will be asked to return your Garmin watch
- You will be asked to participate in a 30-minute interview at the end of the study that will take place by either telephone or videoconference. The aim will be to review how you use the app. We would also like to ask a caregiver (e.g., family member, spouse, friend) some questions (~10-20 minutes) over the telephone about the app.

- Throughout the study and for the following year after completing the study, we will collect health information from your medical records (e.g., primary disease, diagnosis date, medications, surgeries, etc.). This information will be helpful to identify health changes that may be due to the study activities. At the end of this consent form, we will request your permission to review your medical records from databases held by Alberta Health and Alberta Health Services, including but not limited to the Discharge Abstract Database, PIN, vital statistics, NetCare and laboratory datasets.

WHAT ARE THE RISKS AND DISCOMFORTS?

The main side effect from exercise testing and training is muscle soreness. You may notice that your muscles are sore for a couple of days after the testing session and during the first week or so of the exercise program. We expect that these symptoms will get better as you get used to the exercise. As well, the exercise program will be personalized to you to minimize excessive soreness and modified as needed if you experience any excessive muscle soreness or fatigue from your exercise sessions.

It is not possible to know all the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

During the current COVID-19 situation, baseline and end-of-study testing will take place in person with the remainder of the study taking place on-line. All COVID precautions will be taken during any in-person assessments.

For participants randomized to the Heal-Me app, this app uses technology such as videoconferencing to connect you with exercise specialists and dietitians when you are not at the same location. During your virtual exercise or nutrition sessions, you and the research staff may talk about how you are feeling, review your exercise plan and options, and may give you health information and education.

Alberta Health Services Virtual Health technology connections are secure. Any personal or health information you share with research staff during the appointment is used only for your care and treatment and other purposes allowed by law. This information is confidential, which is the law under Alberta's Health Information Act.

If we find out anything new during the research which may change your willingness to be in the study, we will tell you about these findings.

WHAT ARE THE BENEFITS TO ME?
Participation in this study may or may not be of personal benefit to you. Possible benefits include improved fitness and better energy. Based on the results of this study, it is hoped that in the long-term, patient care can be improved.

DO I HAVE TO TAKE PART IN THIS STUDY? Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time and it will in no way affect the care or treatment that you are entitled to.

For either the surveys or interviews/focus groups, you do not have to answer any questions that you are not comfortable with.

If you opt out of the study, the researchers will not collect new health information, but will need to keep the data already collected.

WILL I BE PAID TO BE IN THE STUDY? No, you will not be paid to participate in the study. Mailing costs will be covered by the research team.

WILL MY INFORMATION BE KEPT PRIVATE? During the study we will be collecting data about you. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

The investigator or their study staff may need to look at your personal health records or at those kept by other health care providers that you may have seen in the past (i.e., your family doctor). Any personal health information that we get from these records will be only what is needed for the study.

During research studies it is important that the data we get is accurate. For this reason, your health data, including your name, may be looked at by people from the University of Alberta or the Human Research Ethics Board.

By signing this consent form, you are saying it is okay for the study team to collect, use and disclose information about you from your personal health records as described above.

After the study is done, we will still need to securely store your health data that was collected as part of the study. At the University of Alberta, we keep data stored for a minimum of 5 years after the end of the study.

If you leave the study, we will not collect new health information about you, but we may need to keep the data that we have already collected.

End-of-Study Interviews: While we will work to protect the confidentiality of the data that you provide, the researchers cannot guarantee that others from the group will do the same.

WHAT IF I HAVE QUESTIONS? If you have any questions about the research now or later, please contact project coordinator Graeme Purdy at 780-718-5188, Dr. Tandon (principal investigator) at 780-492-9844 or Dr. Margaret McNeely (principal investigator) at 780-248-1531.

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

The researchers do not have actual or potential conflicts of interest with respect to remuneration received from the funding agency for conducting or being involved with any part of the study and/or the possibility of commercialization of research findings. The study is being sponsored by Alberta Innovates through a research grant awarded to Dr. Tandon and Dr. McNeely.

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CONSENT

Title of Study: HEAL-Me – PiONEeR study
Patient Participant
Principal Investigator: Dr. Puneeta Tandon and Dr. Margie McNeely
Phone Number: 780-492-9844 and 780-248-1531

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time without having to give a reason and without affecting your future medical care.	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your study records, including personally identifiable health information?	☐	☐
Medical chart review The study team is requesting your explicit permission to review and document Medical information that is "linked to electronic databases held by Alberta Health and Alberta Health Services including, but not limited to, the Discharge Abstract Database, PIN, vital statistics, NetCare and laboratory datasets.	☐	☐
Future Contact Are you interested in being contacted for future research projects our research group carries out that you may eligible for?	☐	☐

Who explained this study to you? _____

I agree to take part in this study.

Signature of Research Participant: _____

(Printed Name): _____

Date: _____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee_____ Date _____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

APPENDIX 12 – ETHICS APPROVAL PiONEer STUDY

Approval Form

Date:	September 22, 2020
Principal Investigator:	Puneeta Tandon
Study ID:	Pro00103715
Study Title:	Heal-Me PiONEeR (Personalized Online Nutrition and Exercise Routines) - Reconnecting vulnerable outpatients with multidisciplinary care - an RCT assessing 3 levels of online programming in the time of COVID
Approval Expiry Date:	September 21, 2021
Date of Informed Consent:	Approval Date / Approved Document 9/22/2020 Consent_Heal_Me_Pioneer_studystaff_Aug.22.20.docx 9/22/2020 Consent_HealMe_Pioneer_patient_Aug.22.20.docx 9/22/2020 Consent_Heal_Me_Pioneer_caregiver2_Aug.22.20.docx
Funding/Sponsor:	Alberta Innovates Health Solutions

Thank you for submitting the above study to the Health Research Ethics Board - Biomedical Panel. Your application has been reviewed and approved on behalf of the committee. The following documentation forms part of this approval:

- Protocol (Undated)
- COVID plan for Heal-Me Pioneer
- Consent_HealMe_Pioneer_patient (dated both 22 Aug 2020 and 25 Mar 2020)
- Consent_Heal_Me_Pioneer_caregiver2 (22 Aug 2020)
- Consent_Heal_Me_Pioneer_studystaff (22 Aug 2020)
- SF-36
- 24-Hour Food Log
- Heal-Me Innovates Nutrition & Exercise_COM-B scale_QUESTIONNAIRES_Aug.22.20 v1
- UTAUT_Heal-Me_Patients_Aug.29.20 for ethics
- UTAUT_Heal-Me_Trainers_Aug.22.20 for ethics
- Heal-Me- Patient_Qual_Intv1
- Heal-Me-Provider_Qualv1
- Exercise Preference Questionnaire
- PARQQuestionnaire_AlbertaCance
- LowerExtremityFunctionalScale_
- VirtualFitnessAssessmentBaseli
- UpperExtremityFunctionalScale
- WHO-5 well being index
- Connor Davidson Resilence-10
- Sample_UK__English__EQ-5D-5L_Paper_Self_complete_v1.0__ID_24700_
- SatisfactionSurvey_HEALMEACECo
- Patient Data Collection Sheet_elements_HealMe_Pioneer
- ISAT-Dec-21-2017
- MPDQ short form questions
- Computer Proficiency Questionnaire 12

Approval by the Research Ethics Board does not encompass authorization to recruit and/or interact with human participants at this time. ***Researchers still require operational approval as applicable (eg AHS, Covenant***

Health, ECSD etc) and where in-person interactions are proposed, institutional and operational requirements outlined in the Resumption of Human Participant Research - June 24, 2020 must be met.

The Health Research Ethics Board assessed all matters required by section 50(1)(a) of the Health Information Act. Subject consent for access to identifiable health information is required for the research described in the ethics application, and appropriate procedures for such consent have been approved by the HREB - Biomedical Panel. In order to comply with the Health Information Act, a copy of the approval form is being sent to the Office of the Information and Privacy Commissioner.

Any proposed changes to the study must be submitted to the REB for approval prior to implementation. A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date (September 21, 2021), you will have to re-submit an ethics application.

The membership of the Health Research Ethics Board - Biomedical Panel complies with the membership requirements for research ethics boards as defined in Division 5 of the Food and Drug Regulations and the Tri Council Policy Statement. The HREB - Biomedical Panel carries out its functions in a manner consistent with Good Clinical Practices.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Alberta Health Services or other local health care institutions for the purposes of the research. Inquiries regarding administrative approval, and operational approval for areas impacted by the research should be directed to the Alberta Health Services Research Administration office (Edmonton Zone) at nactrc.contracts@albertahealthservices.ca or Covenant Health Research Administration (research@covenanthealth.ca) as applicable.

Sincerely,

Donald W. Morrish, MD, PhD, FRCPC
Associate Chair, Health Research Ethics Board – Biomedical Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).