

# **Enabling Health Professionals to Provide Effective Self-Management Support for Cancer-Related Fatigue**

By

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# ABSTRACT

**Background:** Cancer-related fatigue (CRF) is one of the most prevalent and distressing symptoms experienced by people diagnosed with cancer. Managing CRF requires individuals to adopt a range of self-management behaviours, thus quality self-management support (SMS) is critical. Clinicians report that a lack of clear guidance on SMS practices hinders their provision of supportive care for CRF. This doctoral thesis focuses on enabling health professionals to support cancer survivors to self-manage their CRF. Specifically, this study contributes to the literature by identifying the core practices required by health professionals to deliver effective SMS to cancer survivors experiencing CRF.

**Aims:** The aims of this doctoral thesis were to: 1) examine and identify the core components, theories, and effectiveness of self-management interventions in relation to management of CRF for cancer survivors; 2) develop a framework of best practice guidance for SMS in managing CRF in cancer survivors; and 3) gain an understanding of clinical interactions as part of SMS practices in relation to CRF between health professionals and cancer survivors.

**Methods:** Three studies were conducted. Study 1 was a systematic literature review of randomised controlled trials that examined CRF SMS programs. Study 2 was a modified Delphi study (informed by Study 1) with cancer care clinicians, researchers, and cancer survivors to inform the development of a clinical practice guidance framework for CRF SMS. Study 3 was a conversation analysis of video-/audio-recorded consultations between trained cancer nurse-counsellors and cancer survivors in CRF SMS clinic sessions, to understand how SMS tasks are accomplished in a real-world clinical setting.

**Results:** In Study 1, 51 papers representing 50 unique studies were identified following a systematic literature search. Synthesis of data illustrated CRF SMS delivered after cancer treatment, facilitated by health professionals, with at least one in-person contact appeared to produce the most favourable fatigue and behavioural outcomes in cancer survivors. Additionally, studies reporting the provision of additional training to intervention facilitators most frequently produced positive intervention effects for CRF and associated behavioural outcomes. Study 2 comprised two modified Delphi study rounds. Fifty-two panel participants in Round 1, and 32 panel participants in Round 2, produced consensus on a clinical practice framework with 44 items (13 Key Practices and 31 Practice Components). Lastly, the investigation of CRF SMS communication in Study 3 indicated that during supportive care sessions, clinicians should focus the conversation on CRF SMS early in the consultation, by clearly introducing the agenda of the consultation from the outset, followed by seeking client agreement. Additionally, Study 3 found that formulating or summarising patient's talk allows clinicians to maintain a focus on matters relevant for self-management fatigue planning; tie divergent conversation back to support for CRF; and potentially provide supportive care within limited time frames.

**Conclusions:** The clinical practice framework offers an evidence- and consensus-based model of best practice for health professionals providing SMS for CRF to cancer survivors. Future work is required to identify different stakeholders' needs in supporting the implementation of the framework in their local settings.





# DECLARATION

I, Oluwaseyifunmi Andi Agbejule, certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed:

A solid black rectangular box redacting the signature of the author.

Date: 21/07/2023

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# LIST OF RELEVANT PUBLICATIONS COMPLETED DURING CANDIDATURE

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**Agbejule, O. A.**, Hart, N. H., Ekberg, S., Crichton, M., & Chan, R. J. (2022). Self-management support for cancer-related fatigue: A systematic review. *International Journal of Nursing Studies*, 129, e104206. <https://doi.org/10.1016/j.ijnurstu.2022.104206>

**Agbejule, O. A.**, Hart, N. H., Ekberg, S., & Chan, R. J. (2023). Development of a self-management support practice framework for addressing cancer-related fatigue: a modified Delphi study. *Journal of Cancer Survivorship*. Advance online publication. <https://doi.org/10.1007/s11764-023-01348-7>

**Agbejule, O.A.**, Chan, R. J., Ekberg, S., Ashbury F. D., Kleckner., A. S., Hart, N. H. (2023) Cancer-related fatigue self-management: a MASCC-endorsed practice framework for healthcare professionals to optimally support cancer survivors. *Supportive Care in Cancer*, 31(12), 666. <https://doi.org/10.1007/s00520-023-08130-6>

## Relating to Self-management Support

Chan, R. J., Mayer, D. K., Koczwara, B., Loerzel, V., Charalambous, A., **Agbejule, O. A.**, & Howell, D. (2020). Building capacity in cancer nurses to deliver self-management support: A call for action paper. *Cancer Nursing*, 43(5), 341–342. <https://doi.org/10.1097/NCC.0000000000000855>

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# CONFERENCE PRESENTATIONS, POSTERS, AND AWARDS

## Conference Presentations and Posters

- PC4 Scientific Symposium 2021
  - *Survivorship Education for Primary Care Providers (E-poster Presentation)*
- Clinical Oncology Society of Australia (COSA) Cancer Survivorship Conference, 18th-19th March 2021
  - *Cancer Survivorship Education for Primary Care Providers (E-poster presentation)*
  - *Bridging the Research to Practice Gap: A Systematic Scoping Review of Implementation of Cancer-Related Fatigue Management (E-poster presentation)*
- 4th Victorian Cancer Survivorship Conference 25th - 26th March 2022
  - *Self-management Support for Cancer-related fatigue (Presentation)*
- COSA Cancer Survivorship Conference, 9th-10th March 2023
  - *Developing of a Self-management Support Framework for Cancer-related Fatigue (Physical Poster)*
- Multinational Association for Supportive Care in Cancer, 22<sup>nd</sup> -24<sup>th</sup> June, Japan 2023
  - *A Clinician Practice Framework for Supporting The Management Of Cancer-Related Fatigue: A Modified Delphi Study (E-poster presentation)*

## Awards

- Primary Care Collaborative Cancer Clinical Trials Group (PC4) Symposium Best Poster Award 2021
  - *Survivorship Education for Primary Care Providers*
- Margaret Fay Fuller PhD Top-Up Scholarship 2022
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  - *Development of a self-management support practice framework for addressing cancer-related fatigue: a modified Delphi study*

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# 1.0 INTRODUCTION

## Background and Scope of the Problem

For the last 15 years, cancer has been the leading cause of health burden in Australia, currently accounting for 18% of the total disease burden in the nation (Australian Institute of Health and Welfare, 2022). Due to advancements in early detection, diagnostics, and treatment, it is estimated that by 2040, almost 1.9 million Australians will be living with, or beyond cancer, increasing the non-fatal burden of cancer on the Australian population and health system (Cancer Australia, 2017; Hunter et al., 2019). As survival continues to improve, the pertinent need to address the many symptoms, late effects, and resulting long-term health needs of individuals living with cancer also increases. The term 'cancer survivor' encompasses the entire spectrum of an individual's experience of cancer including diagnosis, treatment, remission, surveillance, after-cancer care, and end of life (Miller et al., 2019; Rodriguez & Foxhall, 2018). The provision of continual treatment support and long-term survivorship care is made complex as survivors must often manage multiple new and pre-existing comorbidities, highlighting the increasing role of the cancer survivor as well as their health care teams in self-managing follow-up care. This doctoral thesis examines supporting the self-management of one of the most prevalent symptoms experienced by cancer survivors.

## Cancer-related fatigue

Cancer-related fatigue (CRF) is one of the most common and debilitating symptoms reported in people diagnosed with cancer (Banipal et al., 2017; Bower et al., 2000; Horneber et al., 2012; Luthy et al., 2011; Weis & Horneber, 2014). Although there are several existing definitions, CRF is commonly defined as "a distressing, persistent, subjective sense of physical, emotional, and/or cognitive exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning" (Berger, Mooney, et al., 2015). Moreover, unlike 'normal' fatigue, CRF is not alleviated with rest or sleep and leaves the individual with a prolonged and overwhelming sense of exhaustion (Narayanan & Koshy, 2009).

Several studies have demonstrated that the duration and intensity of CRF greatly affects the quality of life (QOL) of cancer survivors during and after treatment; reducing physical, mental, emotional and social wellbeing (Banipal et al., 2017; Bower et al., 2000; Charalambous & Kouta, 2016; Curt et al., 2000; Lis et al., 2009; Luthy et al., 2011; Rodríguez Antolín et al., 2019). Studies have also identified that the adverse effects associated with CRF often persist long after treatment cessation, with one longitudinal study (Bower et al., 2006) reporting that

34% (n=259) of participants experienced significant fatigue 5-10 years post treatment (Biering et al., 2020; Goedendorp et al., 2012; Servaes et al., 2002). Additionally, a recent retrospective study found that cancer survivors reported more general ( $p=0.04$ ), and mental fatigue ( $p=0.02$ ) compared with controls, up to 15 years post-cancer diagnosis (Gernier et al., 2020).

Numerous management strategies have been investigated for alleviating and reducing CRF severity. Pharmacological treatments (e.g., erythropoietin, methylphenidate, modafinil, steroids, anti-depressants, etc.) are largely ineffective for CRF, with those that do demonstrate effectiveness often resulting in treatment-related adverse effects (Bohlius et al., 2014; Finnegan-John et al., 2013; Tomlinson et al., 2018). For example, in a recent meta-analysis of 117 trials, Tomlinson and colleagues found that CRF was significantly reduced with pharmacologic agents including erythropoietin [standardised mean difference (SMD):  $-0.52$ ; 95%CI:  $-0.89$  to  $-0.14$ ] and methylphenidate (SMD:  $-0.36$ ; 95%CI:  $-0.56$  to  $-0.15$ ). However, the study authors highlighted that the limited sustainability of such improvements in fatigue, and the adverse effects relating to both pharmacologic agents (e.g., insomnia, decreased appetite, weight loss, nausea, rapid pulse rate, etc.), reduced their clinical usefulness. As such, non-pharmacological interventions (e.g., exercise, psychosocial therapy, integrative therapies, energy conservation, multimodal therapy) have been recommended as first-line therapies for managing CRF (NCCN, 2017).

A persuasive body of quality evidence (Corbett et al., 2019; Finnegan-John et al., 2013; Hilfiker et al., 2018b; Mustian et al., 2017) concludes that physical activity and psychological-based interventions (e.g., cognitive behaviour therapy; CBT) are both effective and superior in managing CRF. For example, in a meta-analysis by Mustian and colleagues (Mustian et al., 2017), physical activity (WES, 0.30; 95% CI, 0.25–0.36;  $P < .001$ ) and psychological interventions (WES, 0.27; 95% CI, 0.21–0.33;  $P < .001$ ) exhibited significant moderate effects on CRF improvement both during and after primary cancer treatment. Similarly, Hilfiker and colleagues explored the effects of specific exercises and psychological interventions in their indirect-comparisons meta-analysis (Hilfiker et al., 2018a), concluding that relaxation exercise ranked highest for managing CRF during treatment (SMD of  $-0.77$ ; 95% CI:  $-1.22$  to  $-0.31$ ); whilst yoga had the greatest effect after treatment (SMD of  $-0.68$ ; 95% CI  $-0.93$  to  $-0.43$ ); with combined physical activity and CBT; aerobic exercise, resistance training, and combined aerobic-resistance training; being beneficial both during and after treatment, despite their lower effect size level (Hilfiker et al., 2018a). The impact of integrative therapies (i.e., acupuncture, massage, mindfulness-based stress reduction, energy conservation) on alleviating CRF have also been explored. Although, several trials have demonstrated integrative therapies can result in reduced CRF, these studies often had limitations (i.e., small



sample sizes or non-randomised); with two systematic reviews concluding there was insufficient and conflicting data to facilitate clinical recommendations on the effectiveness of such therapies (Finnegan-John et al., 2013; Sood et al., 2007).

### **Self-management, Cancer-Related Fatigue, and Self-management Support**

With the increased side effects and co-morbidities that come with cancer, cancer treatment and living longer, cancer survivors are expected to assume a greater role in self-managing their follow-up care. Although conceptualisations vary, self-management can be broadly defined as the “day-to-day management of chronic conditions by individuals over the course of an illness” (Grady & Gough, 2014). The self-management model of care has been highlighted as a critical component to ensure patient wellbeing, particularly in chronic illness and the use of non-pharmacological approaches to symptom management (Grady & Gough, 2014). In fact, all evidence-based CRF management strategies presented in the section above aim to address behavioural risk factors (e.g., sleep disturbance, physical inactivity, poor nutrition, depression) and require cancer survivors to play a key role in guiding their care through self-management (e.g., increasing exercise, conserving energy, improving nutritional status) (Chan et al., 2016). Engagement in these fatigue self-management behaviours can be complex, and can often require cancer survivors to recognise, track, self-monitor, self-report, and apply problem solving skills to manage their fatigue along with their other comorbid conditions (Howell et al., 2021) – tasks that are not typically part of their regular behaviour. Additionally, factors such as fatigue symptom burden, socioeconomic status, mental health, cognitive status, age, performance status, or other situational factors also make it challenging for those diagnosed with cancer to self-manage their fatigue (Berger, 2019; Howell et al., 2021). To navigate the complexities associated with fatigue management, cancer survivors therefore require access to comprehensive self-management support (SMS) that assists and enables them to manage their fatigue while accounting for their capacity, capability, confidence levels, and priorities. Moreover, SMS strategies (e.g., motivational interviewing, goal setting, action planning, progress evaluations) which assist cancer survivors to address behavioural risk factors and incorporate behaviour change are increasingly recognised as essential elements of CRF management (Girgis, 2020).

SMS is defined by the Institute of Medicine as “the systematic provision of education and supportive interventions to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support” (Institute of Medicine Committee on Identifying Priority Areas for Quality Improvement, 2003). As the non-fatal burden of cancer in Australia continues to increase (Cancer Australia, 2017; Hunter et al., 2019), and cancer expenditure consistently remains in

the top three spending categories in the nation (including expenditure on hospital admissions, pharmaceuticals, medical specialists, and national screening programs) (Australian Institute of Health and Welfare, 2021), the need to strengthen the self-management model of care through SMS initiatives has become more apparent (Grady & Gough, 2014). A 2017 report by the Australian Government Department of Health included SMS as one of five priority areas for Australia in a national framework for improving the quality of life of individuals with chronic conditions (Australian Health Ministers' Advisory Council, 2017). More specifically, Australian policymakers called for increased efforts to provide tailored SMS interventions as well as appropriate SMS training and education of the health workforce. Systematic evidence has shown that clinicians supporting people to self-manage their chronic symptoms reduces health service utilisation without compromising patient health outcomes (de Silva, 2011; Panagioti et al., 2014). Further, the provision of clinician SMS moves beyond the paternalistic 'expert' view of health care to a more patient-centred approach that prioritises an individual's goals in treatment decisions (Gudgeon et al., 2022). This patient-centred approach to care has been shown to contribute to better patient outcomes, and patient satisfaction with the quality of care received (Kuipers et al., 2019).

Health professionals play a key role in promoting and empowering cancer survivors to self-manage their CRF. For example, such support could involve oncologists or primary care providers overseeing treatment and offering guidance specific to an individual's cancer therapies; nurses providing symptom monitoring and education; or specialists like exercise physiologists, psychologists, and nutritionists contributing with tailored exercise, mental health support, and dietary guidance aimed at managing and alleviating CRF during and after cancer treatment. It is therefore integral that clinicians possess the appropriate CRF SMS knowledge and expertise. Moreover, effective SMS requires the specific education and training of health professionals (Jordan et al., 2008), with studies demonstrating that clinician knowledge and education of SMS is associated with the improved uptake and implementation of patient self-management programs and interventions (Holman & Lorig, 2004; Jordan et al., 2008; Lawn & Battersby, 2009). Further, the significance of empowering and providing cancer survivors with the knowledge and skills needed to manage their symptoms and adjust health behaviours through self-management is well recognised, with several studies reporting on the efficacy of SMS programs on a range of cancer-related symptoms (Boland et al., 2018; Boogaard et al., 2016; Cuthbert et al., 2019; Goldberg et al., 2019; Hammer et al., 2015; Howell et al., 2017; Kim et al., 2017; Smith-Turchyn et al., 2016).

## **Translation of CRF Management Strategies to Practice**

As noted at the beginning of this chapter, the effective management of CRF is well established, with multiple prominent organisations – National Comprehensive Cancer Network (USA), American Society of Clinical Oncology, European Society of Medical Oncology, Canadian Association of Psychosocial Oncology – producing and disseminating evidence-based recommendations and guidelines for cancer fatigue management (Berger et al., 2015; Bower et al., 2014; Fabi et al., 2020; Howell et al., 2013; NCCN, 2017). However, the effective translation of these guidelines to clinical practice is rare (Agbejule et al., 2021; Hilarius et al., 2011; Jones et al., 2021; Pearson et al., 2017), resulting in CRF being under-reported, under-diagnosed, and undertreated (Hilarius et al., 2011; Lisy et al., 2019; Stone et al., 2000; Vogelzang et al., 1997; Wang et al., 2018). A systematic scoping review undertaken to inform the research reported in this doctoral thesis synthesised knowledge around the implementation of CRF interventions in routine clinical practice and presented the outcomes of implementation strategies used (Agbejule et al., 2021; see manuscript in Appendix 1). The review examined original research articles (i.e., randomised controlled trials, observational studies, qualitative studies, mixed methods studies, study abstracts, and program evaluations) as well as other grey literature (e.g., evaluations of modules, online programs, and institutional/government interventions) to understand efforts to implement CRF interventions in clinical care, and the outcomes of these implementation efforts. Despite the high prevalence of CRF and evidence-based interventions for managing CRF, the review found that there was limited evidence informing the sustainable implementation of CRF interventions. Potential reasons for lack of implementation are discussed in detail below. This limited evidence highlights the disconnect between the established ‘gold-standard’ management strategies for CRF, what occurs presently in routine clinical care, and what cancer survivors experience (i.e., CRF being under-reported and under-treated) (Agbejule et al., 2021). This systematic scoping review was not included as a main study of this doctoral thesis as it did not focus on the implementation of SMS programs. However, the key gaps in knowledge, and priorities for research identified in the review, informed the aims and objectives of this doctoral thesis.

It is well recognised across evidenced-based literature that systemic (e.g., policy work, embedding supportive care monitoring into the electronic health records, reimbursement for supportive care services), organisational (e.g., difficulties reviewing past notes, difficulties for HCPs to follow-up on referrals, a reactive approach to symptom management) and cancer survivor-level changes (e.g., improving survivor attitudes and beliefs about CRF) are needed to accelerate the translation of evidence on CRF management to clinical practice (Abdallah et al., 2014; Agbejule et al., 2021; Berger et al., 2015; Berger & Mooney, 2016; Hilarius et al., 2011; Jones et al., 2021). However, Berger and colleagues (2015), note that although

improved processes and policies can enable the translation of CRF guidelines to clinical practice, the role of the health professional is one of the most important. This is because clinicians remain the access point for cancer survivor care. Further, Berger and colleagues emphasise the importance of collaboration between health professionals and cancer survivors, concluding that the adoption of CRF guidelines is reliant on health professionals supporting cancer survivors to create tailored CRF management strategies, and providing cancer survivors with adequate instruction to support the execution of those strategies (Berger, et al., 2015). For this reason, the current doctoral thesis focuses on the role of health professionals in supporting cancer survivors to self-manage their CRF.

***Lack of clinician knowledge of CRF management strategies and poor communication affecting clinician-cancer survivor partnerships***

For guided self-management to be successful, a positive patient-physician relationship has been shown to be a key factor (Coulter, 1997; Clark and Gong, 2000; Holman and Lorig, 2000). Difficulties in communication between cancer survivors and health professionals represent a key barrier to the implementation of CRF management strategies to practice, and is a large contributor to cancer survivors feeling dissatisfied with the CRF SMS they currently receive from clinicians (Jones et al., 2021; Jones et al., 2020). Implementation of CRF self-management strategies relies on cancer survivors' understanding of the strategies and their importance. Further, when communication between cancer survivors and their healthcare teams is poor or ineffective, cancer survivors are left to self-initiate strategies through trial and error, despite often having limited knowledge and misconceptions of fatigue management strategies (Fitch et al., 2008). This poor communication can lead cancer survivors to distrust their health providers, and can result in non-compliance with, or inadequate implementation of, fatigue management strategies (Fitch et al., 2008; Pertl et al., 2014). A recent mixed-methods study emphasised that a lack of health professional knowledge on CRF management strategies along with breakdown in cancer survivor-provider communication, are key factors hindering the translation of evidence-based CRF management to practice (Jones et al., 2021). The study found that cancer survivors rarely received support from their health care teams on how to effectively manage their fatigue and often felt that they could not rely on health professionals for CRF management support (Jones et al., 2021). Additionally, cancer survivors often felt dismissed and discouraged in managing their CRF due to inconsistencies in clinician attitudes; screening and assessment strategies used; and the normalization of CRF without specific management strategies (Jones et al., 2021). Similarly, a survey of 2508 cancer survivors found that almost 60% did not feel well informed about fatigue, and 87% of cancer survivors that perceived they had severe fatigue did not receive support from their health teams (Schmidt et al., 2021). Deficits in clinicians' knowledge of the causes and appropriate

management strategies for CRF, negatively impact cancer survivors (Pertl et al., 2014; Schmidt et al., 2021), with clinicians reporting their lack of CRF knowledge contributes to their unwillingness to communicate and initiate support discussions with survivors (Borneman et al., 2011).

Although the importance of health professional knowledge in the management of CRF is well documented; clinicians often find existing management guidelines too long, complicated, or lacking relevant information for optimal clinical utility (Hilarius et al., 2011; Jones et al., 2021; Pearson et al., 2017). A mixed-methods study by Pearson and colleagues (2017) found that the translation of CRF management guidelines to clinical practice was often hindered by guideline complexity, with clinicians reporting barriers such as guideline content being too broad (i.e., assessing the literature) whilst also lacking specific steps or strategies to inform clinical guidance (Pearson et al., 2017). Moreover, their study demonstrated that there is a pertinent need for pragmatic, practical, clinician-friendly frameworks that detail CRF management strategies and can be applied in a variety of settings (e.g., acute cancer, primary care, maintenance, etc.).

### ***Lack of clinician knowledge on self-management support strategies***

Despite being emphasised by national (Australian Health Ministers' Advisory Council, 2017) and international policy agendas (Institute of Medicine National Research Council, 2006; National Health Service, 2019), SMS is not always integrated into clinical care (Duprez et al., 2018; Kantilal et al., 2022; Rimmer et al., 2021; Slev et al., 2017). Education on SMS competencies are often not integrated into medical, nursing, or allied health undergraduate curricula or professional development pathways (Duprez et al., 2017; Gudgeon et al., 2022). Additionally, evidence shows that clinicians rarely provide SMS (Jongerden et al., 2019; Norris & Kilbride, 2014); and lack competency and confidence in support activities such as collaborative goalsetting, shared decision making, and coordinating follow-up care (Duprez et al., 2018). A study of health professionals in an Australian health care setting, found that 65% of participants had received no formal training in self-management techniques (Lake & Staiger, 2010). Further, when SMS is provided, it primarily consists of information provision alone (e.g., presenting patients with leaflets) which coincidentally involves the lowest level of patient participation (Duprez et al., 2018; Elissen et al., 2013). Findings from qualitative studies highlight that health professionals frequently rely on their own expert opinions during patient interactions, and struggle to relinquish control, often disregarding the expertise of the patient or their support networks (Matthews & Trenoweth, 2015; Mudge et al., 2015; Norris & Kilbride, 2014). Further, a perceived lack of guidance and time are commonly cited barriers to SMS provision (Gudgeon et al., 2022). A recent review by Kantilal and colleagues (2022) sought to

understand the influences involved in facilitating clinicians to provide routine SMS to cancer survivors. Study authors found that health practitioners are more likely to engage patients in discussions of self-management if they have the appropriate SMS knowledge, consultation skills, a clear understanding of their SMS role and responsibilities, and an organisation and health system configuration that enables integration of support provision into routine care (Kantilal et al., 2022). SMS is integral in the management of CRF; however, several studies have demonstrated that health professionals often lack the confidence, knowledge, and ability to provide effective SMS to cancer survivors experiencing CRF which hinders the uptake of CRF management guidelines to practice (Hilarius et al., 2011; Jones et al., 2021). Evidence highlights that cancer survivors report they do not regularly receive support from their health care teams to effectively manage their CRF (Hilarius et al., 2011). Additionally, in instances where supportive counselling does occur, education on ineffective CRF management strategies (such as increased rest) are commonly provided (Fitch et al., 2008; Hilarius et al., 2011). Hilarius and colleagues (2011) attribute these deficiencies to complex guidance and posit that guidance on SMS and counselling for CRF need to be further clarified and reformulated into best practices, with the most essential support strategies being highlighted (Hilarius et al., 2011).

### ***Difficulties in conceptualising self-management support for CRF***

The identification of effective SMS strategies for CRF, together with the development and optimisation of SMS best practices, is needed to ensure health professionals (in acute, primary, and community care) have the needed capabilities to support cancer survivors to manage their fatigue and improve CRF outcomes. Current reviews on SMS interventions for individuals experiencing CRF do not examine or identify the essential self-management elements and mechanisms needed to establish a successful CRF SMS program. Lack of awareness of effective SMS practices and CRF management strategies are barriers to the successful implementation of CRF management guidelines to practice, and as such, efforts must be directed to improving health professional understanding in this area through the identification of SMS best practices. Recent reviews on SMS programs for individuals experiencing CRF do not explore or identify key SMS components or principles; a gap that has been routinely highlighted across the survivorship literature. For example, in their systematic review on SMS interventions for cancer survivors, Boland and colleagues (2018) emphasised that standardised definitions of self-management and essential SMS elements are needed to determine the effectiveness of certain components to improve health outcomes. Additionally, Howell and colleagues' review of self-management education programs identified that consensus on the essential components of self-management programs is critical to facilitate consistent and effective delivery of SMS (Howell et al., 2017). Inconsistency of self-

management conceptualisations, terms, and definitions has been identified as a key issue in self-management literature (Grady & Gough, 2014), and is a significant barrier to intervention development, the translation of research to clinical practice and, self-management knowledge advancement (Ryan & Sawin, 2009). In fact, systematic reviews of self-management interventions regularly conclude that variability in self-management definitions and intervention reporting impedes study synthesis and increases difficulty in determining the distinction of outcomes gained as a result of self-management practices (Boland et al., 2018; Boogaard et al., 2016; Cuthbert et al., 2019; Goldberg et al., 2019; Hammer et al., 2015; Howell et al., 2017; Smith-Turchyn et al., 2016). Moreover, the lack of clarity, definition and identification of SMS strategies utilised in CRF management hinders clinical implementation efforts (Hoffmann et al., 2014).

## **Research problem**

An extensive body of evidence on CRF and its effective management exist. Despite this, management strategies are rarely translated to clinical practice, and CRF remains one of the most prevalent symptoms and unmet needs in cancer survivors (Lisy et al., 2019; Molassiotis et al., 2017; Wang et al., 2018). Lack of health professional knowledge on effective CRF management and CRF SMS strategies, as well as low cancer-provider communication, have been highlighted as key barriers to CRF intervention translation. There is urgent need to move beyond the investigation of intervention effectiveness to the identification, dissemination, and implementation of evidence based CRF self-management strategies into clinical care, through the establishment of effective SMS practices (Agbejule et al., 2021).

## **Research Plan**

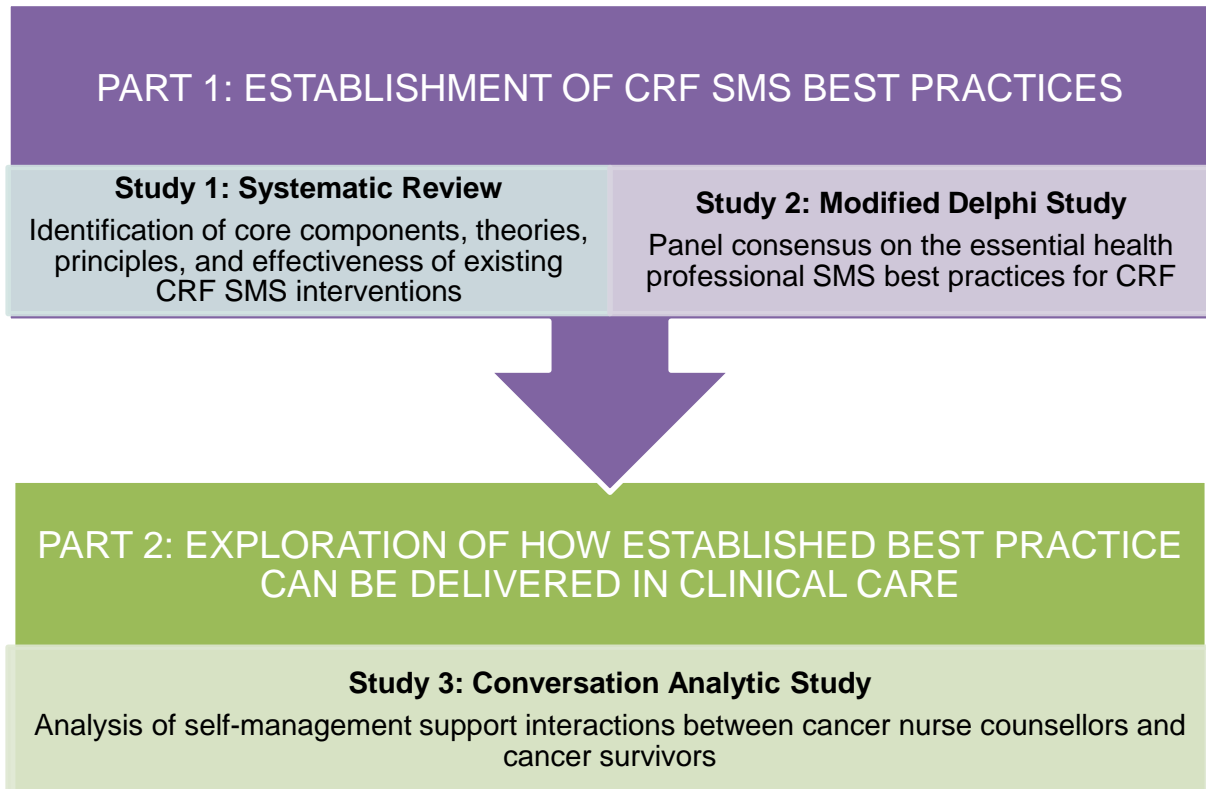
This doctoral research develops an evidence-based framework of best clinical practice guidance for SMS in managing CRF in cancer survivors (see Figure 1). This best practice framework outlines the essential SMS practices needed for health professionals to successfully facilitate cancer survivor uptake of CRF management strategies. Additionally, this doctoral thesis examines how these practices have been applied by clinicians in current clinical practice at an operational level and provides insight how practices could be executed at an interactional level.

## **Aims**

The aims for this doctoral thesis are to:

- i. examine and identify the core components, theories, and effectiveness of SMS interventions in relation to management of CRF for cancer survivors (Study 1).

- ii. develop a framework of best practice guidance for SMS in managing CRF in cancer survivors (Study 2).
- iii. gain an understanding of clinical interactions as part of SMS practices to manage CRF in cancer survivors (Study 3)



**Figure 1:** Graphical Representation of Research Plan

## Objectives

The objectives of this doctoral thesis are to:

- i. Conduct a systematic review to identify the core components and effectiveness of SMS interventions for CRF in cancer survivors.
- ii. Conduct a modified Delphi study with cancer care clinicians (medical, nursing, and allied health), researchers, and cancer survivors to inform the development of a clinical practice guidance framework for SMS in managing CRF in cancer survivors.
- iii. Conduct a conversation analysis of video-/audio-recorded consultations between trained cancer counselling nurses and cancer survivors in their CRF clinic sessions to understand how SMS tasks are accomplished in clinical practice.



## **Research Questions**

**Study 1** – Systematic review of core components and effectiveness of SMS interventions for CRF in cancer survivors.

1. What is the effectiveness of SMS interventions on improving CRF and other relevant behavioural outcomes (e.g., frequency of behaviours, self-efficacy, intention) for cancer survivors?
2. What self-management theories, strategies and intervention components are associated with higher acceptability, and improved behavioural and CRF outcomes in cancer survivors?

**Study 2** – Modified Delphi study to develop consensus on a health professional practice framework for the SMS of CRF.

1. What are the key practices and practice components needed for health professionals to deliver comprehensive SMS for CRF?

**Study 3** – Conversation analysis of interactions between cancer nurses and survivors with CRF to understand how SMS for CRF is accomplished in clinical practice.

1. What communication practices are used by cancer nurses during SMS intervention consult actions with cancer survivors experiencing CRF?
2. What are the interactional consequences of these practices?

## **Thesis Outline**

This chapter has presented a background to the research problem, aims, and objectives for this doctoral thesis. Chapter 2 explores relevant health behaviour and self-management theories and contextualises the theoretical framework that will underpin the doctoral research. Chapter 3 presents a systematic review on the effectiveness of SMS interventions for relieving CRF. This systematic review also identifies and synthesises the key SMS components of effective interventions. Chapter 4 details the research design and results of a modified Delphi study that will inform the development of clinical practice guidance for SMS in managing CRF in cancer survivors. Chapter 4 also presents the resulting best practice guidance framework for health professionals providing support for those experiencing CRF. Chapter 5 details the methodology, methods, research design, and findings of a conversation analytic study examining clinical interactions as part of CRF SMS practices used by cancer nurse counsellors. Chapter 6 presents a discussion of the key findings and implications of the doctoral work, as well as future directions. The Appendices include a systematic scoping review that was conducted and published during the early stages of the doctoral program, as well as other supporting information.

## **2.0 THEORETICAL AND CONCEPTUAL FRAMEWORK**

### **Chapter Introduction**

This chapter explores the relevant health behaviour and self-management theories that underpin this doctoral research.

### **History of Chronic Illness Self-management**

One of the earliest theories of self-management was produced by Corbin and Strauss in 1985. Their qualitative study identified three core sets of tasks associated with managing chronic illness at home: (1) medical management (e.g., medication adherence); (2) meaningful behaviour change and maintenance (e.g., smoking cessation); and (3) emotional management – learning to manage the emotions that often accompany chronic conditions – (e.g., fear, depression, anxiety, frustration) (Corbin & Strauss, 1985). Over subsequent years, several researchers built on the model purported by Corbin and Strauss to enhance understanding of self-management in chronic illness (Dunbar et al., 2008; Grey et al., 2006; Lorig & Holman, 2003; Ryan & Sawin, 2009). For example, Lorig and Holman (2008) expanded on Corbin and Strauss' three tasks and proposed five core self-management skills required by individuals with chronic illness: problem solving, decision making, resource utilisation, the formation of patient-provider partnerships, and action-planning. Ryan and Sawin's (2009) Individual and Family Self-management Theory, delved into the context (e.g., condition specific factors, individual and family factors), process (e.g., knowledge and beliefs, skills and abilities); and proximal (e.g., uptake of symptom management strategies) and distal (e.g., overall health status) outcomes of self-management practices. The internationally recognised Chronic Care Model (CCM) (Wagner et al., 1996) also recommended self-management as one of six essential elements needed to provide better care for individuals with chronic conditions and emphasises the importance of clinician-patient collaboration in improving care.

Although conceptualisations, terms and definitions of self-management differ across the literature, a central objective across many self-management models, theories and support programs is the achievement of sustainable positive outcomes through the preparation and strengthening of an individual's self-efficacy (a person's belief in their capabilities to exert control over their own functioning and over events that affect their lives) to adopt self-management strategies and adapt health behaviours (Bandura, 1977; Lorig & Holman, 2003; Ryan & Sawin, 2009). The enhancement of self-efficacy is an important mechanism for self-management programs (Chan et al., 2016; Peters et al., 2019; Tan et al., 2021), with several

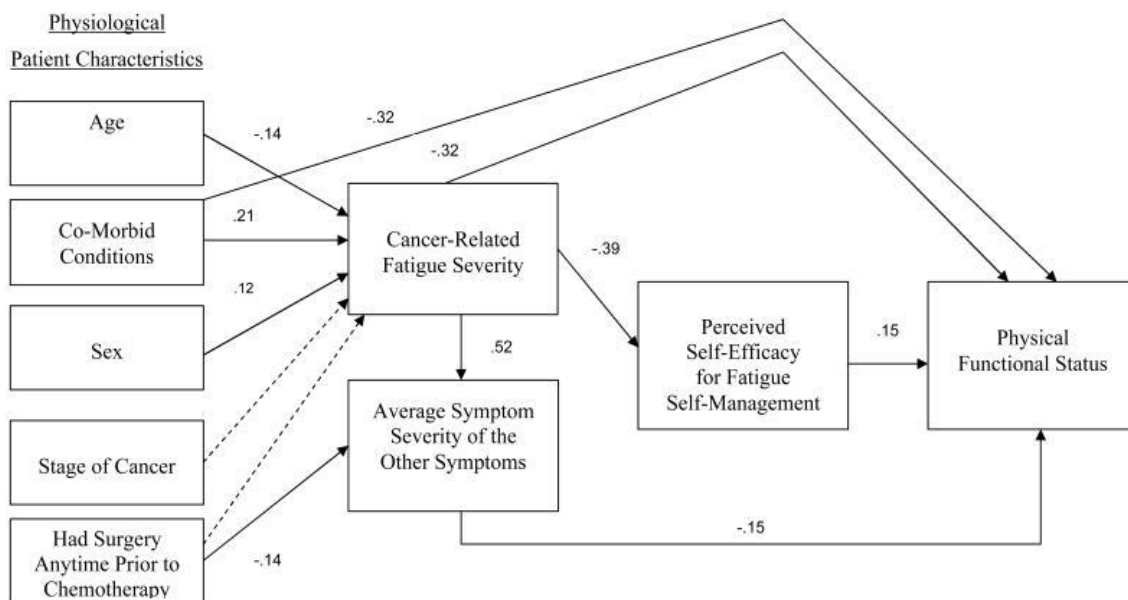
systematic reviews (Gong et al., 2021; Thornton et al., 2021; Zhang et al., 2022), and experimental studies (O'Leary, 1992; Peters et al., 2019; Sarkar et al., 2007) demonstrating that self-efficacy are associated with improvements in health outcomes, and are one of the largest predictors of positive health practices (Yarcheski et al., 2004). For example, a systematic review by Náfrádi and colleagues found that high self-efficacy was routinely associated with improved medication adherence (Náfrádi et al., 2017). Additionally, the authors of the review concluded that promoting medication adherence requires health professionals engaging in support activities to foster clinician-patient relationships and promote patient empowerment. Similarly, high levels of self-efficacy in cancer survivors have consistently been found to promote physical and psychosocial symptom self-management, nutritional intake, physical activity and exercise, and other health self-management behaviours (Gong et al., 2021; Thornton et al., 2021; White et al., 2019). High self-efficacy has also been associated with lower symptom occurrence and distress, and improved general health and quality of life (White et al., 2019). Evidently, self-efficacy is a necessary component of self-management and SMS programs, and a key concept in how and why SMS programs facilitate the adoption and adaptation of health behaviours. Thus, before considering the SMS model of care that frames this doctoral thesis, it is important to understand the specific factors that influence self-efficacy and ascertain the significance of self-efficacy in CRF management.

## **Self-efficacy, self-management, and cancer-related fatigue**

Self-efficacy is a fundamental construct in several self-management and behaviour change theories. Bandura (1977) conceptualised self-efficacy as a descriptive model of human behaviour, whereby self-efficacy has a causal influence with expected behavioural outcomes (i.e., the higher an individual's self-efficacy, the increased likelihood they will engage in a behaviour and succeed). Bandura suggests four primary sources that influence the development of self-efficacy: (1) mastery experience, (2) vicarious experience, (3) verbal persuasion, and (4) psychological arousal (Bandura, 1977). Mastery experience (or performance outcomes) refers to the experience an individual gains when they succeed or fail at a particular task. Bandura posits that past experiences provide evidence as to whether an individual perceives they can succeed, with past successes building perceived efficacy and past failures undermining self-efficacy (particularly before a sense of self-efficacy is established) (Bandura, 1977). Vicarious experiences (or social role modelling) refer to the positive impacts of observing how other people succeed, whereby an individual is more likely to believe they can complete a task if they observe other individuals (particularly in similar circumstances) successfully completing a task (Bin Hasan et al., 2014). Verbal (or social) persuasion involves the continuous provision of explanation and feedback to convince an

individual they have the capability to succeed at undertaking a task. Lastly, physiological arousal describes how the emotional, physical, and psychological well-being of an individual influences their judgement in their abilities to complete a task. For example, depression and anxiety are significantly associated with low total, physical and emotional self-efficacy (Tahmassian & Jalali Moghadam, 2011), which can result in the creation of unrealistic and unattainable goals during action planning activities (Kenioua & El-Kadder, 2016). Thus, strategies that minimise negative states (e.g., worry, anxiety, sadness) and promote positive affects (e.g., tranquillity, happiness) should be used to assist in enhancing perceived self-efficacy.

As mentioned in Chapter 1, the effective management of CRF involves the use of non-pharmacological strategies such as physical activity and exercise, cognitive behaviour therapy, and energy conservation through activity management. Further, all CRF management strategies (including those that are pharmacological) require individuals to self-monitor, self-manage and undergo a level of lifestyle change (Chiba et al., 2019). Thus, the importance of cancer survivor self-management in managing CRF cannot be overstated. Chan and colleagues demonstrate perceived self-efficacy as a significant factor underpinning cancer survivor’s perceived uptake and adoption of CRF self-management behaviours (Chan et al., 2016). Similarly, in a theoretical model designed to map the role of perceived self-efficacy for self-management on an individual’s ability to manage CRF, Hoffman and colleagues identified that greater perceived self-efficacy predicted greater physical functional

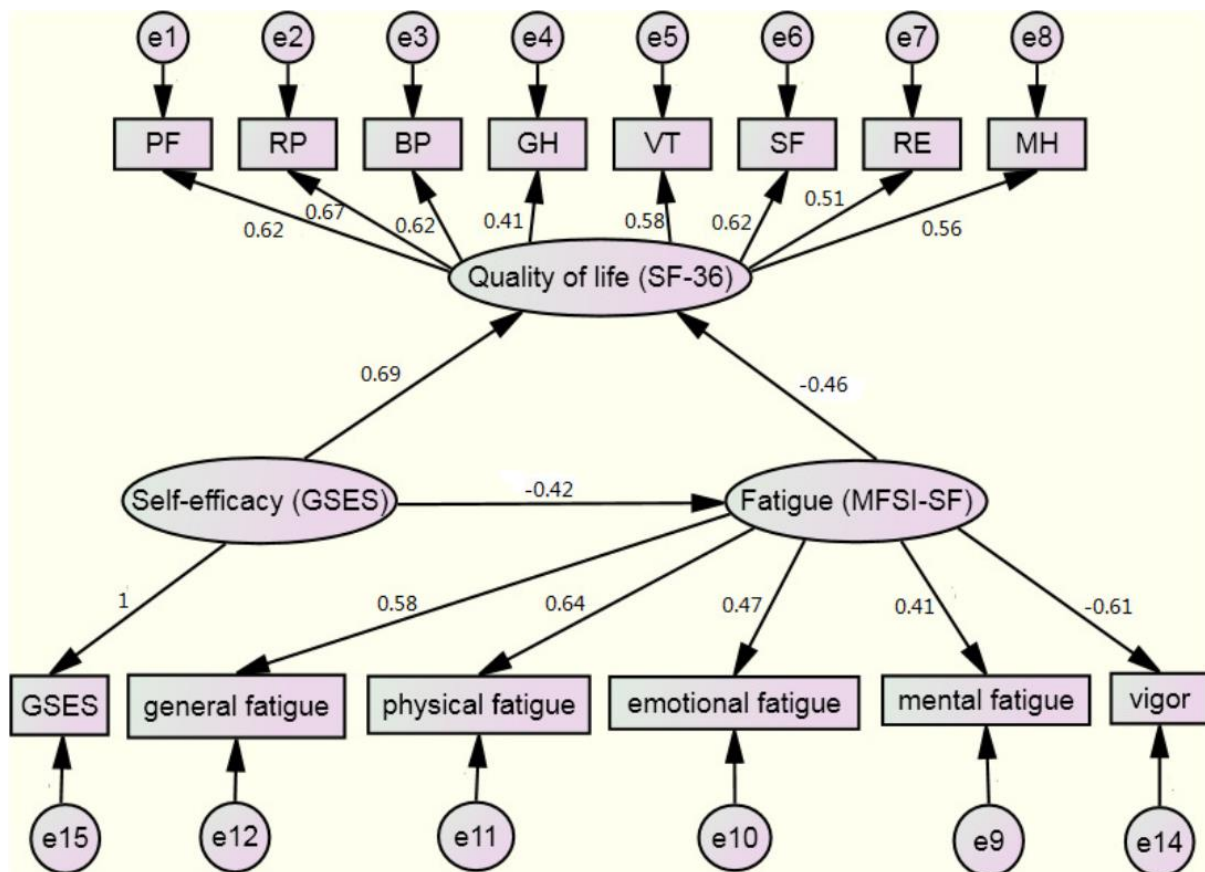


**Figure 2a:** Theoretical Model of Perceived Self Efficacy for Fatigue Self-Management

(Hoffman et al., 2009). *Reproduced with permission from Wolters Kluwer Health, Inc.*

**Solid line means a significant direct path ( $t > +/- 2.0$ ). • Dashed line means a nonsignificant direct path ( $t < 2.0$ ). • The numerical values represent standardized path coefficients.**

status, as illustrated in Figure 2a (Hoffman et al., 2009). In contrast, individuals with greater CRF severity had reduced self-efficacy to manage their fatigue, leading to worse treatment-related outcomes. Similar relationships between self-efficacy and CRF have been replicated in numerous studies across literature (Chen et al., 2018; Chin et al., 2021; Saito et al., 2022; Zhang et al., 2022). For example, in Chen and colleagues' (2018) prospective cohort study of 456 lung cancer patients, self-efficacy had a direct influence on CRF, and was found to be a high ( $r=0.69$ ) predictor of increased quality of life, and a moderate predictor ( $r=-0.42$ ) of reduced CRF (see Figure 2b).



**Figure 2b:** Self-efficacy, Cancer-related fatigue, and Quality of Life Model (Chen et al., 2018). Reproduced with permission from John Wiley and Sons.

*PF=physical functioning, BP=bodily pain, GH=general health, VT=vitality, SF=social functioning, RP=role limitations due to physical problems, RE = role limitations due to emotional problem, MH=mental health*

Accordingly, these findings emphasise that SMS strategies and programs that enhance perceived self-efficacy are crucial to facilitate sustained behavioural uptake of fatigue self-management activities, better CRF control, and improved health outcomes (e.g., improvements in physical functioning, bodily pain, general health, vitality, social functioning, role limitations due to physical and emotional problem, and mental health). The following section will present the SMS conceptual framework that informs this doctoral thesis.

# Conceptual Framework: Flinders Capabilities for Self- Management Support

## Introduction

This doctoral thesis focuses on enhancing the support provided to health professionals engaging in SMS activities for CRF. The *Capabilities for Supporting Prevention and Chronic Condition Self-Management* offers an ideal framework for this doctoral thesis as it emphasises the role health professionals play in building self-efficacy and conceptualises self-management as an active process that requires an essential set of collaborative and partnership building behaviours, skills, knowledge, and attitudes. Other self-management models and frameworks such as the Chronic Care Model, Individual and Family Self-management Theory, or the Chronic Disease Self-Management Program have been widely adopted by various health care systems in the USA, United Kingdom, Canada, Australia, and New Zealand (Grady & Gough, 2014). However, these frameworks focus on patient self-management education programs, and generic systems-level changes that may impact on patient-related and provider-related factors, as opposed to specific strategies to enhance clinician SMS (Grady & Gough, 2014). A review by O'Connell and colleagues (2018) identified eight SMS frameworks for chronic disease that were published between 2008 and 2017. Although six out of the eight frameworks prioritised training and education for health care professionals as key courses of action to support self-management, none of the frameworks provided specific recommendations of the required competencies, skills or activities needed to undertake SMS (O'Connell et al., 2018), and instead presented a general view of the SMS training needed (e.g., priority statements, calls to action, general objectives and missions statements).

Clinicians frequently report they are unaware of fatigue support strategies, are often unwilling to initiate support discussions about fatigue with patients (Borneman et al., 2011; Mudge et al., 2015; Vogelzang et al., 1997), and have called for specific guidance on CRF SMS practices (Hilarius et al., 2011). Thus, a health professional capability framework was considered particularly appropriate, as this doctoral thesis seeks to improve the capacity of health professionals to provide SMS care for CRF through the development of a practice guidance framework. The *Capabilities for Supporting Prevention and Chronic Condition Self-Management* framework operationalises the self-management models such as the Chronic Care Model and other SMS frameworks by providing actionable, pragmatic capabilities for SMS that can be easily translated to clinical practice and applied to health professionals caring for cancer survivors. Additionally, the *Capabilities for Supporting Prevention and Chronic Condition Self-Management* framework was designed using input from prominent national organisations representing Australian patients, primary health professionals, and educators,

and therefore is relevant and suitable for use in the Australian context. Finally, the framework is particularly relevant to the doctoral research as it was used to inform the T-CRF intervention that was analysed in the conversation analysis study (Study 3).

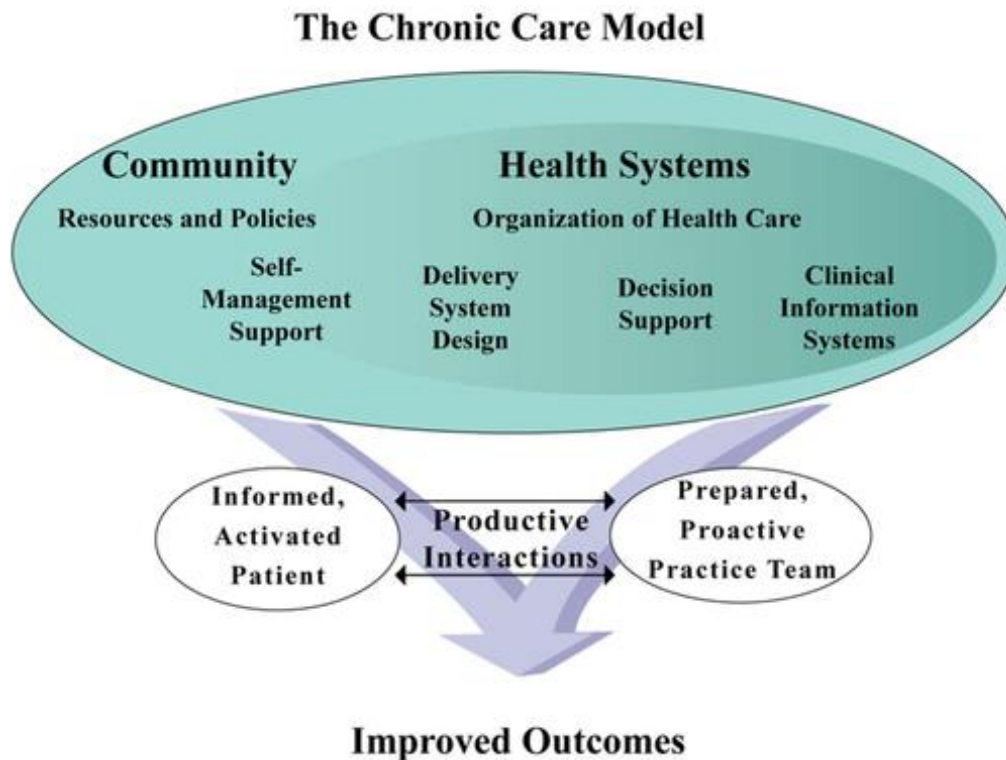
## **Background**

*The Capabilities for Supporting Prevention and Chronic Condition Self-Management* (hereinafter referred to as The Flinders SMS Capabilities Framework, or 'FCF') was designed as a joint health initiative between Flinders University and the Australian Department of Health and Ageing (Lawn & Battersby, 2009). The framework provides evidence-based guidance on the core skills required by health care professionals for SMS to be successfully implemented into practice. Although primarily developed for use by the primary health care workforce, the FCF has been applied in a variety of health contexts and is considered appropriate for use in the context of cancer-related symptom management (Lawn & Lawton, 2011; Turner et al., 2014). Most recently, the framework was used to inform a self-management intervention for head and neck cancer survivors that was facilitated by oncology nurses (Turner et al., 2014). For the remainder of this document, the FCF will be described in the context of cancer and CRF.

The FCF proposes 19 Core Capabilities needed for health professionals to successfully support individuals and their carers to self-manage chronic conditions. These 19 capabilities were informed by an extensive review of SMS literature and curricula and a survey of key stakeholders. These stakeholders included the national primary health care workforce; training organisations delivering self-management education; tertiary education providers from the medical, nursing and allied health disciplines; professional accreditation bodies; and other clinical delivery sectors (Lawn & Battersby, 2009). Additionally, the framework was heavily underpinned by the Chronic Care Model introduced earlier in this chapter (Wagner et al., 1996).

The CCM was developed to improve health outcomes by enhancing and optimising interactions between health professionals and patients. Wagner suggests that improved health outcomes are reliant on the reconfiguration of clinical systems to address the needs and concerns of individuals with chronic conditions (Grover & Joshi, 2014). The CCM classifies six key elements that interact to enable quality chronic disease care: (1) a health system design that fosters a quality improvement culture of chronic disease service delivery; (2) clinical information systems that efficiently support chronic care and facilitate exchange of information between patients and providers (e.g., quality records, follow-up, recall); (3) decision support using evidence-based guidelines; (4) delivery system design that enables individuals to receive co-ordinated, tailored care by well-informed clinicians; (5) SMS; and (6)

the development of partnerships and alliances with the community to support the health care efforts of clinicians (Grover & Joshi, 2014; Savage, 2009) (see Figure 3).



**Figure 3:** The Chronic Care Model (Wagner, 1998)

*Reproduced with permission from ACP-ASIM Journals and Book.*

Although, placing particular emphasis on the SMS component, the FCF considers all elements of the CCM and suggests that to action and operationalise the six CCM features posited, clinicians require appropriate knowledge, skills and attitudes (i.e., skills to support behaviour change; knowledge on planning care and accessing external resources; an understanding of social determinants of health and health promotion; how to work collaboratively within teams and systems; skills for effective communication). Moreover, the importance of cancer survivor-centred communication is particularly emphasised in both the CCM and FCF, and is considered integral to empower survivors to self-manage, reduce risk, and maintain wellness (Lawn & Battersby, 2009).

The importance of clinician-survivor partnership in the CCM is demonstrated in Figure 3, which displays that improved health outcomes are dependent on productive interactions between patients and the health care team. Similarly, the FCF asserts that to successfully support cancer survivors to self-manage their symptoms (e.g., fatigue), clinicians must acquire patient-centred skills for effective engagement and communication between cancer survivors, health



professionals and health systems. The required knowledge and attitudes posited in the FCF are expanded further in the suggested 19 Core Capabilities needed for providing SMS.

### 19 Core Capabilities

The 19 Core Capabilities proposed in the FCF encompass the essential knowledge, attitudes and skills needed by health professionals to support cancer survivors to self-manage. These core capabilities are displayed in Table 1 below.

**Table 1:** Nineteen Core Capabilities and Self-efficacy (Lawn & Battersby, 2009)

<b>General Patient-Centred Capabilities</b>	<b>Behaviour Change Capabilities</b>	<b>Organisational/Systems Capabilities</b>
<ol style="list-style-type: none"> <li>1. Health promotion approaches</li> <li>2. Assessment of health risk factors</li> <li>3. Communication skills</li> <li>4. Assessment of self-management capacity (understanding strengths and barriers)</li> <li>5. Collaborative care planning</li> <li>6. Use of peer support</li> <li>7. Cultural awareness</li> <li>8. Psychosocial assessment and support skills</li> </ol>	<ol style="list-style-type: none"> <li>9. Models of health behaviour change</li> <li>10. Motivational interviewing</li> <li>11. Collaborative problem definition</li> <li>12. Goal setting and goal achievement</li> <li>13. Structured problem solving and action planning</li> </ol>	<ol style="list-style-type: none"> <li>14. Working in multidisciplinary teams/interprofessional learning and practice</li> <li>15. Information, assessment, and communication management systems</li> <li>16. Organisational change techniques</li> <li>17. Evidence-based knowledge</li> <li>18. Conducting practice-based research/quality improvement framework</li> <li>19. Awareness of community resources</li> </ol>

The FCF emphasises the importance of operationalising the SMS Core Capabilities into a self-management care plan. In the context of CRF, a best practice care plan should contain an assessment of self-management capacity and provide cancer survivors with specific skills and tasks to assist in managing CRF (e.g., goal setting, action planning, problem solving, emotional management, fatigue management, psychosocial skills, cognitive change skills, and relapse prevention skills). Further, these components will engage cancer survivors in managing their treatment and care, enhance the cancer survivor-clinician relationship, and enhance survivors' ability to maintain changes once fatigue self-management outcomes are achieved (Lawn & Battersby, 2009).

The FCF suggests that an additional key objective of the SMS Core Capabilities (and self-management care plan) is to enhance the self-efficacy and confidence of cancer survivors to perform self-management tasks (e.g., 150 minutes of moderate intensity aerobic activity a

week) and achieve improved health outcomes (e.g., reduced fatigue severity) (Lawn & Battersby, 2009). This is particularly evident as strategies addressing and/or incorporating the four factors influencing self-efficacy (mastery experience, vicarious experience, verbal persuasion, psychological arousal) can be found across many of the proposed SMS Core Capabilities. For example, *goal setting*, and *motivational interviewing* techniques use ‘verbal persuasion’ to help cancer survivors overcome resistance and build confidence in their ability to perform a task (e.g., exercise). Additionally, the incremental achievement of goals derived during action planning and goal setting (e.g., completing 4,000 steps a day) is an example of ‘mastery experience’, as direct performance accomplishments increase perceived capability and self-efficacy, which in turn, increases the likelihood of task progression and performance. The *assessment of health risk factors* and *self-management capacity* also link into mastery experience as they assist health professionals to create tailored, smaller, more manageable goals that are more likely to be accomplished. Likewise, *psychosocial assessment and support* and other assessments can also minimise the negative effects of ‘psychological arousal’ on perceived ability and self-efficacy. Additional examples of self-efficacy influencing factors included across the SMS Core Capabilities are displayed in Table 2.

**Table 2:** SMS Core Capabilities and Self-efficacy

<b>Factors influencing Self-Efficacy</b>	<b>FCF Capability</b>	<b>Methods</b>
Mastery Experience	(1) Health promotion approaches (2) Assessment of health risk factors (4) Assessment of self-management capacity (12) Goal setting (13) Structured problem solving and action planning	Successful perseverant efforts such as incremental achievement of goals (e.g., achieving 4000 steps per day) and other manageable tasks which in turn increase survivor willingness and confidence to engage and improve other CRF self-management behaviours.
Vicarious Experience	(6) Use of peer support	Observing similar role models complete a task (e.g., group classes, cancer survivor stories) increases perceived ability to undergo behaviour change (e.g., increase daily exercise).
Verbal Persuasion	(3) Communication Skills (5) Collaborative Care Planning (10) Motivational Interviewing (11) Collaborative Problem definition (12) Goal setting (13) Structured Problem Solving and action planning	The provision of encouragement, feedback and coaching through communication to foster cancer survivor confidence in their capability to achieve success and build a sense of mastery (e.g., verbal feedback from clinicians, app notifications).

Psychological Arousal	(2) Assessment of health risk factors (4) Assessment of self-management capacity (5) Collaborative Care Planning (8) Psychosocial assessment and support skills (11) Collaborative Problem definition	Assessment and collaboration with cancer survivors to determine the psychological, emotional, and social barriers that may impede confidence in ability; with the referral to relevant professionals as needed. The provision of tailored support (coping skills, relaxation exercises, other techniques) to minimise distress (e.g., anxiety) and cultivate eustress (beneficial stress) to improve perceived ability to perform tasks (e.g., exercise).
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## Conclusions

This chapter presented a brief history of self-management, the influence of self-efficacy in SMS and fatigue management, and introduced the FCF as the conceptual framework for this research. The FCF is particularly relevant for this doctoral thesis as it was used to guide the development of the clinician SMS guidance framework for CRF (Study 2 – Chapter 4). The FCF also informed the Telehealth Cancer-Related Fatigue (T-CRF) intervention (Ladwa et al., 2022) described in the conversation analysis study (Study 3 – Chapter 5). Briefly, cancer nurses delivering the T-CRF intervention received training and utilised the SMS Core Capabilities proposed in the FCF (e.g., motivational interviewing, goal setting, collaborative care planning) to empower cancer survivors to manage their CRF. The FCF focuses on the role of health professionals in supporting individuals to self-manage chronic conditions – which aligns with the aims of the current doctoral thesis which focuses on the role of clinicians in supporting cancer survivors to manage their CRF. For this reason, the FCF was considered a suitable conceptual framework for this doctoral thesis.

# **3.0 COMPONENTS, PRINCIPLES, AND PROCESSES OF SELF-MANAGEMENT SUPPORT FOR CANCER-RELATED FATIGUE (STUDY 1)**

## **Chapter Introduction**

As highlighted in Chapter 1, current reviews on SMS interventions for individuals experiencing CRF do not examine or identify the essential self-management elements and mechanisms needed to establish a successful CRF SMS program. Further a lack of identification of these important components has been highlighted as a barrier to the successful implementation of CRF management guidelines to practice, subsequently affecting the care cancer survivors receive (Hilarius et al., 2011; Jones et al., 2021). This chapter details the methodology and findings of a systematic review, that aimed to collate and examine knowledge on the effectiveness, elements, and processes of SMS interventions for individuals with CRF found in published literature. This review informs the development of a CRF SMS guidance framework for health professionals and explores the following two questions:

1. What is the effectiveness of SMS interventions on improving cancer related fatigue and other relevant behavioural outcomes (e.g., frequency of behaviours, self-efficacy, intention) for cancer survivors?
2. What self-management theories, strategies and intervention components are associated with higher acceptability, and improved behavioural and CRF outcomes in cancer survivors?

This systematic review was accepted for publication in the International Journal of Nursing Studies on 10<sup>th</sup> February 2022 (DOI: <https://doi.org/10.1016/j.ijnurstu.2022.104206>) and has been included in this chapter.

## Background

As previously stated in Chapter 1, the effective management of CRF mainly involves the use of non-pharmacological strategies such as physical activity, exercise, cognitive behaviour therapy (CBT), and daily activity management (Corbett et al., 2019; Finnegan-John et al., 2013; Hilfiker et al., 2018b; Mustian et al., 2017). These management strategies aim to address behavioural risk factors for CRF (e.g., sleep disturbance, physical inactivity, poor nutrition, depression) and require individuals to play a key role in guiding their care through the adoption of fatigue self-management behaviours (e.g., increasing weekly physical activity, conserving energy, improving nutritional status) (Chan et al., 2016).

Such engagement is a complex patient-led endeavour that involves active self-monitoring, adherence to treatment, purposeful changes to multiple health and lifestyle behaviours, contact with healthcare providers, and engagement with peer and family support (Araújo-Soares et al., 2019; Schulman-Green et al., 2012). SMS for CRF aims to promote and facilitate cancer survivor behaviour change and can occur through a variety of approaches, including self-efficacy enhancement; motivational interviewing; behavioural counselling based on stages of change; counselling and behavioural modification; and other complex interventions (Minton et al., 2013). Further, effective SMS through the provision of problem solving and decision-making support, education, resources, regular assessment of progress, defined goals, and an established patient-health care provider partnership (Dineen-Griffin et al., 2019), have been widely identified as necessary and vital components of CRF management (Chiba et al., 2019; Girgis, 2020; Huang et al., 2019).

Although the effective management of CRF is well established, the effective translation of management strategies to practice is rare (Agbejule et al., 2021; Hilarius et al., 2011; Jones et al., 2021), resulting in CRF being under-reported, under-diagnosed and undertreated.

As highlighted earlier in Chapter 1, recent reviews on SMS programs in the cancer population do not explore or identify key SMS components or principles; a gap that has been routinely highlighted across cancer survivorship literature. In addition to the literature discussed in Chapter 1, three systematic reviews (Hernandez Silva et al., 2019; Kim et al., 2017; Xu et al., 2019) have investigated the impact of SMS programs on CRF demonstrating varying results of program efficacy and effectiveness. However, these reviews only focused on web-based interventions (e.g., mobile health applications, electronic health) and did not explore or identify the essential self-management components, theories, or behaviour change techniques of included interventions; a gap that has been routinely highlighted across SMS literature in

cancer survivors (Boland et al., 2018; Cuthbert et al., 2019; Howell et al., 2017; Kim et al., 2017).

Identifying SMS components is key to ascertaining whether a program can be successfully implemented, effectively evaluated, and improved over time; and is essential to determine the relevant educational and training requirements of clinicians and the impact, efficacy, and effectiveness of specific components on certain outcomes (Blase & Fixsen, 2013). This review seeks to address the identified gaps in literature by moving beyond the examination of program effectiveness, to gain a greater level of understanding of SMS for cancer survivors experiencing CRF.

To date, no systematic review has examined the theories, components, and effectiveness of SMS interventions for individuals experiencing CRF. To address this gap, the aim of this systematic review was to understand (1) the effectiveness of SMS interventions on improving CRF and other related behavioural outcomes (e.g., frequency of behaviours, self-efficacy, and intention) for cancer survivors; and (2) the self-management theories, strategies, and intervention components associated with improved behavioural and CRF outcomes in cancer survivors.

## **Methods**

This systematic review was reported according to the 2020 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement (Page et al., 2021) and was registered in the PROSPERO international prospective register of systematic reviews by the National Institute for Health Research (NIHR). Protocol registration ID: CRD42020207121.

### **Identification of studies and inclusion criteria**

Population, Intervention, Comparison and Outcome (PICO) framework information are presented in Appendix 2. The following databases were searched for articles published from inception to June 2021: Cumulative Index to Nursing and Allied Health Literature (CINAHL), US National Library of Medicine National Institutes of Health (PubMed), Cochrane CENTRAL, and the Excerpta Medica Database (EMBASE), as they provided collective coverage of medical, nursing, and allied health journals. Free text terms and relevant subject headings (i.e., MeSH, Emtree) for “self-management support” and “cancer-related fatigue” were used. The full search strategy is presented in Appendix 3. Citation searching of relevant studies (e.g., self-management support systematic reviews, and included studies) was also conducted.

Included studies were required to meet the following criteria: (1) evaluate the effects of interventions designed for cancer survivors, where fatigue associated with cancer or cancer treatment is an outcome of interest; (2) aimed at supporting the self-management of cancer survivors; (3) published in English; and (4) a randomised controlled trial. To ensure that included studies reported on interventions where fatigue associated with cancer, or cancer-treatment was a prominent outcome of interest, studies which only reported tiredness using a question in a greater quality of life scale (e.g., European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 - EORTC-QLQ-C30) were not included.

SMS interventions for CRF target cancer survivor behaviour change and support the reduction of fatigue severity through behavioural mechanisms (Hoffman et al., 2017). As such, fatigue severity was the primary outcome of this review, and behavioural outcomes were assessed as secondary outcomes (see Appendix 2). Behavioural outcomes can include fatigue management behaviours such as diet, physical activity, and exercise; and associated determinants such as fatigue self-efficacy (confidence to undertake fatigue self-management behaviours), other types of self-efficacy outcomes, and the intention to change behaviours.

While there is no 'gold standard' definition of a SMS intervention, this review employed the Taxonomy of Self-Management Support (or The Self-management Support Taxonomy) developed by Howell and colleagues (Howell et al., 2019) – an adaptation of the Practical Reviews in Self-Management Support Taxonomy (Pearce et al., 2016). The Taxonomy of Self-management Support comprises 14 components that can be used to support self-management when delivered to a cancer survivor or their carer (Pearce et al., 2016). Briefly, components comprise the provision of information about the condition, and its physical and psychosocial management; goal setting; regular clinical review; provision of equipment; monitoring of the condition with feedback, social support; lifestyle advice and support, and coaching for different coping strategies. Studies including an intervention with at least one of the core SMS components described in this taxonomy were considered for inclusion.

### **Study screening and data extraction**

Search titles and abstracts were screened by the thesis author and another researcher (Stuart Ekberg). The full text of eligible studies were then independently assessed for inclusion. Disagreements were resolved with another researcher (Raymond Chan) acting as arbiter where consensus could not be reached. All articles that met the specified inclusion criteria were included in the systematic review.

Data extraction was conducted by the thesis author and checked by another researcher (Megan Crichton). Data extraction included: study setting; participant and demographic characteristics; disease-specific factors (i.e. tumour type, tumour stage, treatment characteristics); time since completion of treatment; self-management or behavioural theories underpinning the intervention; intervention information for each arm of the study (e.g. method of delivery, intervention type, content, duration, number of sessions, duration of each session); descriptions of providers of the intervention and comparison intervention/s, timing, frequency and duration of follow-up for each outcome and key study findings. The Self-management Support Taxonomy (Howell et al., 2019) was used to extract SMS components. While primarily focussing on support delivered directly to cancer survivors or caregivers, the taxonomy also refers to indirect SMS provided to intervention facilitators (e.g., nurses, social worker, physical trainers, psychologists etc.). As such, information on any assistance (i.e., education and training; provision of equipment; prompts; feedback and review; financial incentives) that enabled facilitators to deliver SMS was also extracted. SMS strategies not included in the taxonomy were also recorded.

### **Study quality assessment and data analysis**

Quality assessment was independently conducted by the thesis author and another researcher (Megan Crichton) using the Revised Cochrane Risk-of-Bias tool for Randomised Trials (Sterne et al., 2019). This validated critical appraisal tool includes five domains: (1) bias arising from the randomisation process, (2) bias due to deviations from intended interventions, (3) bias due to missing outcome data, (4) bias in measurement of the outcome, (5) bias in selection of the reported result. Each domain was given a risk of bias judgement (low, some concerns, high). These decisions contribute to an overall risk of bias (low, some concerns, high) for each study. Any disagreements were resolved by another researcher (Raymond Chan) acting as arbiter. Due to study heterogeneity (i.e., diversity of populations studied; outcome measures; intervention duration, components, and aims; and duration of follow-up period), a meta-analysis could not be conducted. Rather, data were synthesised descriptively as having statistically significant, positive, negative, or null effects as reported by authors of the included studies.

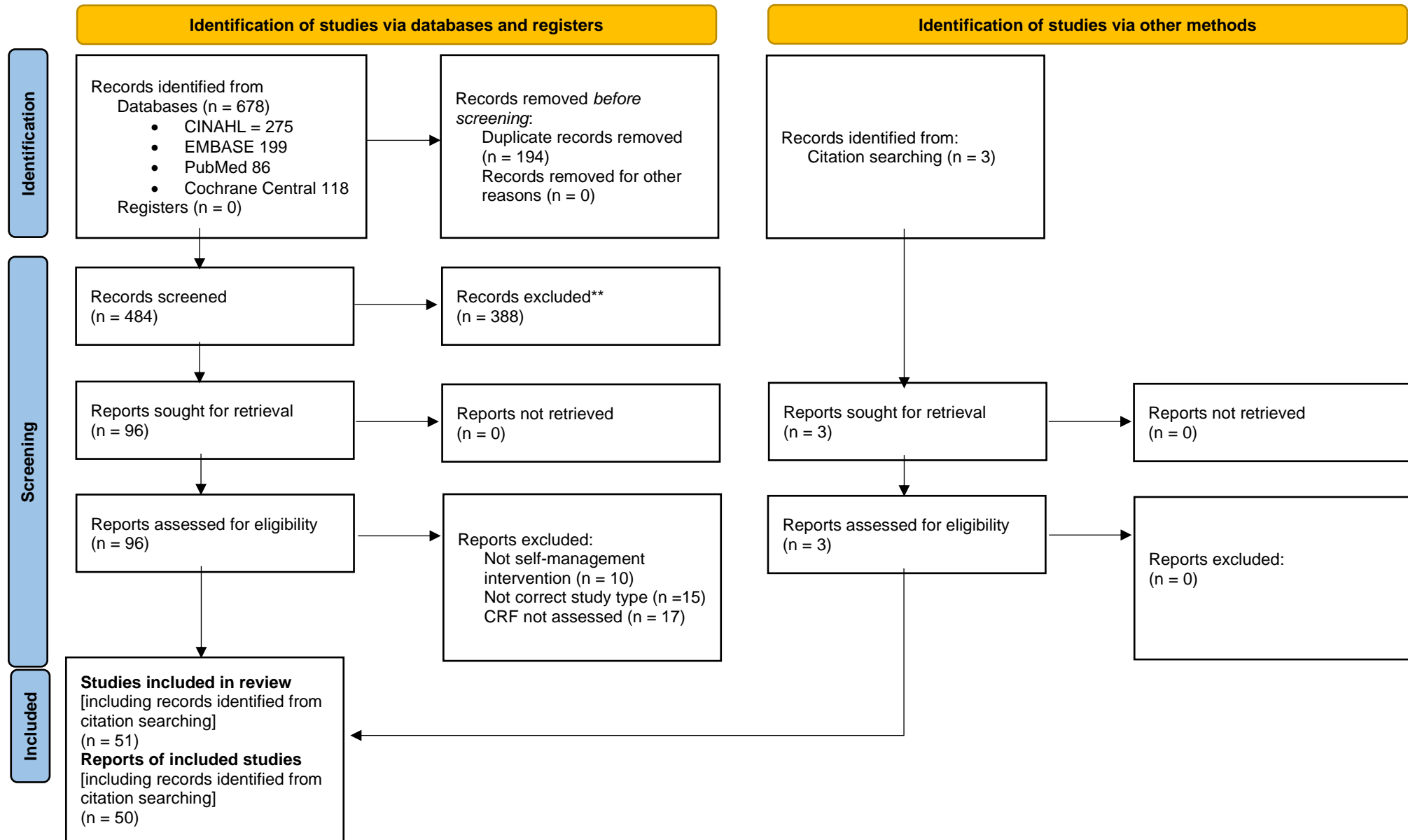
## **Results**

Initial search results produced 772 articles. After removal of duplicates and title-abstract screening, 96 articles were assessed for full-text eligibility. Articles that reported findings from the same intervention were considered as one study, using the author's name associated with the earliest publication date. As such, 50 studies involving a total of 7,383 cancer survivors were included in the review (Abrahams et al., 2017; Armes et al., 2007; Bantum et al., 2014;



Barsevick et al., 2010; Barsevick et al., 2004; Bennett et al., 2007; Bruggeman-Everts et al., 2017; Chan et al., 2011; Dodd et al., 2010; Donnelly et al., 2011; Fillion et al., 2008; Foster et al., 2016; Freeman et al., 2015; Galiano-Castillo et al., 2016; Godino et al., 2006; Gokal et al., 2016; Golsteijn et al., 2018; Grégoire et al., 2020; Hoffman et al., 2017; Johns et al., 2016; Johns et al., 2015; Johnston et al., 2011; Lam et al., 2018; Lee et al., 2014; W. H. C. Li et al., 2018; Mooney et al., 2017; Naraphong, 2015; Purcell et al., 2011; Ream et al., 2015; Ream et al., 2006; Reif et al., 2013; Ritterband et al., 2012; Sandler et al., 2017; Savard et al., 2005; Schjolberg et al., 2014; Smith et al., 2019; Spahn et al., 2013; Stanton et al., 2005; Steel et al., 2016; Vallerand et al., 2018; van der Lee & Garssen, 2012; van Waart et al., 2015; van Weert et al., 2010; Vargas et al., 2014; Wang et al., 2011; Wangnum et al., 2013; Willems et al., 2017; Yates et al., 2005; Yun et al., 2012; Zhang et al., 2018). The selection of articles, including reasons for exclusion are outlined in Figure 4. All included studies used patient self-reported scales and questionnaires (e.g., Greater Fatigue Scale, Brief Fatigue Inventory, Schwartz Cancer Fatigue Scale, Multidimensional Fatigue Inventory) to measure all outcomes of interest.

**Figure 4: PRISMA Flow Diagram**



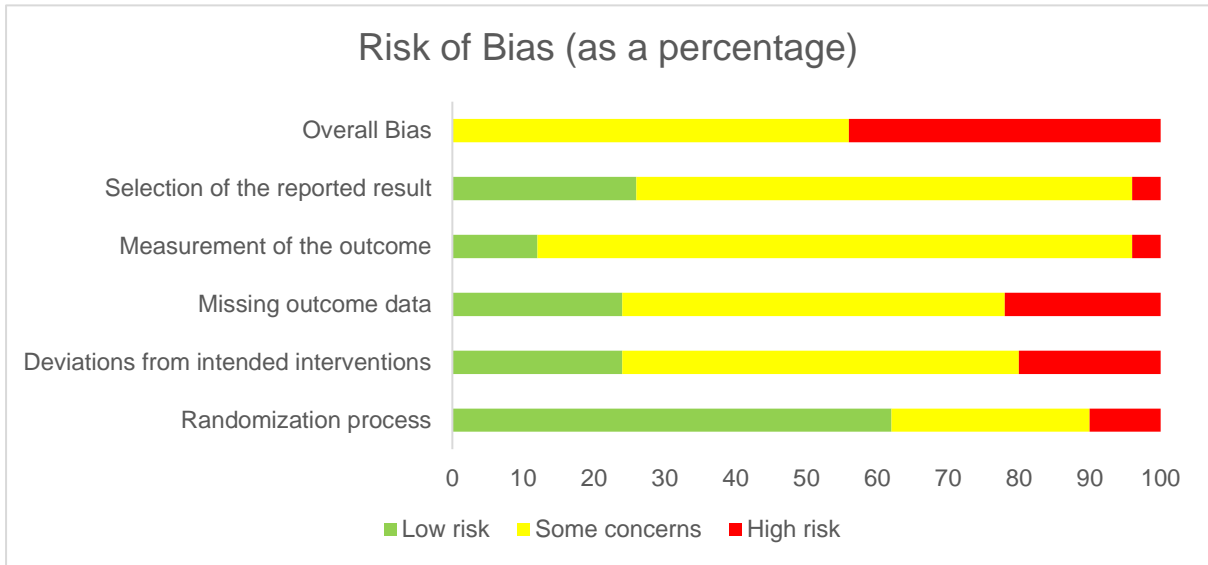
## **Characteristics of Included Studies**

Study characteristics are summarised in Appendix 4. Studies and SMS programs were mostly developed in the United States of America (n=15/50, 30%), United Kingdom (n=6/50, 12%), and the Netherlands (n=7/50, 14%). Participant sample size across studies ranged from 13 to 588. Follow-up assessments were completed in 29 studies with follow-up periods ranging from 2 to 12 months. Fourteen studies (28%) used a waitlist control, 12 studies (24%) used an attention control group, one study (2%) did not specify control type, and the remaining studies (n=23/50, 46%) utilised usual care. Interventions were predominantly targeted towards cancer survivors with mixed cancer type (n=16/50; 32%), breast cancer survivors (n=16/50; 32%), and lung cancer survivors (n=6/50, 12%). The average intervention duration was 9.6 weeks (median = 8.5 weeks). Twenty-eight (55%) interventions were delivered post cancer treatment, 20 (39%) delivered during treatment, and three (6%) delivered during and following cancer treatment. One study (2%) compared post-cancer treatment intervention delivery alone with intervention delivery during and post-cancer treatment.

## **Risk of Bias**

A summary of the risk assessment across all studies is presented in Figure 5. Risk of bias for each included study is presented in Appendix 5. Twenty-two studies (n=22/50; 44%) had a high risk of bias, and 28 studies (n=28/50; 56%) had some concerns, with no studies presenting with an overall low risk of bias. Randomisation processes were sufficiently described in most studies and were a source of the lowest risk of bias (62% of studies reported low risk for this domain). The domains with the highest risk of bias were measurement of the outcome (84% some concerns, 4% high risk), missing outcome data (54% some concerns, 22% high risk), and deviations from intended interventions (56% some concerns, 20% high risk). The largest source of bias was the influence of self-reporting on blinding and outcome assessments, insufficient evidence that results were not biased by missing data (e.g., lack of sensitivity analyses), and a lack of detailed trial protocols.

**Figure 5: Risk of Bias in Included Studies**



**Description of Self-management Support Programs**

***Cancer-related Fatigue Management Interventions***

CRF management strategies described as interventions included: education (Bantum et al., 2014; Foster et al., 2016; Godino et al., 2006; Hoffman et al., 2017; Purcell et al., 2011; Reif et al., 2013; Schjolberg et al., 2014; Smith et al., 2019; Wangnum et al., 2013; Yun et al., 2012), physical activity (Bennett et al., 2007; Bruggeman-Everts et al., 2017; Donnelly et al., 2011; Gokal et al., 2016; Golsteijn et al., 2018; Lam et al., 2018; W. H. C. Li et al., 2018; van Waart et al., 2015; Wang et al., 2011), psychoeducation (Chan et al., 2011; Fillion et al., 2008; Stanton et al., 2005; Steel et al., 2016; Willems et al., 2017; Yates et al., 2005), exercise (Dodd et al., 2010; Galiano-Castillo et al., 2016; Naraphong, 2015), CBT (Abrahams et al., 2017; Ritterband et al., 2012; Savard et al., 2005), energy conservation (Barsevick et al., 2010; Barsevick et al., 2004), mindfulness-based cognitive therapy (Bruggeman-Everts et al., 2017; van der Lee & Garssen, 2012), mindfulness-based stress reduction (Johns et al., 2016; Johns et al., 2015), imagery-based behavioural therapy (Freeman et al., 2015), a symptom monitoring system (Mooney et al., 2017), cognitive behavioural stress management (Vargas et al., 2014); and combinations of self-care education and self-hypnosis (Grégoire et al., 2020), education and acupuncture (Johnston et al., 2011), exercise and diet education (Lee et al., 2014), exercise and mind-body therapy (Spahn et al., 2013), exercise and CBT (Sandler et al., 2017; Zhang et al., 2018), physical activity and CBT (van Weert et al., 2010), and fatigue education through MI and counselling (Ream et al., 2015; Ream et al., 2006).

### ***Mode of Self-management Support Delivery***

Modes of intervention delivery varied across studies and included web-based (n=9/50, 18%), face-to-face (n=20/50, 40%), home-based (n=2/50, 4%), telephone-based (n=7/50, 14%), and mixed hybrid approaches (n=12, 24%). Most interventions were delivered in a one-on-one format (n=33/50, 66%) (Abrahams et al., 2017; Armes et al., 2007; Barsevick et al., 2010; Barsevick et al., 2004; Bennett et al., 2007; Bruggeman-Everts et al., 2017; Dodd et al., 2010; Donnelly et al., 2011; Foster et al., 2016; Galiano-Castillo et al., 2016; Godino et al., 2006; Gokal et al., 2016; Golsteijn et al., 2018; Hoffman et al., 2017; Johnston et al., 2011; Lam et al., 2018; Lee et al., 2014; Mooney et al., 2017; Naraphong, 2015; Ream et al., 2015; Ream et al., 2006; Ritterband et al., 2012; Sandler et al., 2017; Smith et al., 2019; Stanton et al., 2005; Steel et al., 2016; Vallerand et al., 2018; van Waart et al., 2015; Wang et al., 2011; Wangnum et al., 2013; Willems et al., 2017; Yates et al., 2005; Yun et al., 2012). One study (2%) described two separate interventions for delivery at the group and individual level (van Weert et al., 2010), and another study (2%) did not specify the target type (Chan et al., 2011). The remaining studies were delivered either in a group (Fillion et al., 2008; Freeman et al., 2015; Grégoire et al., 2020; Johns et al., 2016; Johns et al., 2015; W. H. C. Li et al., 2018; Purcell et al., 2011; Reif et al., 2013; Savard et al., 2005; Schjolberg et al., 2014; Spahn et al., 2013; van der Lee & Garssen, 2012; Vargas et al., 2014) (n=13/50, 26%), or mixed one-on-one-group format (n=2/50, 4%) (Bantum et al., 2014; Smith et al., 2019).

### ***Facilitation of Self-management Support***

Interventions were supervised by health professionals (Barsevick et al., 2004; Bennett et al., 2007; Bruggeman-Everts et al., 2017; Chan et al., 2011; Fillion et al., 2008; Godino et al., 2006; Grégoire et al., 2020; Hoffman et al., 2017; Johns et al., 2016; Johns et al., 2015; Johnston et al., 2011; Lam et al., 2018; W. H. C. Li et al., 2018; Mooney et al., 2017; Purcell et al., 2011; Ream et al., 2015; Ream et al., 2006; Reif et al., 2013; Sandler et al., 2017; Savard et al., 2005; Schjolberg et al., 2014; Smith et al., 2019; Spahn et al., 2013; Stanton et al., 2005; Steel et al., 2016; van der Lee & Garssen, 2012; van Waart et al., 2015; van Weert et al., 2010; Wang et al., 2011; Wangnum et al., 2013; Yates et al., 2005; Zhang et al., 2018), were entirely self-directed (Foster et al., 2016; Golsteijn et al., 2018; Naraphong, 2015; Smith et al., 2019; Willems et al., 2017; Yun et al., 2012), or were facilitated by other cancer survivors (Bantum et al., 2014), or research staff (Armes et al., 2007). Facilitators were not recorded or were unclear in eight studies (Dodd et al., 2010; Donnelly et al., 2011; Galiano-Castillo et al., 2016; Gokal et al., 2016; Naraphong, 2015; Ritterband et al., 2012; Vallerand et al., 2018; Vargas et al., 2014); however, one of these studies indicated that participant family members were invited to assist in SMS coaching (Dodd et al., 2010).

### ***Theories guiding Self-management Support Intervention Development***

Most studies (n=45/50, 90%) mentioned the use of behaviour change and self-efficacy enhancing techniques. Thirty-one (n=31/50, 62%) studies explicitly reported their use of a specific behavioural theory or model to guide intervention development. These included the Common Sense Model (Barsevick et al., 2010; Barsevick et al., 2004); Stress Coping Model (Bruggeman-Everts et al., 2017); Cognitive Behaviour change principles (Abrahams et al., 2017; Bruggeman-Everts et al., 2017; Foster et al., 2016; Ritterband et al., 2012; Sandler et al., 2017; Steel et al., 2016; Vargas et al., 2014; Willems et al., 2017; Yun et al., 2012; Zhang et al., 2018); Adult Learning Theory (Dodd et al., 2010); Transtheoretical Model (Donnelly et al., 2011; Golsteijn et al., 2018; Lee et al., 2014; van Waart et al., 2015; Yun et al., 2012); Self-efficacy Theory (Foster et al., 2016; Lam et al., 2018; Wang et al., 2011); Theory of Planned Behaviour (Gokal et al., 2016; Golsteijn et al., 2018); Social Cognitive Theory (Golsteijn et al., 2018; Johnston et al., 2011; Lam et al., 2018; Yun et al., 2012); Health Belief Model (Golsteijn et al., 2018; Purcell et al., 2011); Translational Care Model (Hoffman et al., 2017); Theory of Symptom Self-management (Hoffman et al., 2017); Integrative Medicine Theory (Johnston et al., 2011); Kolb's experiential learning theory (Lam et al., 2018; W. H. C. Li et al., 2018); Leventhal's self-regulatory theory (Ream et al., 2015); a Behaviour Change model for internet interventions (Ritterband et al., 2012); the Multi-process Action Control framework (Vallerand et al., 2018); elements of cognitive therapy and mindfulness-based principles (van der Lee & Garssen, 2012); Problem Solving Therapy (Willems et al., 2017), Green's PRECEDE model of health behaviour (Yates et al., 2005); and other self-management and patient empowerment approaches (Grégoire et al., 2020); social learning, health action processes, precaution adoption processes and theories of self-regulation (Golsteijn et al., 2018; Stanton et al., 2005).

### ***Self-management Support Components, Strategies and Approaches***

SMS components and strategies of included interventions are summarised in Table 3, with specific Self-management Support Taxonomy components used in each study presented in Appendix 6. SMS approaches varied across studies and included information provision (n=32), goal setting (n=27), problem solving (n=21), self-monitoring (n=18), coaching (n=16), action planning (n=14), sharing experiences (n=13), positive feedback (n=13), stress management (n=10), peer modelling (n=7), counselling (n=7), and motivational interviewing (n=3). The average number of Self-management Support Taxonomy components used across all studies was 6.1 out of a possible 14 Taxonomy components.

### ***Self-management Support Facilitator Training***

Outside of education associated with professional qualification or registration, 30% (n=15/50) of studies described additional skills development for the cancer survivors or health

professionals who delivered interventions. Most of these 15 studies reported a positive intervention effect on CRF ( $n=11/15$ , 73%) and other behavioural outcomes ( $n=5/6$ , 83%), for at least one timepoint (immediate post intervention or follow-up). Study authors provided intervention facilitators with counselling (Barsevick et al., 2004), motivational interviewing (Bennett et al., 2007; Ream et al., 2015), muscle relaxation (Chan et al., 2011), CBT (Fillion et al., 2008; Zhang et al., 2018), and mindfulness-based stress reduction training, (Johns et al., 2016; Johns et al., 2015; van der Lee & Garssen, 2012) along with other study specific training (Armes et al., 2007; Bantum et al., 2014; Lam et al., 2018; Reif et al., 2013; Stanton et al., 2005; van Weert et al., 2010). Further detail on facilitator training is presented in Table 3.

**Table 3:** Summary of self-management support components and strategies used across studies with positive intervention effects.

<b>Self-management Support for Cancer Survivors Experiencing Fatigue</b>	
<b>Key Components of Self-management Support for Cancer-related Fatigue (CRF)</b>	<b>Strategies Used to Accomplish Components</b>
Providing visual, written, or verbal information about CRF and/its management	<p>Providing information on:</p> <ul style="list-style-type: none"> <li>• the definition of CRF</li> <li>• the causes, presenting characteristics, and potential effects/ interferences on daily living</li> <li>• recognised coping strategies (i.e., sleep hygiene, cognitive restructuring, physical activity, activity management, stress management, etc.).</li> <li>• the benefits of proposed CRF strategies (i.e., physical activity, cognitive restructuring) on wellbeing.</li> </ul>
Providing visual, written, or verbal information about managing the psychosocial consequences of cancer and CRF	<ul style="list-style-type: none"> <li>• Information on how psychological and psychosocial factors contribute to and are exacerbated by CRF.</li> <li>• Information and solution-focused counselling on the management of symptoms such as fear of cancer recurrence, anxiety, depression, stress, uncertainty.</li> <li>• Information on coping approaches for: <ul style="list-style-type: none"> <li>○ processing and communicating emotional experiences with others</li> <li>○ dealing with difficult emotions and thoughts</li> <li>○ establishing emotional boundaries and personal needs</li> <li>○ talking with others about cancer experiences.</li> </ul> </li> </ul>
Providing visual, written, or verbal information about available social support resources and navigating transitions.	<ul style="list-style-type: none"> <li>• Providing information on re-entry into 'normal' life after cancer, return to work, and seeking social support.</li> <li>• Providing counselling on how to communicate CRF and cancer to personal social networks and employers.</li> <li>• Providing links to external resources.</li> </ul>
Creating a CRF action plan in collaboration with the cancer survivor and/ or their social network	<ul style="list-style-type: none"> <li>• Education on effective goal setting and planning (e.g., SMART goals).</li> <li>• Collaborative goal setting and written action planning for improving lifestyle behaviours: <ul style="list-style-type: none"> <li>○ sleep hygiene</li> <li>○ healthy food choices</li> <li>○ exercise and physical activity</li> <li>○ activity management</li> <li>○ general wellness.</li> </ul> </li> <li>• Collaborative reformulation of goals as needed</li> <li>• The inclusion of cancer survivor social networks (family, carers, friends) in action planning</li> <li>• Discussion and establishment of long-term goals at the cessation of self-management support</li> </ul>



Providing regular clinical review of CRF, the uptake of CRF self-management behaviours, and any adverse events related to self-management of CRF.	<ul style="list-style-type: none"> <li>• Using in-person or telehealth consultations, or logbook/ dairy reviews to monitor: <ul style="list-style-type: none"> <li>○ CRF severity and CRF interference on day-to-day activities</li> <li>○ CRF associated symptoms (i.e., depression, anxiety, stress)</li> <li>○ CRF self-management progress (e.g., progress with exercise, diet modification, activity management; addressing any identified barriers; assessing self-management self-efficacy; discussion of perceived future issues, addressing questions).</li> </ul> </li> <li>• Provision of additional counselling, management strategies, and management strategy modification if needed.</li> <li>• Providing progress feedback (i.e., goal attainment, treatment modification, relevant counselling and information, links to external training modules or resources).</li> </ul>
Providing practical support to assist with self-monitoring of CRF, reporting of associated symptoms, CRF self-management adherence	<ul style="list-style-type: none"> <li>• Using diaries, logs, physical activity trackers, heart rate monitors, frequent telephone calls, regular consultations, automated email/ text message reminders, and home visits to assist CRF self-monitoring, symptom reporting (i.e., sleep habits, fatigue log, changes in energy level, factors that impacted fatigue) and intervention adherence (i.e., exercise, medication habits, physical activity, dietary habits).</li> <li>• Automated email and text message reminders (intervention adherence, reminder of goals, messages of encouragement)</li> </ul>
Providing equipment to enable cancer survivors to participate in CRF self-management activities in their personal environments	<ul style="list-style-type: none"> <li>• Providing equipment that enables cancer survivors to engage in physical activity or exercise in their homes</li> <li>• Recording of self-management support coaching/consult sessions to facilitate home practice</li> </ul>
Providing access to CRF management advice or support on cancer survivor request	Availability of a health professional for symptom review, treatment modification and/ or counselling if symptom thresholds exceeded (i.e., additional CBT counselling on request, accessibility to care coordinators, nurse practitioners, and psychologists for concerns and additional support).
Training rehearsal to communicate CRF with healthcare professionals	<p>The provision of problem-solving and solution focused skills to support survivors to communicate about fatigue and other cancer symptoms with treatment teams (family members and employers). Examples below:</p> <ul style="list-style-type: none"> <li>• Providing examples of questions to ask healthcare professionals and examples of goals to prepare for discussions (“Tomorrow morning I will write a list of questions about fatigue to take with me to my appointment with the nurse next week.”)</li> <li>• Advising survivors to show fatigue diary to health teams, invite significant others to accompany them to consults and explain fatigue interference in terms of everyday life (e.g., difficulty climbing stairs, cooking etc.)</li> <li>• Training on how to ask clarifying questions</li> </ul>
Providing coaching for lifestyle modifications that support living with CRF	Tailored coaching on exercise (aerobic, resistance, yoga, balance), physical activity (daily walking, morning stretches) meditation, relaxation and breathing exercises, dietary changes, changing sleep habits, structuring activities, goal setting, etc.
Providing skills and problem-solving strategies for coping with CRF-related psychological symptoms.	<ul style="list-style-type: none"> <li>• Coping with fear of cancer recurrence, anxiety, stress, depression <ul style="list-style-type: none"> <li>○ cognitive restructuring, cognitive reframing, relaxation exercises, mind-body therapy, meditation, yoga, breathing exercises, activating positive emotions, overcoming depressive periods, guided imagery meditation</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>• Coaching on interpersonal relationships, distress management, sharing experiences with family and other cancer survivors, and assignments for building mental and social activity.</li> </ul>
Providing Social support	<ul style="list-style-type: none"> <li>• Education and information available on social support (e.g., online modules, links to available resources and how to seek support, navigating relationships and social support, caregiver monitoring and support)</li> <li>• Facilitating the involvement of the patient's support network (family members, friends, carers, significant others) in fatigue self-management activities</li> <li>• Coaching and encouragement on how to communicate fatigue with others</li> <li>• Modifying cancer survivor expectations of social support</li> <li>• Facilitating the exchange of experiences and discussions between cancer survivors (via online discussion forums, face-to-face group formats, individual chat functions in an online environment, etc.).</li> </ul>
Providing general health promotion and education on lifestyle adaptation strategies	Advice on sleep hygiene, exercise, diet, activity management/regulation, physical activity, stress management, maintaining general health and wellbeing (preventing weight gain, increasing fluid intake, anger management) improving concentration, energy conservation, dealing with inter-personal relationships, pain control.
Structuring self-management interventions to align with survivors' 'everyday life'	<ul style="list-style-type: none"> <li>• Providing pre-intervention consultations/assessments (fatigue severity, fatigue interference, level of physical activity, diet, stage of change, readiness to change)</li> <li>• Creation of a priority list of usual activities that are then used to formulate an action plan (e.g., energy conservation, physical activity, etc.)</li> <li>• Planning daily and weekly activities based on survivor livelihood</li> <li>• Modifying treatment/ self-management strategies based on cancer survivor feedback</li> <li>• Engaging significant others to assist with action planning and structuring cancer survivor treatment activities</li> <li>• Incorporating survivor lifestyle and culture into intervention activities</li> <li>• Home visits to establish familiarity with cancer survivors</li> </ul>
Other self-management support strategies	<p>Checking patient understanding of CRF self-management</p> <ul style="list-style-type: none"> <li>• Knowledge quiz to test understanding of CRF and CRF management</li> </ul> <p>Placing cancer survivors in charge of the support they receive to improve agency (fatigue self-efficacy)</p> <ul style="list-style-type: none"> <li>• Allowing cancer survivors to choose their treatment type/ intensity</li> <li>• Allowing cancer survivors, the option to choose intervention delivery method (in-clinic consult, telemedicine, home-visit)</li> </ul> <p>Retrieving cancer survivor feedback during the intervention to iteratively improve self-management support provided</p> <p>Social/ peer modelling to improve confidence to undertake fatigue self-management behaviours</p> <ul style="list-style-type: none"> <li>• role model videos, patient stories, transcripts, cancer survivors delivering interventions</li> <li>• Facilitating anonymous communication between cancer survivors</li> </ul> <p>The provision of constant encouragement to improve fatigue self-management confidence</p> <ul style="list-style-type: none"> <li>• (During scheduled sessions, telephone calls, emails, text messages)</li> </ul>

**Self-management Support Facilitator Training** (support delivered to intervention facilitators)

<p>Training Skills/Content</p> <ul style="list-style-type: none"><li>• Information on CRF</li><li>• How to respond to cancer survivor comments</li><li>• Goal setting</li><li>• Motivational interviewing – MI – (overview of MI, developing core skills, using MI in chronic disease settings)</li><li>• Counselling</li><li>• Skills to facilitate experiential learning, common barriers to physical activity</li><li>• Principles of communication</li><li>• Training on adult education, lifelong learning, group leadership, group pedagogy, group therapy and communication skills</li><li>• Progressive muscle relaxation training</li><li>• Mindfulness-based stress reduction training</li></ul> <p>Mode of Training Delivery</p> <ul style="list-style-type: none"><li>• Didactic lectures</li><li>• Individual &amp; group exercises</li><li>• Roleplay scenarios</li><li>• Case studies</li><li>• Skills assessment to test understanding</li></ul> <p>Training materials</p> <ul style="list-style-type: none"><li>• Written manuals/booklets</li><li>• In-person day training</li><li>• Multi-day in-person workshops</li><li>• Multiweek courses</li><li>• Online courses &amp; content</li></ul>
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Abbreviations: CBT – cognitive behaviour therapy; CRF – cancer-related fatigue; MI – motivational interviewing; SMART – specific, measurable

## **Effectiveness of Self-management Support Programs**

Fatigue and behavioural outcomes are summarised in Figures 6 and 7, with further details on study outcomes including outcome measures and follow-up periods presented in Appendix 7.

### **Fatigue outcomes**

Fatigue outcomes were assessed in all studies. No studies reported a negative intervention effect. Twenty-nine studies reported a positive intervention effect for fatigue immediately post intervention completion (Abrahams et al., 2017; Armes et al., 2007; Barsevick et al., 2004; Donnelly et al., 2011; Fillion et al., 2008; Freeman et al., 2015; Galiano-Castillo et al., 2016; Gokal et al., 2016; Golsteijn et al., 2018; Grégoire et al., 2020; Hoffman et al., 2017; Johns et al., 2015; Lam et al., 2018; Lee et al., 2014; Mooney et al., 2017; Ream et al., 2015; Ream et al., 2006; Ritterband et al., 2012; Sandler et al., 2017; Savard et al., 2005; van der Lee & Garssen, 2012; van Waart et al., 2015; van Weert et al., 2010; Wang et al., 2011; Wangnum et al., 2013; Willems et al., 2017; Yates et al., 2005; Yun et al., 2012; Zhang et al., 2018); and were mostly delivered post-cancer treatment (n=15/29, 52%), facilitated by health professionals (n=20/29, 69%), targeted at the individual level (n=22/29, 76%), guided by a specific behaviour change theory (n=21/29, 72%), and incorporated an in-person face-to-face component (n=19/29, 66%). The average number of Self-management Support Taxonomy components used across the 29 immediately effective studies was 6.6 (of possible number of 14). The average intervention duration was 10.5 weeks (median = 9 weeks).

Twenty-nine studies (n=29/50, 58%) completed a follow-up assessment of fatigue (follow-up period ranging two to three months post intervention). Of these, 10 studies (34%) (Donnelly et al., 2011; Galiano-Castillo et al., 2016; Golsteijn et al., 2018; Johns et al., 2015; Lam et al., 2018; Reif et al., 2013; Smith et al., 2019; van der Lee & Garssen, 2012; Vargas et al., 2014; Zhang et al., 2018) reported positive follow-up effects for fatigue, and comprised of physical activity programs (n=3), education-based programs (n=2), a mindfulness-based stress reduction program (n=1), an exercise program (n=1), mindfulness-based cognitive therapy (n=1), cognitive behavioural stress management (n=1), and an exercise with CBT intervention (n=1). The majority of these 10 studies were targeted at the individual level (n=6/10, 60%), facilitated by health professionals (n=5/10, 50%; three of ten studies were unclear), incorporated a face-to-face component (n=7/10, 70%), and were delivered solely post-cancer treatment (n=5/10; 50%). Five of the ten (50%) interventions were informed by a specific behaviour change theory or model. The average number of Self-management Support Taxonomy components used across the ten studies was 5.6, and the average intervention duration was 11.2 weeks (median = 10 weeks). One study (Li et al., 2018) reported a null

intervention effect immediately post intervention but reported a positive intervention effect six months after study completion at follow-up.

### **Self-management Behavioural outcomes**

Seventeen studies assessed physical activity outcomes (Armes et al., 2007; Bantum et al., 2014; Bennett et al., 2007; Fillion et al., 2008; Gokal et al., 2016; Golsteijn et al., 2018; Hoffman et al., 2017; Lam et al., 2018; W. H. C. Li et al., 2018; Naraphong, 2015; Purcell et al., 2011; Reif et al., 2013; Sandler et al., 2017; Vallerand et al., 2018; van Waart et al., 2015; Wang et al., 2011; Wangnum et al., 2013); eight studies assessed self-efficacy for physical activity (Bennett et al., 2007; Hoffman et al., 2017; Lam et al., 2018; W. H. C. Li et al., 2018; Naraphong, 2015; Reif et al., 2013; Wang et al., 2011); three studies assessed diet outcomes (Bantum et al., 2014; Lee et al., 2014; Wangnum et al., 2013); two studies assessed self-efficacy for fatigue self-management (Foster et al., 2016; Hoffman et al., 2017), and single studies assessed chronic disease management self-efficacy (Smith et al., 2019), cancer self-efficacy (Yates et al., 2005), general self-efficacy (Reif et al., 2013), stage of change (motivational readiness) (Lee et al., 2014), and the ability to complete leisure and self-care activities (Purcell et al., 2011; Smith et al., 2019).

No studies reported a negative intervention effect for any behavioural outcome. Of the studies that assessed physical activity outcomes, ten (n=10/17, 59%) reported a positive intervention effect for physical activity immediately post intervention, and five (n=5/17, 29%) reported sustained positive interventions effects at follow-up (follow-up ranging from 1.5 to six months post intervention). Of the three studies that assessed dietary outcomes, all reported a positive intervention effect immediately post intervention. No follow-up assessments for dietary outcomes were conducted.

Of the studies that assessed physical activity self-efficacy, seven (n=7/8, 88%) reported a positive intervention effect immediately post-intervention, and three (n=3/8, 38%) reported a sustained intervention effect at follow-up (follow-up ranging from 1.5 to six months post intervention). Of the two studies that assessed fatigue self-management self-efficacy, one reported a positive intervention effect post-intervention while the other reported null intervention effects immediately post intervention and at follow-up. A positive intervention effect was reported for general self-efficacy six months post intervention, no results were reported immediate post intervention. Null intervention effects were reported for chronic disease self-efficacy, cancer self-efficacy, motivational readiness, and leisure and self-care activity participation at all time points.

## FATIGUE OUTCOMES

	IMMEDIATE POST INTERVENTION	FOLLOW-UP		IMMEDIATE POST INTERVENTION	FOLLOW-UP		IMMEDIATE POST INTERVENTION	FOLLOW-UP
Abrahams 2017	+	DID NOT COMPLETE	Gregoire 2020	+	DID NOT COMPLETE	Schjolberg 2014	∅	∅
Armes 2007	+	∅	Hoffman 2017	+	DID NOT COMPLETE	Smith 2019	NR	+
Bantum 2014	∅	DID NOT COMPLETE	Johns 2015	+	+	Spahn 2013	∅	∅
Barservick 2004	+	DID NOT COMPLETE	Johns 2016	∅	∅	Stanton 2005	∅	∅
Barsevick 2010	∅	DID NOT COMPLETE	Johnston 2011	∅	DID NOT COMPLETE	Steel 2016	∅	DID NOT COMPLETE
Bennet 2007	NR	∅	Lam 2018	+	+	Vallerand 2017	∅	DID NOT COMPLETE
Bruggeman-Everts 2017	NR	+	Lee 2014	+	DID NOT COMPLETE	Van der Lee 2012	+	+
Chan 2011	+	∅	Li 2014	∅	DID NOT COMPLETE	Van Waart 2015	+	∅
Dodd 2010	NR	∅	Mooney 2016	+	DID NOT COMPLETE	Van Weert 2010	+	DID NOT COMPLETE
Donnelly 2011	+	+	Naraphong 2015	∅	DID NOT COMPLETE	Vargas 2014	NR	+
Fillion 2008	+	∅	Purcell 2010	∅	∅	Wang 2011	+	DID NOT COMPLETE
Foster 2016	∅	∅	Ream 2006	+	DID NOT COMPLETE	Wangnum 2013	+	DID NOT COMPLETE
Freeman 2015	+	∅	Ream 2015	+	DID NOT COMPLETE	Willems 2017a & 2017b	+	∅
Galiano-Castillo 2016	+	+	Reif 2013	NR	+	Yates 2005	+	∅
Godino 2006	∅	DID NOT COMPLETE	Ritterband 2012	+	DID NOT COMPLETE	Yun 2012	+	DID NOT COMPLETE
Gokal 2015	+	DID NOT COMPLETE	Sandler 2017	+	∅	Zhang 2018	+	+
Golsteijn 2018	+	+	Savard 2005	+	∅			

**Figure 6:** Fatigue Outcomes

*DID NOT COMPLETE* (did not complete follow-up assessment); NR (not recorded); + (positive effect); ∅(null effect).

## BEHAVIOURAL OUTCOMES

	IMMEDIATE POST INTERVENTION	FOLLOW-UP		IMMEDIATE POST INTERVENTION	FOLLOW-UP		IMMEDIATE POST INTERVENTION	FOLLOW-UP
<b>PHYSICAL ACTIVITY OUTCOMES</b>			<b>DIET OUTCOMES</b>			<b>SELF-EFFICACY FOR CHRONIC DISEASE MANAGEMENT</b>		
Armes 2007	+	+	Bantum 2014	+	<b>DID NOT COMPLETE</b>	Smith 2019	∅	∅
Bantum 2014	+	<b>DID NOT COMPLETE</b>	Lee 2014	+	<b>DID NOT COMPLETE</b>	<b>CANCER SELF-EFFICACY</b>		
Bennet 2007	NR	∅	Wangnum 2013	+	<b>DID NOT COMPLETE</b>	Yates 2005	∅	∅
Fillion 2008	∅	∅	<b>SELF-EFFICACY FOR PHYSICAL ACTIVITY</b>			<b>GENERAL SELF-EFFICACY</b>		
Gokal 2015	+	<b>DID NOT COMPLETE</b>	Bennet 2007	+	+	Reif 2013	NR	∅
Golsteijn 2018	+	+	Hoffman 2017	+	<b>DID NOT COMPLETE</b>	<b>STAGE OF CHANGE (MOTIVATIONAL READINESS)</b>		
Hoffman 2017	+	+	Lam 2018	+	+	Lee 2014	+	<b>DID NOT COMPLETE</b>
Lam 2018	NR	+	Lee 2014	+	<b>DID NOT COMPLETE</b>	<b>LEISURE AND SELF-CARE PARTICIPATION</b>		
Li 2014	+	+	Li 2014	+	+	Purcell 2010	∅	∅
Naraphong 2015	+	<b>DID NOT COMPLETE</b>	Naraphong 2015	+	<b>DID NOT COMPLETE</b>			
Purcell 2010	∅	∅	Reif 2013	NR	∅			
Reif 2012	NR	+	Wang 2011	+	<b>DID NOT COMPLETE</b>			
Sandler 2017	∅	∅	<b>SELF-EFFICACY FOR FATIGUE SELF-MANAGEMENT</b>					
Vallerand 2017	+	<b>DID NOT COMPLETE</b>	Foster 2016	∅	∅			
Van Waart 2015	+	∅	Hoffman 2017	+	<b>DID NOT COMPLETE</b>			
Wang 2011	+	<b>DID NOT COMPLETE</b>						
Wangnum 2013	∅	<b>DID NOT COMPLETE</b>						

**Figure 7:** Behavioural Outcomes

*DID NOT COMPLETE* (did not complete follow-up assessment); NR (not recorded); +(positive effect); ∅(null effect).

## Discussion

This review aimed to identify the optimal SMS intervention features and components that were associated with improved CRF and behavioural outcomes. A graphical summary of these findings are presented in Figure 8.

## **Cancer-related Fatigue Management Interventions**

Various approaches to CRF self-management have been used to date. Across studies reporting positive intervention effects for CRF, several management strategies were used (e.g., exercise, psychoeducation, mindfulness, cognitive behaviour therapy, etc.) with no strategy clearly presenting as the most favourable. Conversely, psychoeducation and education interventions reported no statistically significant effect on CRF more often than any other management strategy. This finding is consistent with those from a recent systematic review (Bennett et al., 2016), which identified that self-management educational interventions have little effects on the severity, interference, and intensity of CRF; but may potentially produce a more moderate effect on fatigue distress in those with non-advanced cancer. Despite this, it is recognised that education and psychoeducation may still be useful in the management of CRF, particularly when used in synergy with other effective strategies, or in the development of knowledge of self-management skills (Bennett et al., 2016). This review identified that most psychoeducation and education interventions that reported no effect on CRF, incorporated minimal clinician-survivor interactions and were of short duration; potentially indicating that general information provision delivered over a short period of time may be insufficient to facilitate the uptake of CRF self-management behaviours. Evidently, more research is needed to identify how these education and psychoeducation sessions are being delivered, and to determine the optimal education content and delivery approach (e.g., timing of intervention, duration, number of contact points, modality) depending on clinical context (e.g., early-stage or late-stage cancer, advanced/non-advanced cancer, baseline fatigue severity level).

## **Self-management Support Delivery**

SMS delivered after cancer treatment, in one-on-one formats, facilitated by health professionals, while incorporating at least one in-person (i.e., face-to-face) contact was most likely to have positive effects on CRF and behavioural outcomes. Additionally, programs with positive intervention effects were longer in duration than the average (9.6 weeks vs 11.2 weeks).

Several studies have linked factors such as self-management intervention duration and frequency (number of contacts per week, number of minutes per contact), with improvements in health behaviours (e.g., diet and physical activity or exercise) (Barrett et al., 2021; Eakin et al., 2007; Stormacq et al., 2020). As CRF can persist long after treatment cessation (Weis & Horneber, 2014), it is conceivable that an extensive intervention incorporating multiple contact points that promotes an environment where partnerships can be developed between intervention facilitators, cancer survivors, and their caregivers would be favourable for durably



supporting CRF management (Banbury et al., 2023). However, while extensive support with sustained maintenance, in-person guidance, and face-to-face contact might be beneficial, cancer survivors may appreciate the simplicity of receiving support from the comfort and familiarity of their own home. Additionally, survivors may not have the time to commit to prolonged interventions. As posited by Bennet and colleagues (Bennett et al., 2016), future intervention developers should seek the preferences of those receiving support, and qualitatively evaluate the comparative benefits of different delivery options.

### **Facilitation of Self-management Support**

Notably, this systematic review found that studies which reported the provision of additional training to intervention facilitators – see Table 3 – (e.g., training on motivational interviewing, goal setting, counselling, communication, etc.), were more likely to report a positive intervention effect for both CRF and behavioural outcomes. This finding indicates that supporting and upskilling those providing SMS – by ensuring they have the necessary capabilities – is essential to facilitate cancer survivor uptake of CRF self-management strategies (Kennedy et al., 2005).

### **Theories Underpinning Self-Management Support Programs**

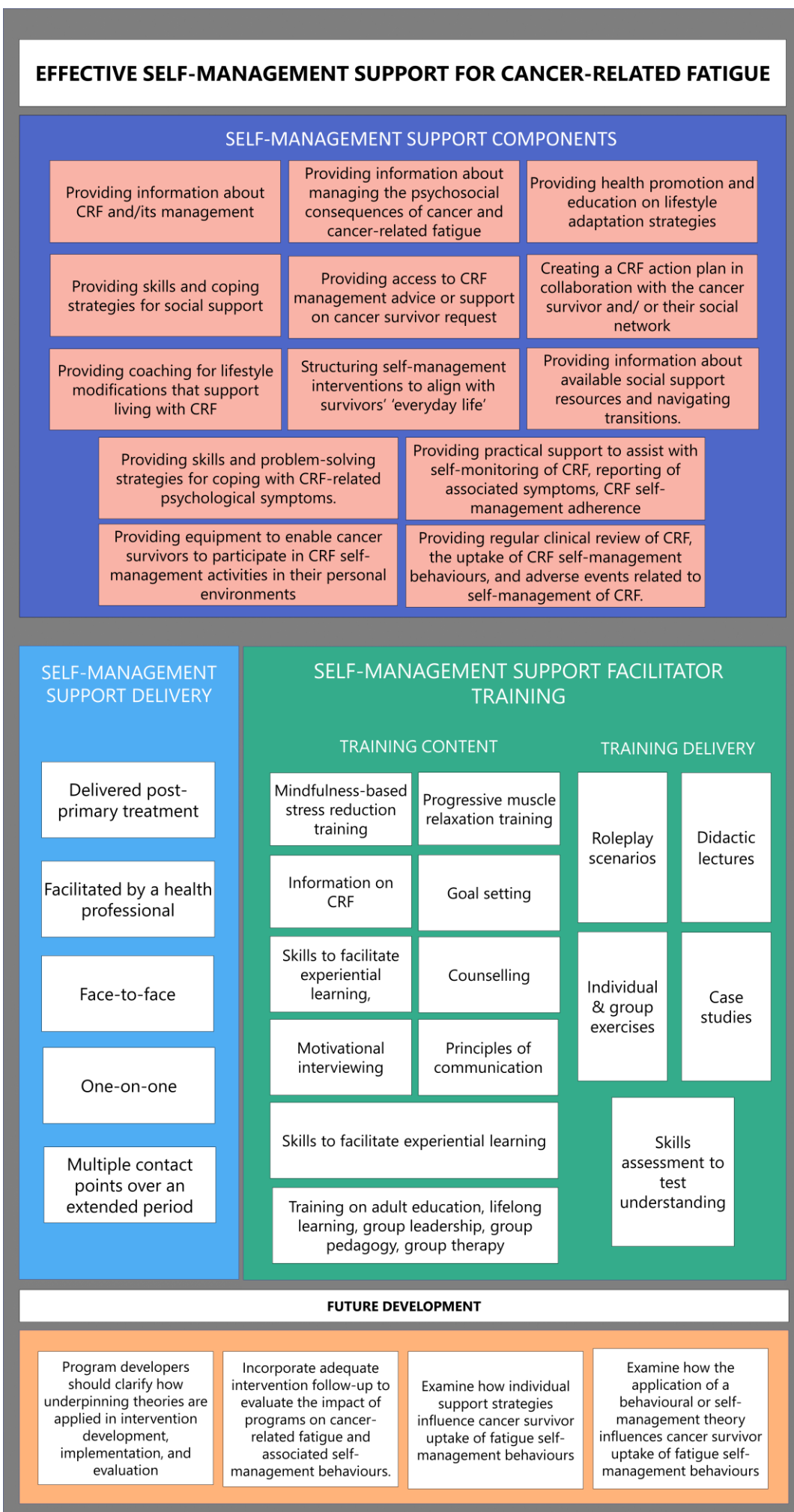
Most SMS interventions reporting positive intervention effects for CRF (n=21/29, 72% at immediate post-intervention; and n=5/10, 50% at follow-up post-intervention) and/or behavioural outcomes (n=9/15; 60%) were guided by a behaviour theory. While several factors can influence intervention effectiveness, this potentially indicates that theory use may be associated with increased adoption by cancer survivors of CRF coping behaviours: a finding consistent with several studies identifying the superiority of theory-based self-management programs over non-theory-based programs in facilitating patient behaviour change (van Vugt et al., 2013). However, before this potential association can be explored, further examination of the specific impact of each behavioural theory must occur. Further, while a behaviour or self-management theory was indicated in several included studies, in many cases theoretical application was not described at all. An appropriate description of theory use should highlight the theoretical factors underpinning the causes of a behaviour (e.g., low self-efficacy), and explain how these causes were targeted using the appropriate theoretical change methods (whilst also ensuring theoretical methods were used accurately to maximise effectiveness) (Bluethmann et al., 2017; Webb et al., 2010). Studies have demonstrated that when such application occurs the production of behaviour change is enhanced (Bluethmann et al., 2017; Webb et al., 2010). As such, it is recommended that intervention developers move beyond description, and clarify how underpinning theories are applied in intervention development, implementation, and evaluation; to establish more consistent and robust evidence in this area

and improve translatability to practice (Rimmer, Sharp, & on behalf of Ways Ahead study, 2021).

### **Self-Management Support Components**

The heterogeneity and complex multi-component nature of SMS interventions makes it difficult to determine if an optimal number of support components should be implemented to optimise intervention efficacy; and challenging to identify which specific SMS components are associated with intervention efficacy. Nonetheless, this review collated and summarised the specific SMS strategies and components used in studies that had positive intervention effects for CRF at any timepoint, and subsequently demonstrated that all components of the Self-management Support Taxonomy were present. While efficacy of self-management interventions on cancer survivor fatigue can be attributed to several factors (e.g., age; type of active treatment received; type and stage of cancer diagnosis; frequency, duration and intensity of intervention; characteristics of interventionists etc.), and not all taxonomy components were tested to the same extent, it can be said that when implemented well, each component of the Self-management Support Taxonomy (as well as the other identified strategies not included in the taxonomy – Table 3) can potentially be used to effectively support cancer survivors to manage their CRF. This finding is further indicated in a recent qualitative study by Sheridan and colleagues (2017) in which patients and caregivers describe all 14 components of the Taxonomy as crucial for their SMS; although this was in the context of general chronic conditions and primary care.

Despite this, the review went further, and identified that several strategies, including the provision of lifestyle advice and support; training for lifestyle adaptations and everyday activities; training for psychological strategies; practical support with self-management adherence; goal setting and specific clinical action plans; information on psychosocial management, information about CRF and its management, the monitoring of CRF and its management; and the structuring of interventions to align with survivors 'everyday life', were the most frequently featured strategies in interventions with positive intervention effects for any outcome. This potentially indicates that these strategies are associated with improved CRF and uptake of associated management behaviours. Consensus on the best strategies and practices for CRF support have yet to be established in literature, and as such will be examined in the following chapter.



**Figure 8: Key Features of Effective Self-management Support for Cancer-related Fatigue**

## **Strengths and Limitations**

Researchers, health professionals, and cancer survivors have long called for the support of CRF to be examined and defined, and for the essential support strategies and components being highlighted (Hilarius et al., 2011; Jones et al., 2021; Pearson et al., 2017). This review is the first to identify the features, components, and strategies used in effective CRF SMS programs – allowing health professionals and researchers to consider including these elements in future support interventions for CRF. Further, this review not only examined the impact of SMS behavioural interventions on CRF severity, but also investigated the effects of interventions on the adoption of fatigue self-management behaviours; an important factor that is often overlooked.

There are four main limitations to this review. Firstly, due to study heterogeneity a meta-analysis was unable to be conducted; however, this was not unique to this current review; with similar difficulties being demonstrated across the SMS literature (Boland et al., 2018; Hilarius et al., 2011; Jones et al., 2021). Secondly, as a meta-analysis could not be conducted, statistical significance in single studies was largely used to determine intervention efficacy. As statistical significance relates to covariance between variables, a null intervention effect does not necessarily indicate that a self-management intervention is futile or without impact, particularly as SMS is complex with varying outcomes outside of reduced CRF severity and changed behaviours. Thirdly, 22 out of the 51 included studies were scored as having an overall high risk of bias largely due to the inherent nature of interventions under examination: lack of intervention blinding and, lack of sensitivity analyses. As such findings of this review need to be interpreted with caution. Guidance around the choice of sensitivity analysis for non-pharmacological behavioural interventions is unclear, and randomised control trial reporting guidelines (e.g., SPIRIT, CONSORT) do not list the inclusion of a sensitivity analysis as a recommended item; potentially explaining why it was not often conducted. While practices of sensitivity analysis may be improved, the lack of blinding remains an expected challenge for these types of behavioural interventions. Finally, this review only included studies published in English; thus, potentially relevant self-management programs may not have been included.

## **Conclusion**

This review indicated that structured, comprehensive support that facilitates clinician-survivor exchange and is tailored to individual context and priorities can favourably enable CRF self-management. The mapping and categorisation of SMS components used across CRF self-management interventions provides novel insight into the management of one of the most distressing symptoms experienced by cancer survivors to date. This systematic review is crucial in determining the relevant future training and support requirements needed to enable the delivery of CRF care beyond the research context.

## 4.0 MODIFIED DELPHI STUDY (STUDY 2)

### Chapter Introduction

This chapter contributes to the overall aim of the doctoral thesis by presenting a framework of core practices required by health professionals to deliver effective SMS to cancer patients and survivors experiencing CRF, addressing a key barrier to the successful implementation of CRF management (which was highlighted in Chapter 1). Specifically, this chapter outlines the methodology, results, discussion, and implications of the modified Delphi study. This chapter incorporates the Flinders Capability Framework presented in Chapter 2 (e.g., using the 19 core capabilities detailing the essential knowledge, attitudes and skills needed by health professionals to support cancer survivors to self-manage) and the findings from the systematic review presented in Chapter 3 (e.g., co-creating a CRF action plan, etc.) to develop the best practice framework. This modified Delphi study was accepted for publication by the Journal of Cancer Survivorship and published online on the 24<sup>th</sup> of February 2023. The online published article can be accessed via the following link: <https://doi.org/10.1007/s11764-023-01348-7>.

### Background

Effective management strategies for CRF are well established with the existence of a plethora of clinical guidelines including the National Comprehensive Cancer Network (NCCN) Guidelines for CRF (Berger, 2019), the Canadian Association of Psychosocial Oncology (CAPO) Pan Canadian Guidelines for CRF (Howell et al., 2015), and the European Society for Medical Oncology (ESMO) Clinical Practice Cancer-related Fatigue Guidelines (Fabi et al., 2020). Although these clinical guidelines advise health professionals on what strategies they 'should' recommend to those experiencing CRF (e.g., *advise patients to engage in moderate intensity of physical activity 30 minutes per day, 5 days per week as tolerated* (Howell et al., 2015)); they do not provide guidance on 'how' health professionals can support individuals to undergo behavioural change and *adopt* these management strategies (e.g., by providing tools to assist with exercise, creating goals and actions plans that are regularly reviewed, etc.).

As mentioned in Chapter 1, engagement in fatigue self-management behaviours can be complex and can require individuals to recognise, track, self-monitor, self-report, and apply problem solving skills to manage their fatigue along with other comorbid conditions (Howell et al., 2021) – tasks that are not naturally part of an individual's regular behaviour. Additionally, external factors such as socioeconomic status, mental health, cognitive status, age, performance status, and/or other situational factors also make it challenging for those diagnosed with cancer to self-manage their fatigue (Gobeil-Lavoie et al., 2019; Howell et al.,

2021). To navigate the complexities associated with fatigue management, cancer survivors require access to comprehensive SMS that assists and enables them to manage their fatigue whilst accounting for their capacity, capability, confidence levels, and priorities.

Health professionals regularly report they frequently lack the confidence, knowledge, and ability to provide effective SMS to those experiencing CRF (Hilarius et al., 2011; James et al., 2015; Jones et al., 2021; Pearson et al., 2015). Clinicians often describe existing clinical guidance as lacking the relevant information for facilitating SMS (Hilarius et al., 2011; Jones et al., 2021; Pearson et al., 2017). There is need for specific guidance for health professionals to facilitate evidence-based fatigue self-management strategies (Berger & Mooney, 2016; Hilarius et al., 2011; Pearson et al., 2017; Ren et al., 2022). The aim of the current study is to establish a *best practice framework* for facilitating effective SMS for CRF.

This chapter details the research design including the methodology, population, sample, data collection, analytical methods and instruments used. Ethical implications are also discussed.

## **Methodology and Research Design**

### **Methodology**

The modified Delphi technique is a structured group consensus strategy that systematically uses high quality literature, the opinion of stakeholders, and judgment of industry specialists to reach agreement and achieve content validity (Trevelyan & Robinson, 2015). Further, this technique uses a structured, anonymous, and iterative feedback process to establish consensus on a specific topic of interest with an invited panel of 'experts' over a series of rounds.

In a *classic* Delphi study approach, open-ended questions or forums are used to generate ideas and concepts that may inform Delphi study content (Trevelyan & Robinson, 2015). A *modified* Delphi design differs, as initial concepts and ideas are generated through a review of relevant literature. A modified Delphi approach was used for this study to incorporate the extensive CRF SMS strategies identified in literature and to ensure framework comprehensiveness. Moreover, the modified Delphi study technique has been recommended over the classic Delphi study as it reduces complexity and minimises the misinterpretation of objectives; avoids biasing of panellists through the inclusion of inappropriate or unnecessary items; and increases the likelihood that consensus will be achieved in an efficient and timely manner (Custer et al., 1999; Trevelyan & Robinson, 2015). Further, the modified Delphi study method is commonly used when little evidence exists (or is lacking), and thus is considered suitable for this research objective. The validity and quality of a Delphi study process largely

depends on panel expertise, the availability of clearly defined content, and well-developed initial statements and thus, it is essential that all three components are well developed (Custer et al., 1999).

### **Research Design**

A modified Delphi study design was used to generate consensus on the essential clinician SMS practices required by health professionals to deliver effective support to people experiencing CRF. Although, quantifying the level of consensus is important, reaching consensus on all statements is not the general objective of a Delphi survey; therefore, attainment of consensus was not used as a criterion for ending the study (Linstone & Turoff, 2011; Ramos et al., 2016). Two rounds of consultation were chosen because unlike the traditional Delphi approach, initial framework items for consensus were not generated during a Delphi workshop round. Instead, the initial framework was informed by a review of literature; thus, one round was removed.

The use of the term 'expert' is contentious as it is difficult to define (e.g., professional registration or number of years practising does not necessarily indicate topic expertise (Baker et al., 2006)). To avoid misunderstanding and increase clarity, the term 'experts' was not used to describe Delphi study participants. Rather, the criteria used to select panel participants was detailed as per recommendations in literature (Baker et al., 2006; Trevelyan & Robinson, 2015).

### **Defining a Practice Framework**

Practice frameworks have been defined and used variably by different professions (e.g., health, education, research and evaluation) (Connolly, 2007; Stanley et al., 2021). Within healthcare, the term 'practice framework' or 'frameworks for practice' has increased in use, with contextual applications including (but not limited to) the provision of schematic diagrams and policies to improve practice and facilitate practice reform; the presentation of an organisation's values; and guidance on specific professional capabilities for development, or areas of knowledge needed to provide support. This study is informed by the definition used by Connolly (Connolly, 2007), and Stanley and colleagues (Stanley et al., 2021), where a 'practice framework' is summarised as a *"template not based on or informed by organisational imperatives (e.g., budgets or compliance edict) but designed through and informed by value-based practice research, and evidence; that offers a mapping out of what we do and why, offering a rationale for practice, while promoting a range of practice tools for assessments and intervention"*. In the context of this current study, 'value-based practice' refers to an approach to supporting clinical decision-making, which provides practical skills and tools for eliciting

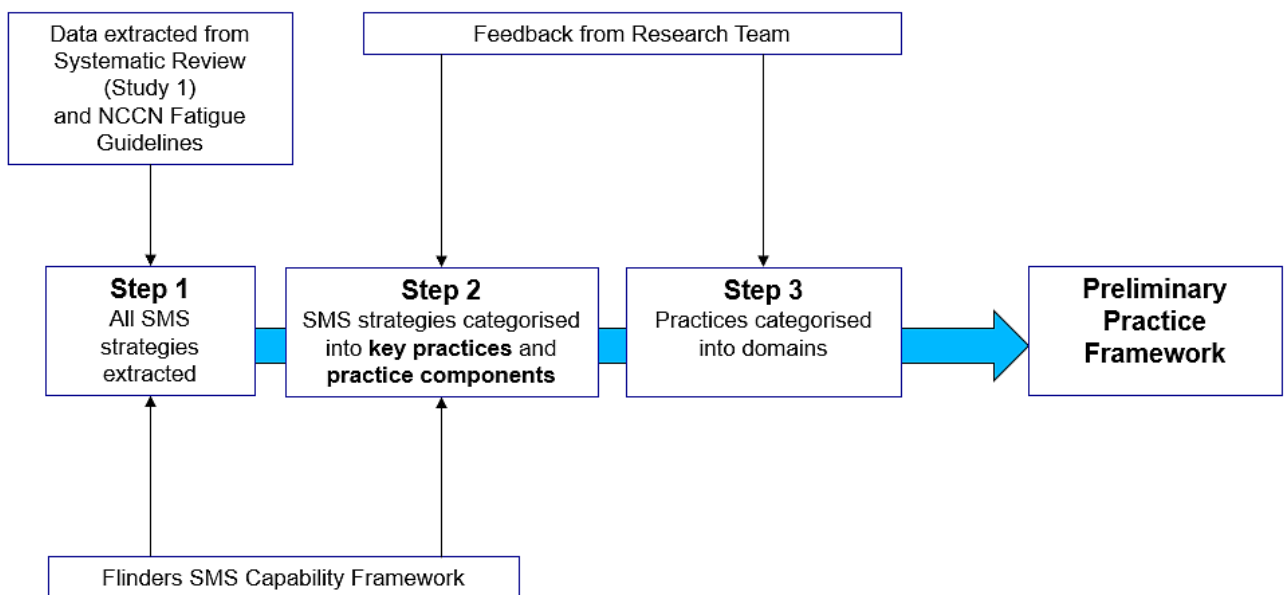
individual values and negotiating these with respect to best available evidence (Petrova et al., 2006). More specifically, this proposed framework focuses on the health professional, and presents the ‘practices’ or tasks required to provide comprehensive SMS for cancer patients and cancer survivors experiencing acute and long-term CRF. Further, the proposed practice framework aims to reinforce what constitutes ‘best’ practice for CRF SMS.

## Developing the Preliminary Practice Framework

### Review of the Literature

To ensure framework comprehensiveness, minimise the number of rounds needed, and maximise the rate of survey completion, the initial statements used in Round 1 were derived from a qualitative synthesis of the systematic review of literature presented in Chapter 3 (Study 1), and the SMS Flinders Capability Framework (FCF) presented in Chapter 2. CRF management strategies from the National Comprehensive Cancer Network (NCCN) Fatigue Guidelines (Berger, 2019) were also incorporated. The development stages of the initial framework domains and components for consensus are shown in Figure 9.

### Initial Statement Development



**Figure 9:** Preliminary Practice Framework Development Process

An iterative process was used to classify SMS components, strategies, and capabilities identified through research (Agbejule et al., 2022). Initially, a list of SMS strategies for CRF were compiled using information derived from Study 2 and the FCF Core Capabilities. CRF management strategies from the National Comprehensive Cancer Network’s (NCCN) Fatigue Guidelines (Berger, 2019) were also incorporated.



A list of CRF SMS strategies were compiled from the information sources listed above, and then classified into core practices through an iterative process involving the creation, removal, and merging of categories to create mutually exclusive 'key practices' and 'practice components'. Key practices described the proposed activities health professionals are required to undertake to provide best practice SMS for CRF. Practice components describe the steps needed to complete a key practice. This process was reviewed by the research team who provided feedback, comment, and suggested changes. After addressing feedback, the practices were then tabulated by concept; analysed for similarities and inconsistencies between concept groups; before being categorised into domains, (e.g., Goal Setting, Action Planning → Care Co-ordination). The final preliminary framework was sent to all research team members for feedback and approval. The research team comprised a clinical radiation therapist with expertise in cancer survivorship and self-management; a professor in cancer nursing with expertise in self-management and cancer related fatigue; an exercise scientist with expertise in cancer survivorship; and a health researcher in psychology. The resulting preliminary framework consisted of 47 practice items (14 Key Practices and 33 Practice Components) categorised under five domains: (1) Establishing Context and Defining the Problem; (2) Developing an Action Plan; (3) Improve Patient Knowledge; (4) Training Rehearsal (Strategy Building); and (5) Care Co-ordination and Maintenance (see Table 4).

**Table 4:** Preliminary Practice Framework

<b>DOMAIN 1: ESTABLISHING CONTEXT AND DEFINING THE PROBLEM</b>
<b>Key Practice 1.</b> Collect and use clinical and behavioural information to inform decision making about the patient's self-management of cancer-related fatigue
<b>Practice Component 1a)</b> Conduct a consultation and assessment with the patient, and if available, other key people in the patient's support network (e.g., carer's; family members) to collaboratively define key concerns, problem areas and priorities.
<b>Practice Component 1c)</b> Collect, record, and store key clinical, symptom and behavioural information.
<b>Key Practice 2.</b> Assess the patient's capacity for self-management.
<b>Practice Component 2a)</b> Identify factors within the patient, and the patient's physical and social environment, that they perceive may improve or worsen their cancer-related fatigue (e.g., more severe fatigue in the afternoon).
<b>Practice Component 2b)</b> Identify the patient's beliefs, attitudes, and knowledge about cancer-related fatigue, and identify their current coping strategies.
<b>Practice Component 2c)</b> Identify factors (i.e., cultural consideration, language literacy levels, availability of peer support network, pre-existing conditions) that may affect the patient's ability to participate in self-management activities.
<b>DOMAIN 2: DEVELOPING AN ACTION PLAN</b>
<b>Key Practice 3.</b> Create a cancer-related fatigue management action plan in collaboration with the patient

<b>Practice Component 3a)</b> Reflect on the patient's capacity for self-management (including barriers), and the clinical and behavioural information gathered during pre-assessments, to refine the patient's priorities, needs, and goals concerning their cancer-related fatigue and general lifestyle.
<b>Practice Component 3b)</b> Plan a culturally and contextually relevant fatigue self-management care plan drawing on clinical and psychosocial information gathered during pre-assessments, the patient's capacity for self-management support and the health professional's applied knowledge of cancer-related fatigue management strategies.
<b>Practice Component 3c)</b> Incorporate the patient's support networks (family, friends, carers) into action planning.
<b>DOMAIN 3: IMPROVE PATIENT KNOWLEDGE</b>
<b>Key Practice 4.</b> Provide information (visual, written, verbal) on cancer-related fatigue and common management strategies
<b>Practice Component 4a)</b> Inform the patient and their support network of the differences between cancer-related fatigue and 'normal' fatigue.
<b>Practice Component 4b)</b> Inform the patient and their support network of the causes, key risk factors, presenting characteristics, and the possible effects and interferences of cancer-related fatigue on daily living.
<b>Practice Component 4c)</b> Communicate tailored evidence-based information to the patient and their support network regarding the benefits of exercise and physical activity for managing cancer-related fatigue and have an awareness of the strength of such evidence.
<b>Practice Component 4d)</b> Communicate tailored evidence-based information to the patient and their support network on other management strategies for cancer-related fatigue (along with their risk and benefits) and have an awareness of the strength of such evidence.
<b>Key Practice 5.</b> Provide tailored evidence-based information on managing common psychosocial consequences of cancer and cancer-related fatigue
<b>Practice Component 5a)</b> Provide the patient and their support network with evidence-based information on how psychological and psychosocial factors (e.g., fear of cancer recurrence or progression, anxiety, depression, and stress) contribute to, and are exacerbated by cancer-related fatigue.
<b>Practice Component 5b)</b> Provide the patient with coping strategies for managing psychological and psychosocial factors
<b>Practice Component 5c)</b> Provide the patient with coping strategies for processing and communicating with others about cancer-related fatigue and cancer experiences.
<b>Key Practice 6.</b> Provide information about available social support
<b>Practice Component 6a)</b> Facilitate the involvement of the patient's support network (family members, friends, carers, significant others) in cancer-related fatigue self-management activities
<b>Practice Component 6b)</b> Provide the patient and their support network with education and information about how to seek further social support and inform the patient of relevant support services in their community.
<b>Practice Component 6c)</b> Facilitate the exchange of cancer and cancer-related fatigue experiences and/or discussions between the patient and other cancer survivors.
<b>DOMAIN 4: TRAINING REHEARSAL (STRATEGY BUILDING)</b>

<b>Key Practice 7.</b> Provide the patient with problem solving and evidence-based solution-focused strategies to communicate with their systems of support (includes health professionals, non-health professionals, personal communities; and voluntary and community groups) about cancer-related fatigue.
<b>Practice Component 7a)</b> Provide the patient with the skills to self-advocate and communicate with health professionals, non-health professionals, personal networks, employees, and others about cancer-related fatigue.
<b>Practice Component 7b)</b> Provide coaching and counselling about navigating relationships and social support
<b>Key Practice 8.</b> Provide evidence-based coaching for lifestyle modifications that support living with cancer-related fatigue.
<b>Practice Component 8a)</b> Provide the patient and their support network with evidence-based tailored coaching and practical strategies for exercise (e.g., aerobic, resistance, yoga, balance) and physical activity (e.g., daily walking, morning stretches).
<b>Practice Component 8b)</b> Provide tailored coaching and practical strategies to the patient and their support network that supports the patient's everyday activities
<b>Practice Component 8c)</b> Refer the patient to relevant services and professionals for support when indicated (e.g., if you are unable to provide tailored coaching).
<b>Practice Component 8d)</b> Involve relevant services and professionals in the planning and decision making of the patient's care
<b>Key Practice 9.</b> Provide the patient with evidence-based problem-solving strategies for coping with the psychological effects or risk factors of cancer-related fatigue.
<b>Practice Component 9a)</b> Provide patients with strategies for coping with anxiety, fear of recurrence or progression, stress, depression, and managing interpersonal relationships.
<b>Key Practice 10.</b> Provide evidence-based general health promotion and education on lifestyle adaptation strategies.
<b>Practice Component 10a)</b> Provide relevant general lifestyle advice and counselling support to the patient and their support network.
<b>DOMAIN 5: CARE CO-ORDINATION AND MAINTENANCE</b>
<b>Key Practice 11.</b> Provide regular review of self-management goals and action plans in collaboration with the patient (and their social network).
<b>Practice Component 11a)</b> Reformulate previously established goals based off the patient's confidence, needs, and progress (i.e., goal attainment).
<b>Practice Component 11b)</b> Establish long term goals prior to the conclusion of support to facilitate continual patient self-care beyond the self-management support program.
<b>Practice Component 11c)</b> Provide scheduled reviews to monitor cancer-related fatigue (e.g., severity and lifestyle interference), associated symptoms (e.g., stress, depression), and review of progress with self-management behaviours (e.g., confidence, physical activity, activity management).
<b>Key Practice 12.</b> Provide practical support that facilitates ongoing self-management.
<b>Practice Component 12a)</b> Provide practical support to assist the self-monitoring of cancer-related fatigue symptom reporting (e.g., fatigue severity, energy levels, and other factors that impacted fatigue), and behaviour change (e.g., exercise, meditation habits, physical activity, and dietary habits).
<b>Key Practice 13.</b> Be able available on request to review the symptoms of cancer-related fatigue.

<b>Practice Component</b> 13a) Be available for symptom review, treatment modification or counselling if symptom thresholds are exceeded.
<b>Key Practice 14.</b> Be able available on request to review the symptoms of cancer-related fatigue
<b>Practice Component</b> 14a) Be available for symptom review, treatment modification and/ or counselling if symptom thresholds are exceeded

## Participants

Potential panel participants were identified through networks within the Multinational Association for Supportive Care in Cancer (MASCC) – including fatigue and self-management subgroups; cancer consumer networks including Cancer Voices Australia, Canadian Cancer Survivor Network, and the Guyana Cancer Foundation; and other relevant groups or individuals identified by the research team. Panel participants were included from the following groups: health practitioners and clinicians (e.g., general practitioners, primary care providers, cancer specialists, medical oncologists, radiation oncologists, surgeons, nurses, allied health); cancer survivorship researchers (academics), and cancer consumers (patients, cancer survivors, and caregivers).

While there is no standard sample size for a modified Delphi study panel, studies suggest a minimum of eight participants, with more members increasing the reliability and applicability of group judgment (Hallowell & Gambatese, 2010; Murphy et al., 1998). A minimum of 40 participants were aimed to be recruited to the modified Delphi process with adequate representation from each group (clinical/ academic and consumer). This sample size takes into consideration the 50% attrition rate commonly reported in literature (Jobst et al., 2013; Khodyakov et al., 2020), thus maximising the likelihood of a sufficient sample size in subsequent rounds of the study.

Criteria for inclusion into the modified Delphi study were as follows:

- Being a minimum of 18 years of age;
- Experience or involvement with cancer, or cancer survivorship;
- Being able to read and understand English to a proficient level;
- Access to a computer/phone/tablet and internet connection.

Potential panel participants received an invitation email seeking 'expressions of interest'. This invitation email comprised written study information; a study video detailing the background and aims of the study; and a link to an expression of interest form designed using the Qualtrics XM (Qualtrics, Provo, UT) survey software platform. This expression of interest form included background information and asked individuals to provide their email address, country of residence, and indicate whether they were a health professional, researcher, or consumer

(i.e., cancer patient, cancer survivor, caregiver). To reduce participant attrition, potential participants were informed of expected time commitments and were asked to confirm their interest to participate in all modified Delphi rounds (Khodyakov et al., 2020). Potential panel participants were encouraged to distribute the expression of interest form to peers and colleagues, approximating a snowball sampling technique. A mailing list of 92 individuals was created through the email addresses obtained through the completed expression of interest forms and was used to distribute the practice items and surveys for the modified Delphi rounds.

## **Instruments**

The online surveys for all modified Delphi study rounds were developed using the Qualtrics XM (Qualtrics, Provo, UT) survey software. The surveys were divided into three sections: (1) participant demographics, (2) participation instructions, and (3) the proposed core SMS components for managing CRF. In the first section, participants were asked to indicate their participant type (e.g., cancer survivor, caregiver, academic, health professional), sex, age-group, race, country of work, country of residence, occupation, years of experience in cancer survivorship care, cancer type, and years since cancer diagnosis.

In the 'participant instructions' section of the survey, participants were provided with task descriptions and detailed instructions on how to participate in the online process and use the online platform. A 'study instruction video' detailing the study aim, and instructions on how to complete the survey was also included. Section three of the survey listed a series of statements detailing the proposed core components and domains of SMS for CRF as determined through the systematic review (Study 2), a SMS capability framework for primary care providers, and the National Comprehensive Cancer Network guidelines for CRF. Participants were asked to rate their agreement with each statement using a five-point Likert scale (1 – strongly disagree; 2 – disagree; 3 – neither agree nor disagree; 4 – agree; 5 - strongly disagree). Open text boxes for additional written comments were also included. After the initial modified Delphi round, a second questionnaire was sent to panel participants in the subsequent round. The surveys were piloted tested by researchers and laypersons in the community to ensure coherence, and usability (e.g., clarity of participation instructions, statement wording, and rating criteria) (Khodyakov et al., 2020).

### **Round 1 Modified Delphi Study**

The preliminary framework was emailed to panel participants through an online survey, accompanied by a consent form, an explanation of study objectives, the consensus process, and instructions. Each panel participant was asked to rate their agreement - that each practice should be included in a final practice framework - on a 5-point Likert scale (from 'strongly disagree' to 'strongly agree'), indicating the degree that each practice statement should be considered best practice and included in the final practice framework. Panel participants were also given the option to provide comments and suggest additional items that may not have been included when initially developing practice items. Survey responses were then qualitatively and quantitatively analysed to appraise consensus among participants. As per recommendations in literature, panel participants were given two weeks to respond (Trevelyan & Robinson, 2015), with a 'reminder to complete' email sent to those who hadn't completed the survey after the first week..

### **Round 2 Modified Delphi Study**

Practice items that did not meet consensus in Round 1, or were newly created or modified based on Round 1 panel feedback, were sent back to panel participants for voting in Round 2. Individuals who did not complete Round 1 of the modified Delphi study were also invited to participate in Round 2 as evidence demonstrates this leads to better representation of originally invited panel participants opinions, reduces the chance of 'false consensus', and does not compromise the outcome of the Delphi process (Boel et al., 2021). Panel participants were provided with a document summarising the changes made from participant feedback in Round 1. Panel participants rated statements using the same methods as Round 1. Practice items that did not meet consensus were not included in the final framework. As with the first round, panel participants were given two weeks to respond, with a reminder email sent after the first week.

### **Analysis**

Survey responses were imported into the statistical software program Jamovi (Version 2.3) for analysis. Descriptive statistics such as frequency, mean, median, percentage, and range were used to describe demographic data. Statistics such as the median and IQR were derived and evaluated for each practice item (De Vet et al., 2005). Consensus on panel participant opinions was defined as  $IQR \leq 1$  – a highly recommended rigorous and objective; widely accepted; and frequently used threshold for Delphi studies (Ahuja et al., 2018; De Vet et al., 2005; Ramos et al., 2016; Trevelyan & Robinson, 2015). As per recommendations in literature, median scores were used to summarise participant agreement with a statement (Ramos et al., 2016). A group median of 4–5 was considered to indicate agreement, and 1-2 disagreement. The percentage

of the panel participants responding to a given category was also recorded. Free-text responses were examined using basic thematic analysis methods (Braun & Clarke, 2006). Thematic analysis focused on concepts and categories used by participants in their free-text response. Analysis iteratively progressed from identifying specific ideas to conceptualising high-level explanations that constitute a patterned response, or ‘theme’. These themes were then used to inform changes to the practice framework.

### **Ethical Considerations**

Panel participants were informed that their participation in the modified Delphi study was voluntary and were given the option to withdraw or refuse participation at any time. No identifiable data was collected. Low-risk ethical approval was obtained from the Flinders University Human Research Ethics Committee (Approval Ref #: HREC CIA4907-1).

## **Results**

### **Demographics**

#### **Round 1**

Of the 92 individuals invited to participate, 52 completed the Round 1 survey (56.5% response rate). Demographic characteristics of participants in each round are presented in Table 5. Most participants identified as White or Caucasian (n=37/52; 71.2%); female (n=37/52; 71.2%); and indicated they were aged between the age groups 56-65 (n=15/52; 28.8%) or over 65 years (n=15/52; 28.8%). Twenty-four of 52 (46.2%) panel participants indicated their participant type as solely a cancer survivor/ patient, 11 (21.2%) indicated they were health professionals only, and nine panel participants as solely researchers/ academics (17.3%). The remaining participants selected more than one participant type with seven (13.5%) indicating they were health professionals and researchers, and one recording they were a health professional, cancer survivor/patient, and caregiver.

**Table 5:** Demographics of panel participants

	<b>Round 1 (n= 52) N,%</b>	<b>Round 2 (n=36) N,%</b>
<b>Sex</b>		
Female	37 (71.2)	26 (72.2)
Male	16 (30.8)	10 (27.8)
Did not answer	1 (1.9)	
<b>Age Group</b>		
18-35 years	5 (9.6)	3 (8.3)
36-45 years	9 (17.3)	6 (16.7)
46-55 years	8(15.4)	5 (13.9)
56-65 years	15 (28.8)	11 (30.6)
Over 65 years	15 (28.8)	11 (30.6)

<b>Race</b>		
Asian	4 (7.7)	3 (8.3)
Multiracial or Biracial	1 (1.9)	
Black, African or African American	1 (1.9)	
White or Caucasian	37 (71.2)	23 (63.9)
Hispanic or Latino		1 (2.8)
A race/ethnicity not listed here	9 (17.3)	9 (25.0)
<b>Participant Type</b>		
Cancer Survivor	25 (48.1)	16 (44.4)
Clinician	19 (36.5)	13 (36.1)
Researcher	16 (30.8)	11 (30.6)
Family/ Caregiver	1 (1.9)	3 (8.3)
<b>Clinician/ Research Academic Data</b>	<b>(n= 28)</b>	<b>(n=21)</b>
<b>Occupation field</b>		
Medicine	14 (50.0)	8 (38.1)
Nursing	6 (21.4)	6 (28.6)
Allied Health	3 (10.7)	2 (9.5)
Psychology	2 (7.1)	
Primary Care	1 (3.6)	1 (4.8)
Social Work	1 (3.6)	1 (4.8)
Epidemiology	1 (3.6)	
Public Health		1 (4.8)
Researcher/ Advisor		1 (4.8)
Physical Medicine and Rehabilitation		1 (4.8)
<b>Region of work</b>		
Europe	14 (50.0)	9 (42.9)
North America	8 (28.6)	6 (28.6)
Oceania	4 (14.3)	5 (23.8)
Asia	2 (7.1)	1 (4.8)
<b>Years of experience in cancer care (research or clinical care)</b>	Ranged from 2 to 45 years, with a median of 15 years.	Ranged from 1 to 35 years, with a median of 14 years.
<b>Cancer Survivor and Family/Caregiver Data</b>	<b>(n=25)</b>	<b>(n=17)</b>
<b>Primary Cancer site of Cancer Survivor</b>		
Solid tumours	20 (80.0)	12 (70.6)
Haematological malignancies	5 (20.0)	4 (23.5)
Did not answer		1 (5.9)
<b>Years since cancer diagnosis</b>		
1-2 years	1 (4.0)	1 (5.9)
2-5 years	2 (8.0)	2 (11.8)
5-10 years	9 (36.0)	5 (29.4)
More than 10 years	13 (52.0)	8 (47.1)
Did not answer		1 (5.9)
<b>Region of residence</b>		
Oceania	16 (64.0)	11 (64.7)
North America	7 (28.0)	3 (17.6)
Europe	2 (8.0)	2 (11.8)
South America		1 (5.9)

Out of the 28 research academics and health professionals, most indicated their occupation was in the field of medicine (n=14/28; 50%), followed by nursing (n=6/28; 21.4%), with the



remainder in various allied health roles. Years of experience in research or clinical cancer care ranged from 2 to 45 years, with the median years of experience equalling 15 years. Region of residence varied across Europe (n=14/28; 50%), North America (n=8/28; 28.6%), Oceania (n=4/28, 14.3%), and Asia (n=2/28; 7.1%).

Out of the 25 cancer consumers (cancer patients/survivors and family member/care givers), most resided in Australia (n=16/25; 64%); indicated breast as the primary cancer site (n=9/25; 36%); and indicated it had been more than 10 years since first cancer diagnosis (n=13/25; 52%).

### **Round 2**

Of the 92 invited individuals, 36 completed the Round 2 survey, resulting in a 39.1% response rate. Most participants identified as White or Caucasian (n=23/36; 63.8%), female (n=25/36; 69.4%); and indicated they were aged between the age groups 56-65 (n=11/36; 32.4%) or over 65 years (n=11/36; 32.4%). Twenty-one (n=21/36; 58.3%) participants indicated they were health professionals and/or research academics and 17 (n=17/36; 47%) were cancer patients/survivors or family/caregivers. Further demographic characteristics of Round 2 participants can be found in Table 5.

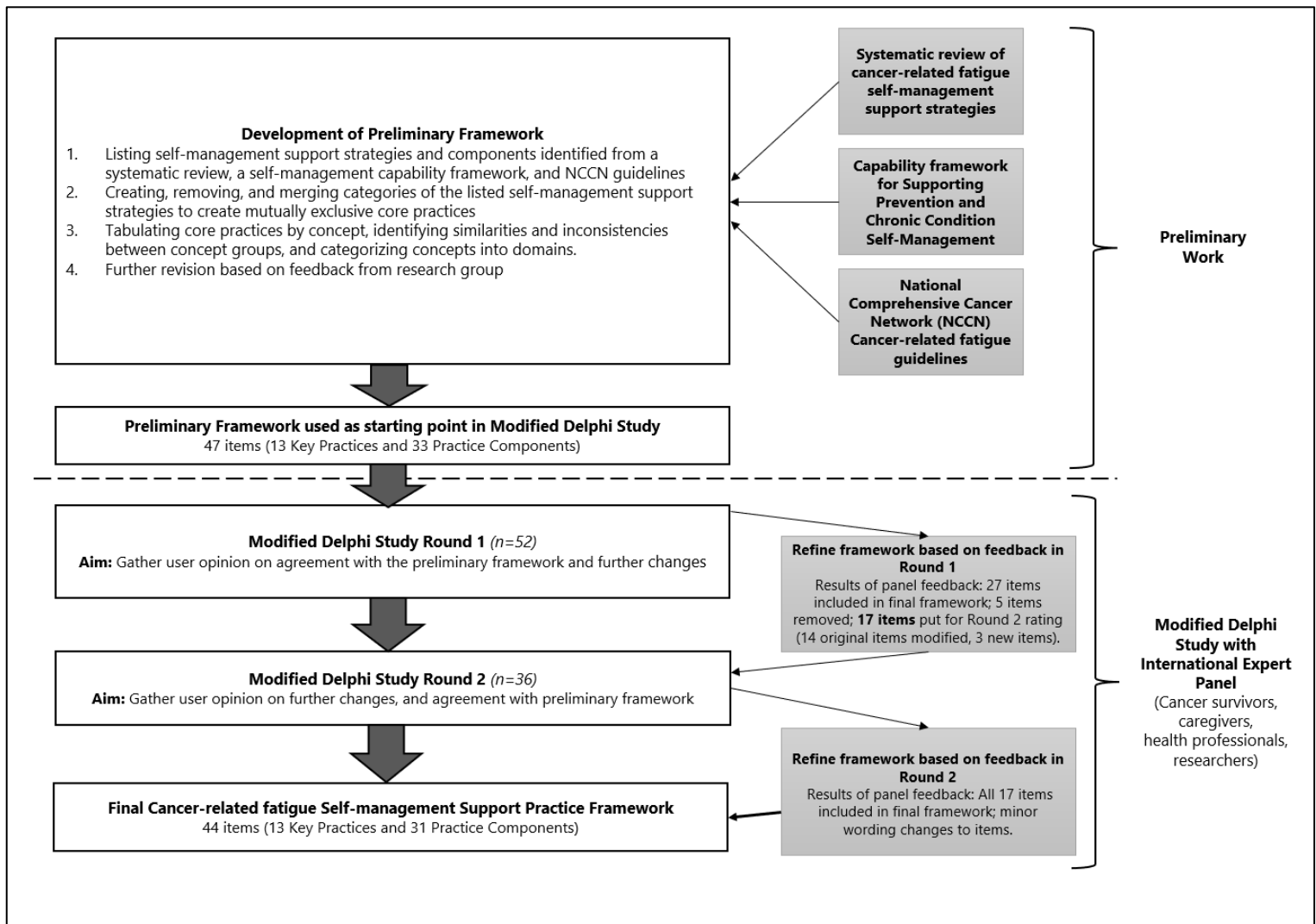
## **Consensus Building**

### **Round 1**

Quantitative consensus (IQR  $\leq$  1, and median of 4 to 5) on whether a key practice or practice component was to be included in the final framework was achieved for all practice items in Round 1. Themes identified from the panel participants free-text responses were also considered by the research team to ensure a co-creative process with participants, whereby the modification and inclusion of practice items were consistent with panel feedback.

In addition to feedback on grammar and formatting changes, priority areas for framework revisions from the panel's written feedback were: (1) the need to consider patient preferences for peer and familial support; (2) considering the needs of the patient's support network; (3) the importance of tailoring support information to different learning needs; (4) identifying risk factors for CRF; and (5) emphasis on referral to other health professionals for continual care. Identified themes, and subsequent responses/ amendments by the research team are presented in Appendix 8. As a result of panel feedback, 27 practice items were designated for inclusion in the final practice framework (Figure 10). Fourteen practice items were modified, and three new items were added and were included in Round 2 for rating. Five items were removed. Specific changes to practice items based on Round 1 panel feedback are displayed

in Appendix 9. Finally, in addition to the practice items, consensus was reached on the definition and components of a CRF SMS action plan Appendix 10.



**Figure 10: Modified Delphi Study Process**

### **Round 2**

All practice items submitted for feedback in Round 2 (n=17) reached consensus for inclusion into the final framework. Qualitative comments included suggestions for wording changes. The research team discussed the minor wording proposals from the panel and accepted or rejected them before finalising the framework. These changes did not go back to panel participants for endorsement through a third round, as they were not of sufficient scope for reappraisal (e.g., changes to grammar, spelling). Some panel participants also suggested that greater clarity and specificity was required for the practice components to be useful for implementation, and teaching and evaluating practice. To address this, a decision was made to re-incorporate the accompanying examples and contextual elements that were included in Round 1, back into

the main practice framework (and not just as supplemental material – see Appendix 8 for further detail). As a result of panel feedback from Round 2, all items were included in the final framework. Thus, the final practice framework consisted of 13 Key Practices and 31 Practice Components. Table 6 depicts the domains and key practices of the framework; the full practice framework is presented in Appendix 10.

**Table 6:** Domains and Key Practices of Self-management Support Practice Framework

<b>Care coordination and Maintenance</b>
<ol style="list-style-type: none"> <li>1. Collect and use clinical and behavioural information to inform decision making about the patient's self-management of cancer-related fatigue.</li> <li>2. Assess the patient's capacity for self-management</li> </ol>
<b>Developing an Action Plan</b>
<ol style="list-style-type: none"> <li>3. Create a cancer-related fatigue management action plan in collaboration with the patient that incorporates evidence-based coping strategies that are aligned with patient preferences.</li> </ol>
<b>Improving Patient Knowledge</b>
<ol style="list-style-type: none"> <li>4. Provide tailored evidence-based information on cancer-related fatigue and common management strategies in a diversity of formats to accommodate different learning styles</li> <li>5. Provide tailored evidence-based information on managing common psychological consequences of cancer and cancer-related fatigue in a variety of formats to accommodate different learning styles</li> <li>6. Provide tailored evidence-based information about available social support in a variety of formats to accommodate different learning styles and check patient understanding</li> </ol>
<b>Training Rehearsal (Strategy Building)</b>
<ol style="list-style-type: none"> <li>7. Provide the patient with problem solving and evidence-based solution-focused strategies to communicate with their systems of support (includes health professionals, non-health professionals, personal communities; and voluntary and community groups) about cancer-related fatigue</li> <li>8. Provide evidence-based coaching for lifestyle modifications that support living with cancer-related fatigue</li> <li>9. Provide the patient with evidence-based problem-solving strategies for coping with the psychological effects or risk factors of cancer-related fatigue</li> <li>10. Provide evidence-based health promotion and education on lifestyle adaptation strategies</li> <li>11. Provide regular review of self-management activities, and self-management goals and action plans in collaboration with the patient, their support network (with the patient's consent), and their health care team</li> </ol>
<b>Care Co-ordination and Maintenance</b>
<ol style="list-style-type: none"> <li>12. Provide practical support that facilitates ongoing self-management</li> <li>13. Attend to requests to review the symptoms of cancer-related fatigue</li> </ol>

## Discussion

This study is the first to develop a framework of core practices required by health professionals to deliver effective SMS to cancer survivors experiencing CRF. This framework had input from an international panel of cancer consumers, health professionals, and cancer researchers.

The modified Delphi study that was used established resounding consensus on the best clinician practices for facilitating CRF SMS at all phases of the cancer continuum.

For self-management to be effective, cancer survivors must be supported in managing their symptoms and conditions. Health professional guidance for fatigue management often lacks detail about effective SMS, contributing to the provision of inadequate and limited support (Agbejule et al., 2022; Hilarius et al., 2011; James et al., 2015; Jones et al., 2021) (e.g., information provision alone, normalisation of fatigue symptoms, advising individuals to simply rest and relax).

The practice framework presented in this study considers the complex nature of CRF management, by conceptualising self-management as an active process that requires an essential set of collaborative-and partnership building behaviours, skills, knowledge, and practices. Further, it presents the ideal practices needed to effectively facilitate the adoption of fatigue self-management behaviours. These include action planning, motivational interviewing, and assessment of self-management capacity to facilitate self-management through enhanced self-efficacy. This framework could be used by clinicians as a tool to guide their provision of CRF SMS. This framework may also allow clinicians to evaluate current practice, determine professional development needs, and support their understanding of the comprehensive nature of effective CRF SMS.

Although primarily directed to health professionals, this practice framework may have functionality across several settings (see Table 7). Clinical leaders and educators could use the framework to build awareness and knowledge among their clinical teams. Researchers could use the framework to synthesise evidence on CRF self-management, a deficiency to address the shortcomings described in Chapter 1 whereby several reviews identified that variability in fatigue self-management definitions, strategies, and intervention reporting impedes study synthesis and increases difficulty in determining the distinction of outcomes gained as a result of self-management practices. Consumers could refer to the framework to advocate for their care, and develop their own understanding on the various roles of SMS for CRF.

**Table 7: Use of the Practice Framework**

The following recommendations are designed to help individuals and organisations make the best possible use of the Practice Framework.

**For the individual health professional**

- Use the Practice Framework as a tool:
  - to guide the provision of self-management support for cancer-related fatigue
  - for determining your professional development needs
  - for evaluating current practice when providing support to those managing cancer-related fatigue
- Use the Practice Framework and associated learning resources to undertake self-directed learning.
- Refer colleagues new to working with people affected by cancer (i.e., cancer survivors, cancer patients) and/or cancer-related fatigue to the framework.
- Use the Practice Framework to develop an understanding about:
  - the extent of cancer-related fatigue impact on those affected by cancer and the importance of its management
  - the various roles of different health professionals in the delivery of self-management support for cancer-related fatigue

**For the clinical leader/ educator**

- Use the Practice Framework as a tool to:
  - develop clinician awareness and knowledge of evidence-based cancer-related management and assessment strategies
  - provide training/in-service programs to improve ability to undertake practices (how to use certain questionnaires, practice developing an action plan, etc.)
  - advocate for system-level changes to provide resources (time, space, and human) to deliver optimal support for cancer-related fatigue management

**For the cancer-related fatigue self-management intervention/program developer**

- Use the Practice Framework to aid development of a cancer-related fatigue self-management intervention/program (determining the specific components that are needed).

**For the researcher**

- Use the Practice Framework as a tool to:
  - describe self-management support interventions for cancer-related fatigue
  - synthesize evidence on cancer-related fatigue self-management

**For the consumer experiencing cancer-related fatigue (and their family/carer's)**

- Use the Practice Framework as a tool to:
  - develop understanding of the various roles of different health professionals in the delivery of self-management support for cancer-related fatigue
  - Advocate for improved delivery of cancer-related fatigue management support.
  - advise your health care team(s) about the existence of the practice framework and teaching and learning resources in efforts to improve your care.

Although panel participants acknowledged framework components as best practice, comments identified a need for further clarity around healthcare professional responsibility (i.e., who should do what). CRF is multifactorial (Bower, 2014; Weis & Horneber, 2014), meaning that there are diverse factors that can contribute to, or cause it (e.g., cancer type, treatment type, anaemia, nutrition factors, psychological factors, etc.). It is therefore expected that the provision of CRF SMS will require a multidisciplinary approach. If a multidisciplinary approach is adopted, it will not be necessary for all healthcare professionals to be proficient and have the commitment to deliver all practice components, especially when these fall outside of a professional's expertise or scope of practice. However, this practice framework

does allow for healthcare professionals to identify areas of care provision that may be achievable within their clinical care domain, and where additional training or collaboration may be encouraged or required.

The execution of the key practices and practice components specified in the framework may require health professionals to apply, adapt, and integrate new and existing evidence-based knowledge or seek professional development opportunities. This framework does not provide, present, or describe the capabilities or competencies required by health professionals, as these are already described in clinical practice guidelines (Berger, 2019; Fabi et al., 2020; Howell. et al., 2013). Rather, the practice framework outlines the support tasks that health professionals and health care teams should undertake when supporting people affected by cancer to self-manage their fatigue.

The consumers involved in this study emphasised the importance of health professionals not merely providing information on self-managing fatigue, but delivering information in a way that promotes the understanding and knowledge of the consumer. Although not explicitly listed in each practice item, it is stressed that the execution of practices outlined in the framework should be underpinned by the presence of effective, person-centred, health professional communication which involves the ability to establish and develop mutual understanding, rapport, trust, respect, and cooperation with people affected by cancer using clear and plain language. This includes making appropriate adjustments (e.g., use of appropriate language and detail, use of appropriate verbal and non-verbal cues, confirming that the other person has understood) to meet the communication and information needs of patients and their support network (e.g., caregivers, family, friends) and providing opportunities for the patient and their support network to demonstrate their understanding.

### **Future Work**

This study has identified the requisite practices needed to effectively deliver fatigue SMS. Although some feedback to enhance framework usability and implementation was received and incorporated, future work could involve further consultation with key stakeholders. This consultation could be used to enhance understanding of stakeholders' perspectives about the acceptability and relevance of the framework to specific clinical, educational, and cultural contexts, and among underserved or high-risk groups. Future work could also identify different stakeholders' needs in supporting the implementation of the framework in their local setting. This includes fine-tuning the language and presentation of the framework for different contexts (e.g., 'cheat sheets', communication tools, role play scenarios for training, flow diagrams, etc.) and determining educational and training requirements. Stakeholder consultation could also be used to further define the roles of different professional disciplines in providing SMS for

CRF. Such developments would fine-tune the framework to provide clinical and implementation guidance that encourages clear professional judgment and explicit decision making.

### **Strengths and Limitations**

Strengths of this study include its online anonymous nature, which allowed for unrestricted expression of panel opinions. This helped reduce the influence of dominant personalities and the effect of panellists' status on results (Ramos et al., 2016). However, the online forum limited the opportunity for robust discussion. Another strength of this work is that the modified Delphi study comprised representation from a diverse international panel of consumers, health professionals, and cancer researchers from varying continents, professional fields, and clinical settings. Although the resulting practice framework incorporated diverse international perspectives, the panel was not representative of participants from every country/region, culture, setting, or scope of practice. Cultural influences on health, fatigue, compliance, and attitudes towards care will need to be considered when adapting the framework to different contexts (Zhang et al., 2020). Limiting panel eligibility criteria to individuals proficient in English could have resulted in potential candidates and viewpoints being missed.

### **Conclusion**

This modified Delphi study presents a framework for health professionals that outlines the essential support practices needed to facilitate the uptake of CRF management strategies. Future work is needed to assess the clinical utility and implementation (including evaluation of such implementation) of the practice framework. The provision of comprehensive SMS by health care teams is key for the uptake and integration of evidenced-based fatigue management strategies into clinical practice and improving the outcomes of patients and cancer survivors. Future work is needed to investigate the practical implementation of the established best practices. The next chapter delves into the application of SMS for CRF in real clinical scenarios.

## 5.0 CONVERSATION ANALYSIS STUDY (STUDY 3)

### Chapter Introduction

Enabling cancer survivors to adopt and sustain CRF management behaviours requires a collaborative partnership between cancer survivors, health care teams, and local and personal communities of support (community organisations, families, friends). The presence of a strong collaborative partnership or therapeutic alliance provides vital and consistent contributions to the outcomes (e.g., improved uptake of health management behaviours, self-management self-efficacy) of supportive care practices (Fitzpatrick et al., 2006). The Flinders SMS Capability Framework, introduced in Chapter 2, affirms that health professionals require an understanding of the impact of their interactions on cancer survivor choices and behaviours, and emphasises that to facilitate successful self-management, health professionals – with relevant expertise and resources – must foster productive interactions with cancer survivors (Lawn & Battersby, 2009). Difficulties in communication between cancer survivors and health professionals represent a key barrier to the implementation of CRF management strategies to practice, and is a large contributor to cancer survivors feeling dissatisfied with the CRF SMS they currently receive from clinicians (Jones et al., 2021; Jones et al., 2020).

The systematic review on SMS interventions for CRF presented in Chapter 3 (Study 1) identified a lack of research to understand exactly how SMS for fatigue has been and should be delivered and emphasised that more research is needed to examine ways communication can be effective in practice. In Chapter 4, a modified Delphi study (Study 2) was used to identify a framework of the requisite practices needed for health professionals to effectively provide CRF SMS to cancer survivors. Although the study participants acknowledged framework components as best practice, some clinician participants expressed hesitancy around the feasibility of undertaking the practices, citing interactional and logistical difficulties (e.g., issues with time availability). Additionally, some clinicians questioned how these support discussions (e.g., identifying barriers and facilitators to client self-management, providing coping strategies, goal setting, etc.), and creation of goals would occur in real-life clinical practice. The successful adoption of self-management CRF behaviours by cancer survivors (e.g., dietary changes, increased physical activity, etc.) is also greatly dependant on the quality of clinician-survivor interaction and the effective provision of efficacious SMS strategies. Further investigation is needed to help understand how the practice framework can be implemented while considering specific challenges that may arise during interactions. To understand the processes that may influence the quality and effectiveness of these critical interactions, it is important to identify, in detail, the communitive practices used by clinicians and cancer survivors during real-life encounters at the micro-level.



The purpose of this study is to investigate at the interactional level the communication practices employed by cancer nurse counsellors when providing support to cancer survivors in managing their CRF and the impact of these practices within consultations. Insights derived from this study complement the formation of the *Cancer-related Fatigue Self-management Support Practice Framework* by examining the application of best practices in routine clinical care at an interactional level.

This chapter describes the design, findings, discussion, and implications of a conversation analytic study to achieve the aims and objectives stated in Chapter 1: To gain an understanding of clinical interactions as part of SMS practices to manage CRF in cancer survivors. This study was conducted to gather insight on the following questions:

1. What SMS communication practices are used by cancer nurses during interventional consultations with cancer survivors experiencing CRF?
2. What are the interactional consequences of these practices?

This chapter describes the methodology used in the study and the research design; the participants of the study; the procedure used; how the data is analysed; and the ethical considerations of the research.

## **Methodology**

Conversation analysis (CA) is underpinned by a distinctive qualitative methodology that facilitates analysis of the constituent elements of interaction in fine-grain detail, focussing on how humans give meaning to each other in conversation through shared interactional methods (White, 2019). Established primarily from the work of the psychologists Sacks, Schegloff, and Jefferson, and rooted in sociology and ethnomethodology, CA seeks to examine and explain the interactional social order and organised reasoning procedures which inform the production of everyday naturally occurring social interaction (Bloor & Wood, 2006; Hutchby & Wooffitt, 2008).

Communication is an integral component of the delivery of safe and effective healthcare, with most healthcare provision performed through social interaction (e.g., clinical handover; interdisciplinary and multidisciplinary collaboration; and clinician-patient consultations). Further, the success of healthcare delivery largely depends on the quality of these interactions, particularly between health professionals, medical staff, and patients (Drew et al., 2001). Conversation analysis is a well-established approach for exploring the details of real-world healthcare communication (Barnes, 2019; Drew et al., 2001; Heritage & Maynard, 2006; Pilnick et al., 2009). Additionally, CA has advantages over other qualitative research, such as approaches that rely on interview data, due to its focus on unaltered naturalistic encounters

where the role and impact of the researcher is minimised (Potter & Hepburn, 2012). Despite the suitability of the CA methodology for examining communication in supportive care, there have been no CA studies on the SMS interactions of health professionals. Moreover, existing CA research has almost exclusively focused on doctor-patient interactions within primary care settings (Barnes, 2005; Drew et al., 2001; Gill & Roberts, 2013; Pilnick et al., 2009). As such, this study delivers novel insights for oncology, CRF, nurse-cancer survivor interactions, and SMS interventions.

CA consists of three fundamental theoretical assumptions: (1) talk is a form of action; (2) action is structurally organised; and (3) talk creates and maintains inter-subjectivity (Peräkylä, 2004; Willig & Stainton Rogers, 2017). The first theoretical assumption – talk is a form of action – focuses on what individuals ‘do’ with talk rather than on what they say, and places emphasis on the fundamental structure of talk-in-interaction such as turn-taking and the organisation of actions into sequences (Willig & Stainton Rogers, 2017). For example, a CA study by Toerien and colleagues (2018) found that neurologists and their cancer patients only agreed that a choice in cancer treatment had been offered in instances where the neurologist had distinctively listed options during consultation (Toerien et al., 2018). This finding was insightful as it identified why patients perceived a lack of choice in their treatment despite neurologists reporting they had provided different treatment options and that there was genuine scope for the patient to choose between them. Further, this example demonstrates how the action and organisation of talk-in-interaction is just as significant (if not more significant) than the content of the conversation itself (Sacks et al., 1974).

The second theoretical assumption – that interaction is structurally organised – delves into specific rules and technical practices that structure talk into sequences of action. The sequential organisation of talk can be categorised into three characteristics. First, when a current speaker provides a particular type of utterance (e.g., treatment options listing), this prompts particular types of responses relevant to next actions for another speaker (e.g., selection from the listed options). Second, speakers are informed by the context of a preceding interaction (most commonly, immediately preceding talk). Third, speakers demonstrate their understanding and interpretation of prior interaction through the production of next actions.

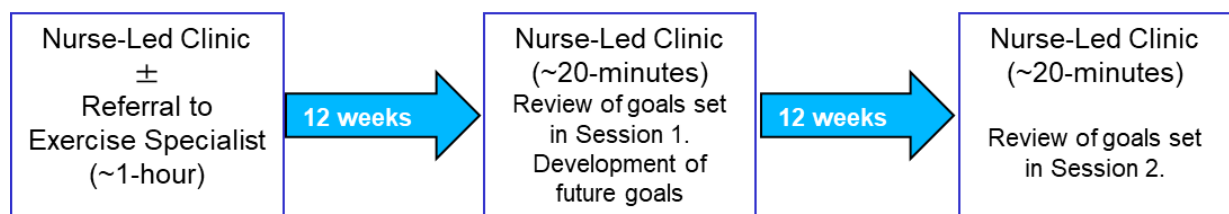
An example of sequential organisation is again observed in Toerien and colleagues' (2018) CA study. The authors analysed the immediate actions of neurology patients following treatment choice conversation, and found that during option listing, if neurologists did not explicitly invite patients to announce their views, the patient tended to trust the first listed option as the best option – when that was not necessarily what the physician was trying to convey (Toerien et al., 2018). This example also links to the final theoretical assumption – talk creates

and maintains intersubjectivity – which posits that conversation depends on the displayed understandings of prior talk. Moreover, due to this, “no detail of an interaction can be considered immaterial, unimportant or inconsequential within the context of interaction” (Peräkylä, 1997; pg. 89). This theoretical assumption underpins the analysis of data, which will be considered in the analysis section below.

## Research Design

### Telehealth Cancer-related Fatigue Self-management Support Clinic

Data for the CA study comprise audio or audio-visual recordings of nurse-cancer survivor consultations conducted between 2021-2022 in a Telehealth Cancer-related fatigue Self-management support clinic (hereinafter referred to as the T-CRF SMS Clinic) in metropolitan Australia (Brisbane, Queensland). These data were collected as part of the Telehealth Cancer-Related Fatigue pilot randomised controlled trial (RCT) of which the full intervention protocol has been published elsewhere (Ladwa et al., 2022). Briefly, the T-CRF SMS Clinic is a 24-week SMS program, informed by the Flinders SMS Capability Framework, that consists of three nurse-led telehealth clinic sessions between cancer survivors experiencing moderate-to-severe fatigue (as determined by the Brief Fatigue Inventory instrument), and trained cancer nurse counsellors. During clinic sessions, nurse counsellors: 1) provide education on fatigue management addressing aspects such as physical activity, symptom-specific and general coping mechanisms; 2) collaboratively create a fatigue management plan with up to three goals; and 3) facilitate referrals to exercise specialists and other relevant support services. During the consultations nurse-counsellor interventionists use different behavioural strategies (i.e., goal setting, coaching, motivational interviewing, and cognitive behaviour therapies) to facilitate cancer survivor behaviour change (i.e., increasing physical activity) with the aim of improving cancer survivor CRF (see Figure 11).



**Figure 11:** The Telehealth Cancer-Related Fatigue (T-CRF) Nurse Consultation Model

## **Context**

The nurse counsellors delivering the T-CRF SMS Clinic, were from the consumer advocacy community group Cancer Council Queensland (CCQ). CCQ is a state-member of Cancer Council Australia, a national, non-profit organisation which aims to promote cancer-control and prevention policies and to improve the quality of life of people diagnosed with cancer in Australia (Cancer Council Australia, 2023). CCQ nurse counsellors have extensive experience caring for cancer survivors and have been trained in counselling and cognitive behaviour techniques. In addition to pre-existing training, prior to commencing the intervention nurse counsellors received written material on how to deliver the intervention; material on effective communication, motivational interviewing, and behavioural cognitive techniques; and attended a full-day workshop incorporating role-play activities (Ladwa et al., 2022).

## **Participants**

### ***Eligibility Criteria***

Cancer survivors were included in T-CRF study if they met the following criteria:

- were at least 6-weeks post-completion of primary cancer treatment, or completed at least 3-months of maintenance treatment;
- were receiving care at Princess Alexandra Hospital outpatient clinics;
- were aged  $\geq 18$  years;
- had a definitive diagnosis of solid tumour or haematological cancer;
- had a score  $\geq 4$  on the Brief Fatigue Inventory;
- had a Eastern Cooperative Oncology Group performance status of  $\leq 2$ ;
- were not currently receiving specialist palliative care;
- had access to a telephone.

Cancer survivors were excluded from study participation if they displayed a presence of mental, cognitive, or physical conditions that would limit their ability to participate in the intervention; had a declared prognosis of less than six months survival expectancy at the discretion of the treating clinician; or for any other reason that they were deemed unsuitable to participate at the discretion of their treating clinician.

## **Procedure**

### ***Recruiting and Consenting Participants***

Cancer survivors for the T-CRF pilot trial were recruited through the Princess Alexandra Hospital's (PAH) outpatient clinics and therapy units of the Division of Cancer Services and Surgical Services, Brisbane, Australia. Eligible cancer survivors were asked to provide written informed consent, which included the following declaration:

*I understand that my information collected as part of this study may be used for secondary analysis for another research purpose.*

Information on the audio and video recording of nurse-led clinic sessions was also provided in the written information sheet that accompanied the informed consent form. Prior to the beginning of each nurse-led clinic, intervention nurse counsellors sought additional verbal consent from participants to record sessions using the Microsoft Teams recording function.

### **Data Collection**

Audio and video recordings of telehealth nurse-led clinic sessions were performed using the Microsoft Teams recording function. As part of standard practice, following participant consent, CCQ nurse counsellors used Microsoft Teams to conduct and record the clinic sessions with cancer survivors. Audio and video data were transcribed verbatim using a professional service that stored the data securely and did not retain a copy of the recording beyond the period required for transcription. Specific cases or verbatim transcripts were then transcribed and annotated using the conversation analytic transcription system developed by Jefferson (Hepburn, 2012; Jefferson, 2004) (see Figure 12). Data was collected and analysed for intervention consultations that occurred between January 2021 and September 2022. At the time of analysis, 41 distinct telehealth consultations had occurred. All 41 consultations were included in the analysis. A description of the sample can be found in the Data section.

### **Analysis**

Video and audio data were analysed using the following standard conversation analytic approach (Schegloff, 1996, 1999; Sidnell, 2012; White, 2019). Unlike many other qualitative research methods, in conversation analysis, observation is commonly used as a basis of theorising (Sacks, 1984; Sidnell, 2012). Accordingly, audio and video recordings were first examined to identify recurrent ways in which talk about self-management of CRF appear to occur. This process involved the general observation of data without seeking specific technical details or preformulated phenomena (Sacks, 1984; White, 2019). Observations such as general changes in social interaction as well as other conduct such as gestures, eye contact, gaze, and body organisation were noted. Instances of phenomena of interest were then transcribed using Jefferson's transcription system described in Figure 12, to facilitate detailed analysis.

Transcription Notation	
Symbol	Correspondence to features of talk
(.)	A dot in a bracket indicates a pause of less than tenths of a second
Word (0.7) Word	A number within parentheses refers to silence, which is measured to the nearest tenth of a second and can occur either as a pause within a current speaker's turn or a gap between two speaker's turns
<u>What</u>	Underlining indicates stress or emphasis in speech
Wo:::rd	Colons indicates the stretching of the immediately preceding sound with multiple colons representing prolonged stretching
<u>Wo</u> :::rd	Underlining followed by one or more colons indicates a shift in pitch during the pronunciation of a sound, with rising pitch on the underlined component followed by falling pitch on the colon component that is not underlined.
Wo[rd ] [Wo]rd	Square brackets mark speaker overlap, with left square bracket indicating overlap onset and right square brackets indicating overlap offset.
Word-	A dash following a word indicates a cut-off sound at the end of the talk
=	Equals sign indicates continuous talk between speakers
↑Word↑	An utterance encased with upwards arrows indicates that the talk is produced at a higher pitch than the surrounding talk.
↓Word↓	An utterance encased with downward arrows indicates that the talk is produced at a lower pitch than the surrounding talk.
°Word°	Words encased in degree symbols indicate utterances produced at a lower volume than surrounding talk.
Word.	A period indicates falling intonation at the end of a unit of talk
Word,	A comma indicates slightly rising intonation
Word?	A question mark indicates rising intonation
>Word<	Words encased with greater-than followed by less than symbols indicate talk produced at a faster pace than surrounding talk.

**Figure 12:** Jeffersonian's Conversation Analysis Transcription Convention

The Jeffersonian transcribed segments were then analysed in fine-grain detail to systematically identify and understand the organisation of phenomena. This process can be undertaken in several ways, but generally involves the in-depth analysis of each identified segment of data to understand the organisation of conversational structure, (such as the way in which turns at talk are organised into sequences of action) (ten Have, 2007).

During this analytic process, particular features of interest become apparent and lead to the collection of instances displaying the same phenomenon. This process of building collections allows the researcher to identify the position and composition of the focal phenomenon. Further, during this approach, boundary or deviant cases (cases that partially or completely go against the trend or pattern that is typical in the collection) should not be ignored as they

may prove the 'rule' or systematic practice observed and may provide further context for understanding that practice (Sidnell, 2012; White, 2019). Deviant case analysis may also warrant revision or refinement of analysis (Maynard & Clayman, 2003). The ultimate goal of collection-based analysis, including deviant case analysis, is to make generalisations across cases, but not at the expense of the applicability of the analysis to individual cases (Stivers & Sidnell, 2012).

The analysis reported below will provide key insight into how SMS interactions occur between health professionals and cancer survivors in clinical practice. More specifically, analysis will seek to identify the methods and communication strategies used by health professionals and cancer survivors to initiate (or avoid) discussions about managing CRF and will explore the interactional impact of these methods on cancer survivor uptake of CRF management strategies. Further, the CA study will provide insight into the state of health professional SMS practices for individuals experiencing CRF and examine whether current practices align with best practice recommendations.

### ***Ethics and Limitations***

Low risk negligible ethics was sought for all recording and analysis as part of the ethics submission for T-CRF RCT, which was approved by the Human Research Ethics Committee (HREC) of Metro South Health (MSH: HREC/2020/QMS/63495). Administrative approval was also provided by the Queensland University of Technology (QUT) HREC (Approval No. 2000000546). The study adheres to the principles of the National Health and Medical Research Statement on Research Involving Human Subjects. All names and identifiers included in transcript fragments are pseudonyms.

### **Data**

Forty-one distinct audio-recorded and audio-visual recordings of telehealth consultations between three different nurse counsellors, and 23 different cancer survivors were examined. Clinic consultation times ranged from 46 to 75 minutes, with an average duration of 52.5 minutes. The age range of cancer survivors in the sample was between 23 and 76 years, with an average age of 53 years. The sample consisted of 14 females and 9 males, all diagnosed within the last 8 years (between 2015 and 2021). Cancer diagnoses comprised of 4 bowel cancer, 9 breast cancer, 4 lung cancer, and a mix of others, including melanoma, testicular cancer, pancreatic cancer, renal cancer, leukaemia, and prostate cancer. Of the 23 cancer survivors, 14 reported moderate fatigue at baseline, while the remaining 9 reported severe fatigue as per the BFI tool. Fragment identification codes are as follows: NC = nurse counsellor, CS=cancer survivor, 0:00 = minute:seconds)].

## **Analysis**

The primary agenda of the nurse-led consultations analysed in this study was to collaboratively establish coping strategies that support the cancer survivor to manage their CRF; in other words, to provide SMS. To facilitate this process, nurse counsellors typically undertake a selection of activities. First, the nurse counsellor begins a process of information gathering to make an assessment of the cancer survivor's fatigue. This can include assessing the cancer survivor's clinical status, determining how fatigue impacts the cancer survivor's day-to-day living, establishing if there is a pattern of fatigue, and identifying potential barriers or enablers to possible fatigue support strategies (e.g., inability to lift items, sleep disturbances). Next, a fatigue management plan is established in collaboration with the cancer survivor, in which behaviour change goals to mitigate CRF are created (e.g., walking continuously for 20 minutes each day of the week). During creation of the fatigue management plan, the cancer survivor is provided with information about CRF as well as coping strategies and a referral to an exercise specialist (i.e., physiotherapist, exercise physiologist) if indicated. Throughout this process the nurse counsellor may also use support strategies such as motivational interviewing, and support practices based on cognitive behavioural techniques. In subsequent consultations the goals developed in the fatigue management plan are reviewed and adjusted according to cancer survivor feedback and needs.

The SMS provided by the nurse counsellor is a complex multi-component process. Although a range of important topics relating to the psychosocial, physiological, and physical impact of the cancer survivor's cancer are discussed during the SMS consultation (e.g., clinical symptoms; psychological and social wellbeing; etc.), the primary agenda – providing support to help cancer survivors manage their CRF – remains focal throughout the intervention. This conversation analysis study demonstrates that a recurrent way this focus is achieved and maintained is through the use of conversational practices such as formulations and establishing the agenda from the outset of the consultation. The use of these conversational practices by the nurse counsellors involved in this study provides scope for holistic consideration of the cancer survivor's circumstances, while also maintaining a core focus on CRF management.

## **Findings**

This section presents instances of nurse counsellors 'establishing the agenda from the outset' and creating formulations during consultations. The interactional consequences of instances where such techniques are not employed are also examined. The analysis finds that structuring SMS consultations using these practices promotes intersubjectivity (i.e., shared understanding) between cancer survivors and nurse counsellors, and sustains a primary focus on the agenda of managing CRF.



## Establishing a focus on fatigue self-management support from the outset of the consultation

SMS consultations differ to the usual types of medical encounters that cancer survivors may have previously experienced. For example, in a typical encounter with a general practitioner (GP), a patient generally states their medical problem, or the reason for their visit, and may provide additional information if prompted by their GP, who then delivers a clinical judgement and provides a treatment recommendation if indicated (Robinson, 2003). In contrast to general practice, most individuals do not have experience with SMS counselling sessions and may not know what to expect, what to do, and how to act in a consultation. This analysis identified that establishing the agenda of consultation from the outset of a session provides an initial opportunity for clinicians to focus the conversation on SMS for CRF and manage the expectations of the cancer survivor.

An example of a nurse counsellor establishing the primary agenda at the outset of the consultation can be seen in the fragment below, which begins five seconds into the recording of the consultation. In Fragment 1, the nurse counsellor begins the consultation by announcing her name and role (lines 2-3). On lines 9 to 13, she establishes what her expectations are from the cancer survivor, (*“Importantly, I’m interested to hear from you today and to find out more about the experience of fatigue...”*). She then sets the agenda of the consultation through the arrangement proposed on lines 14-26.

### Fragment 1 [NC1CS1/0:05]

01 NUR: So, (.) lovely to have that little chat before we started the recording  
02 and (.) so just to um >introduce myself,< my name is Sarah I'm one of our  
03 nurse counsellors. .hhh (0.5) at the Cancer Centre. .hhh and uh >I  
04 understand< you've been referred uh to uh:s, because you've been (.)  
05 experiencing hh a lot of fatigue. .hh(.) an:d I wanna thank you for  
06 completing that questionnaire?=  
07 CLI: Yep. ((Single head nod downward))  
08 NUR: =I've hadda (.) read of that this morning, (0.3) to get >a bit of a  
09 sense<[ of ] what's been happening. Importantly, I'm I'm interested  
10 CLI: [(Cough)] ((short repeated nods, eye contact kept with NUR))  
11 NUR: to hear from you toda::y and to find out mo:re (0.3) about the experience  
12 of fati:gue.=  
13 CLI: ((short repeated nods, eye contact kept with NUR))  
14 NUR: =.hhh uh so I wondered to get us started, if >would it be oka::y< if  
15 (0.3) uh:: I start with some questions? [an::]d to open up our discussion?  
16 CLI: [ yep] ((Single head movement  
17 upwards then downwards))  
18 NUR: an::d feel free at any point to add in anythi[ng that you think °might° be^  
19 of relevance,=  
20 CLI: [((short repeated nods, eye contact kept with NUR))  
21 CLI: Yeh-  
22 NUR: =or that you want to share?  
23 CLI: ((short repeated nods, eye contact kept with NUR)) Yep  
24 NUR: an::d then what we can do is talk aboww:t (.) a plan, (.) of how we might  
25 be able to provi:de some support=  
26 NUR: =[to help in managing the fatigue hhh=I thni-  
27 CLI: [((short repeated nods, eye contact kept with NUR)) °Okeh°

28 NUR: Does that aw:ll sound okay: for you? ((head nodding while gazing at  
 29 cancer survivor with head tilted sideways))  
 30 NUR: [yeh- that (0.2) chat?]  
 31 CLI: [yeah, that's good. ]((double head movement downward, high amplitude  
 32 head movement))  
 33 CLI: Yep=  
 34 NUR: =Yep (.) great

Through this proposed arrangement the nurse counsellor orients the cancer survivor to the structure of the consultation, by establishing her role (i.e., to conduct an initial assessment of the cancer survivor's fatigue by asking questions; to assist the cancer survivor to come up with a plan to help manage his fatigue), and the role and responsibility of the cancer survivor (i.e., to answer questions about his fatigue, provide information that he thinks is relevant to the creation of his fatigue management plan, and to co-develop a plan to manage his fatigue) (Patterson, 1985). Importantly, in this early phase of the consultation, the nurse counsellor explicitly informs the cancer survivor of the agenda – to provide SMS for CRF (“... *then what we can do is talk about a plan, of how we might be able to provide some support to help in managing the fatigue*”, lines 24-26). After providing her proposed arrangement, on line 28 the nurse counsellor produces a pursuit of response (“*Does that all sound okay for you?*”), described by conversation analysts as response solicitation, whereby the arrangement (described on lines 14-26) is contingent upon the recipient's (in this case the cancer survivor's) acceptance (Jefferson, 1981). The cancer survivor's verbal confirmation (“*yeah that's good*”, line 31) and head nod (line 32) in response to the nurse counsellor's response solicitation, accepts the nurse counsellor's proposed plan for the consultation and shows that the cancer survivor and the nurse counsellor have a shared understanding of the tasks and goals of the session; whereby the nurse counsellor is trying to establish a course of activity, and the cancer survivor is aligning with what the nurse counsellor is seeking to undertake.

The alignment and collaborative partnership between the cancer survivor and nurse counsellor is further evidenced by the verbal and embodied conduct used by the cancer survivor throughout the fragment. Specifically, in Fragment 1, the cancer survivor's use of verbal (i.e., yep, yeah) and physical (i.e., head movements or 'nods') response tokens throughout the nurse counsellor's introductory sequence implies they are an attentive recipient of the nurse counsellor's talk, and subsequently possess an understanding on the focus of the session (Kidwell, 1997). Gardner (2001) describes response tokens as actions and utterances that provide feedback to the speaker on the listener's engagement with, and understanding of the conversation (Gardner, 2001). For example, the cancer survivor's head nod and verbal response on line 16 to the nurse counsellor's previous yes/no question (“*is it okay if I start with some questions?*”) confirms the cancer survivor is happy start the consultation with questions. Similarly, the cancer survivor's short, repeated nods while the nurse counsellor is speaking on

lines 10, 13, 23, and 23, (in addition to his use of continuers such as 'yep' on line 23) indicate that he claims to understand what the nurse counsellor is saying. In this fragment, the cancer survivor's verbal and embodied conduct along with the nurse counsellors' utterances (e.g., line 34) claim alignment about the focus for the ensuing session; fatigue and fatigue self-management. As the next fragment shows, although the detail of the opening sequences of the consultation may differ, what is common is that fatigue SMS is presented as the agenda from the outset of the session.

**Fragment 2 [NC2CS2/ 0:15]**

In contrast to Fragment 1, which was conducted via videoconferencing, Fragment 2 provides an instance of establishing a focus on fatigue from the outset of a consultation conducted only via the audio channel of the Microsoft Teams videoconferencing software, demonstrating that alignment can also be produced without relying on embodied conduct. Directly prior to the beginning of this fragment, the nurse counsellor has introduced her name and role, and has asked the cancer survivor if she consents to being recorded.

01 NUR: Um hh (.) so what we'll do today is:s (.) we'll talk a little bit about  
 02 how your fatigue is (.) impacting you? Um and the ways [in which]=  
 03 CLI: [ mm hmm ]  
 04 NUR: =its impacting you, and then at the end of the session we'll come up  
 05 with some hhh (.) uh:m some goals (0.2) of how to [minimise]=  
 06 CLI: [ okay ]  
 07 NUR: =that fatigue or start working towards uhhh (1.0) you know improving  
 08 that fatigue hhhh so Maryan-  
 09 CLI: Yep

As with Fragment 1, after introducing herself (data not shown), the nurse counsellor provides a proposed arrangement that incorporates the agenda ("*so what we'll do today, we'll talk a little bit about how your fatigue is impacting you*", lines 1-2... "*we'll come up with some goals of how to minimise that fatigue...*" lines 4-7). By setting the agenda from the outset, the nurse counsellor establishes the joint role of the cancer survivor and herself in a collaborative partnership to develop a plan to help manage the cancer survivor's CRF. Like Fragment 1, the shared understanding of the focus of the consultation can be indicated through the cancer survivor's use of response tokens such as "mmhm" (line 3), "okay" (line 6), and "yep" (line 9) throughout this opening sequence. These tokens display the cancer survivor's attentive participation (Gardner, 2001) and claim alignment about the focus for the ensuing session. Fragments 1 and 2 are examples of interactional practices that were recurrently observed in the analysed data, and are examples of fatigue and fatigue self-management being presented from the outset of a consultation (usually directly after introducing name and role), facilitating displays of alignment between the cancer survivor and nurse counsellor about the focus of the consultation.

The way in which a therapy session is initiated is crucial for maintaining a collaborative partnership between clinicians and cancer survivors and ensuring a productive therapeutic session (DiMatteo, 1998; Ekberg et al., 2016; Ha & Longnecker, 2010). The analysis identified that consultations where the nurse counsellor did not establish a focus on fatigue self-management from the outset were liable to problems in understanding. An example of this is seen in Fragment 3 below.

***Fragment 3 [NC3CS3/ 0:00***

In contrast to Fragments 1 and 2, after stating her name (data not shown) the nurse counsellor does not immediately present the agenda of the consultation (i.e., which is to provide fatigue SMS through the joint creation of a fatigue management plan). Rather, she refers to the agenda vaguely, describing it as 'this process' on line 2 (*"thank you for being a part of this process I suppose"*), and begins the consultation by posing broad questions to the cancer survivor on lines 3 to 4 (*"How do you feel about it ?"; "Do you know what to expect?"; "What are your thoughts about it?"*).

01 NUR: Oh, I'm (0.7) >so pleased< to be able to get to talk to yo:u. U::m (0.6) Thank  
02 you for (0.5) agree:ing to be part of this um, this process? I suppose, Noah.  
03 Uh::mm hahhheh How do you feel about it? Do you know what to expe:ct or? What's-  
04 what are your th[oughts] about it [hh]  
05 CLI: [No:: ] [I ]have absolutely no- nn no- >nothing well  
06 I'mma bout< (.) to (.) find out.  
07 NUR: hahhheh Okay well, I think it's- the idea is that it's a bit of a joint thing  
08 between (0.3) the two of us.  
09 (0.7)  
10 NUR: uh:m [so:o]=  
11 CLI: [Yeah]  
12 NUR: =I I think we know that a lot of people (0.3) have a problem with fatigue? (0.5)  
13 when they've got a cancer diagnosis? an::d, I gather from the team (0.3) that (.)  
14 you've been experiencing a fair amount? Does that sound right?  
15 (1.5)  
16 CLI: A fair amount of?  
17 NUR: FATIGUE.  
18 (1.0)  
19 CLI: Oh yes, ye:ah.  
20 NUR: Yeah?  
21 (3.0)  
22 CLI: Yeah.  
23 (0.8)  
24 NUR: So:?  
25 CLI: Uh:m, (0.2) yeah probably tiyed, ya know those sorts of things?  
26 NUR: ↑Yea:h↑. And and if it's okay, what I might do, >just to get started< is (.) to  
27 ask you a couple of questions (0.3) about fatigue. [Bu- ]  
28 CLI: [Sure.]  
29 NUR: I also just want to check in and make su:re (0.5) I know um ((clears throat))  
30 what's been happening with you, and what's important to you, cos (0.2) the idea  
31 is m[aybe there-] >look at a bit of a< plan to (0.4) hopefully help=  
32 CLI: [ mmhmmm ]  
33 NUR: =support you, uh::m pt  
34 CLI: yeah.  
35 NUR: maybe (.) maybe get back into some of the >day to day< things? that you (0.4) you  
36 might miss doing? Does that sound all right?  
37 CLI: Yeah. Well, (mbfg) (0.2) um because of the chemo I'm on  
38 (0.7)  
39 NUR: mmmm?  
40 CLI: It- (0.2) it does restrict me going out.  
41 (2.0)  
42 NUR: Why is that (0.2) Noah.

The cancer survivor's reply on line 6 ("*nothing, well I'm about to find out*") in response to the nurse counsellors open-ended queries, indicates that he claims uncertainty about what to expect in the session, highlighting some of the expectations clinicians may need to manage at the outset of an SMS consultation.

Throughout the opening sequence presented in Fragment 3, the cancer survivor's verbal responses, vocal hesitations, pauses, and gaps at his projected turn at talk (i.e., lines 18, 21, and 23) within the conversation possibly indicate a lack of alignment as to the agenda and purpose of the consultation. For example, in response to the nurse counsellor's query on lines 12-17, the cancer survivor produces an extended pause (1 second at line 18) and thus delays his answer; he then answers with ("*Oh, yes yeah*", line 19). Work by Heritage (1998) suggests that the 'oh' that prefaces the cancer survivor's response can indicate that the questions being posed to him are problematic in terms of their pre-suppositions and relevance, and that there

is some lack of fit between the nurse counsellor's question and cancer survivor's answer. In other words, the cancer survivor claims a lack of clarity regarding the purpose and relevance of the questions being posed by the nurse counsellor, as well as the level of detail expected in his responses. Additionally, the absence of any explanation of the cancer survivor's experience of fatigue other than him merely confirming its presence ("Oh, yes yeah", line 19) appears to not align with the nurse counsellor's expected response, showcasing the 'lack of fit'. This misalignment is solidified by the nurse counsellor's additional prompts for further explanation from the client (line 20).

Difficulty in establishing a shared understanding of the consultation persists throughout the fragment. On line 19, the nurse counsellor prompts the cancer survivor for a further response when she says "yeah?" - switching the 'turn at talk' back to him. Again, the cancer survivor does not immediately respond to this prompt and a long gap in the conversation re-emerges (line 21). When the cancer survivor does respond, it is with a single emphasised word response ("Yeah", line 22) which in this context has been shown to imply insufficient agency and commitment to a course of action being assented to (Heritage & Raymond, 2012). Put simply, the cancer survivor is unaware of how to respond to the nurse counsellor's queries and is no longer dedicated to that line of questioning. Further, the cancer survivor's difficulty in providing a response that aligns with the nurse counsellor's need for a more detailed answer and preferred response type is influenced by problems in understanding (Heritage & Raymond, 2012; Pomerantz, 1975). The nurse counsellor again prompts the cancer survivor for a further response on line 24 ("So?"). The nurse counsellor's persistent pursuit displays an understanding that there is something insufficient about the client's response (Jefferson, 1981). Further, work by Raymond (2004) finds that a stand-alone "so" is a prompt often produced in environments of 'misalignment', when silences or other conduct from a recipient (in this case the cancer survivor) do not align with the response the speaker (in this case the nurse counsellor) expects should be- or could be produced (Raymond, 2004). Moreover, when the nurse counsellor produces a "so" prompt, she invites the cancer survivor to reassess his prior turn at talk ("yeah", line 22) and the action it accomplishes. The cancer survivor responds to this prompt with a drawn-out vocal hesitation ("Uhm") and briefly pauses on line 25, which also delays his eventual answer ("*probably, tired you know those sorts of things?*"). The use of the word "probably" at the beginning of the cancer survivor's answer indicates he is unsure if he is answering the nurse counsellor correctly (in a way that the nurse counsellor expects).

Conversational gaps convey meaning, with studies highlighting that repeated extended silences can be influenced by content, and speaker understanding. The pauses and vocal hesitations exhibited by the cancer survivor in this third fragment indicates he is having

difficulty producing an answer to, and thus dealing with, the nurse counsellor's queries and prompts. Pomerantz (1975) observes that features which delay the production of a response, such as vocal hesitations (e.g., umm, ah, I guess, probably), pauses, and gaps usually accompany a dis-preferred response (where the cancer survivor either does not understand the projection, or wishes to say something different to what the nurse counsellor is projecting (Pomerantz, 1975). The cancer survivor's difficulty may also stem from his struggle to respond relevantly to a question where the agenda has not been set. As demonstrated by Ekberg and colleagues (2016), when projecting the proposed arrangement from the outset of a consultation, therapists help clients to understand how they should contribute to the therapeutic process; as without adequate expectation management, cancer survivors have little structure to appreciate how they can contribute (Ekberg et al., 2016). Similarly, in this fragment it is evident that the cancer survivor does not have a clear understanding of his role in the consultation because he has not been given a framework to understand how he can contribute (e.g., what is the consultation about?, is his role to answer questions? what sort of information is he supposed to provide? what level of detail is required in his responses?). The client's clear confusion highlights the importance of clearly establishing the agenda of the consultation at the outset for fatigue self-management consultations. Further, this fragment is one of several instances in the data corpus that exhibit similar findings in establishing a focus on support for fatigue management. Each of these are similar insofar as they do not involve establishing the focus of the session from the outset of the consultation. In these cases, nurse counsellors often struggle to bring the ensuing conversation back to the fatigue management. This analysis has shown that managing expectations at the outset promotes shared understanding between cancer survivors and nurse counsellors and sustains a primary focus on the agenda of managing CRF. Once a primary focus for SMS has been established, a challenge for participants (i.e., nurse counsellor and cancer survivor) can be maintaining that focus. The next section examines one practice through which maintaining a focus on the agenda is accomplished.

### **Formulations**

The provision of SMS for CRF is a complex multi-component process that involves clinicians undertaking several support tasks (Agbejule et al., 2023) (e.g., identifying facilitators and barriers to fatigue management; providing information and coping strategies; providing motivational interviewing; establishing goals) along with navigating the physical and psychological risk factors and side effects of fatigue that may also arise during conversation. These multiple tasks must usually be completed within a set timeframe. Accordingly, to allow for timely completion of these therapeutic tasks, it is crucial to ensure that the fatigue SMS agenda – established from the outset of the consultation – is maintained throughout an entire

SMS session. This analysis found that using ‘*formulations*’ enabled nurse counsellors to maintain a focus on matters relevant for self-management fatigue planning and provided an opportunity to tie divergent conversation back to support for CRF.

Although conceptualisations vary, in simple terms, a formulation is where one speaker summarises talk up to that point (Antaki, 2008; Peckitt & Smart, 2018). It is commonly used in clinical psychology and aims to develop an understanding of a cancer survivor’s (or other service user’s) problems and perspectives (Johnstone & Dallos, 2014). There are generally two types of formulation; “gist”, which provides the sense of talk a up to a certain point, and “upshot” which provides an inference from prior talk (Heritage & Watson, 1980). Formulative techniques are commonly used in clinical scenarios as a method to direct a conversation into a clinician’s or therapist’s preferred direction of talk (Heritage & Watson, 1980). In the current context, formulations are a way to introduce change or new understanding for the cancer survivor. Fragments 4, and 5 pertain to the same nurse counsellor and cancer survivor consultation at different timepoints. This series of fragments show ways the nurse counsellor uses formulation practices to collect relevant information from the cancer survivor.

### **Using formulations to focus on matters relevant for fatigue self-management planning**

This section provides examples of how formulation practices were used to maintain focus on matters relevant for fatigue self-management planning.

#### ***Fragment 4 [NC1CS1/ 14:03]***

At this point in the consultation, the nurse counsellor is attempting to determine potential barriers or facilitators to the cancer survivor undertaking fatigue self-management activities (e.g., physical activity). This assessment of the cancer survivor’s self-management capacity will inform the creation of his fatigue self-management plan. Through her use of formulations, the nurse counsellor selects parts of the cancer survivor’s talk that are ostensibly relevant to her current agenda, and presents this to the cancer survivor in a way that it could be integrated into his fatigue management plan. Prior to the beginning of Fragment 4, the cancer survivor has disclosed that he perceives he is less fatigued around 11 o’clock at night. He expresses that he finds this frustrating as he is a musician, and he thinks he cannot play music at this time.

01 CLI: I'm a musician, (0.6) [you know I can't] play music at [eleven o'clock].  
02 NUR: [ Ah:h oka:ay ] [Yeah, yeah? ]  
03 NUR: okay, yeah yeah. what >sort of< um (0.2) musician, (.) what <instrume:nt>=  
04 CLI: oh-  
05 NUR: =or:r >instruments< or:r? he-  
06 CLI: There's- there's pretty much not an instrument I can't play.  
07 (0.4)  
08 NUR: Yeah oka[y, wow]  
09 CLI: [I've ] been doing this for years, [so- ]



10 NUR: [Yeah,] (.) yeah  
11 CLI: and I miss that.  
12 (0.5)  
13 NUR: Yeah  
14 CLI: Um:mm (0.3)  
15 NUR: Yep  
16 CLI: It's not so much because I don't have the energy?  
17 (0.3)  
18 NUR: mmm  
19 CLI: but because my hands have been damaged? [through the immunotherapy], and it makes  
20 NUR: [ mm:mhm mmhm ]  
21 CLI: it very hard↑ (1.0) to use my fingers and hands,=  
22 NUR: =[ mmmmm. ]  
23 CLI: =[I can't ] explain they're=  
24 NUR: mmm.  
25 (.)  
26 NUR: mmm.  
27 (0.9)  
28 CLI: =some-times almost unusable. [Like ] I can barely pick a cup.  
29 NUR: [↑Okay↑]  
30 NUR: Yeah, (.) okay, (.) yeah  
31 CLI: And so (.) that's pretty common.  
32 NUR: mmhm mm-  
33 CLI: ↑Temperature↑ (0.5) has a >hell of a lot< to do with everything.  
34 NUR: mmhm mmhm[mm]  
35 CLI: [If] I get cold, (2.0) and that can happen in minutes.  
36 NUR: ↓mmmm↓  
37 CLI: Um like if I were to go outside now, (1.0) and uh >in the wind<  
38 NUR: uh huh?  
39 CLI: ee- five minutes (0.2) and I would pay for it for about three- three-  
40 three or four hours.  
41 NUR: Okay. Yeah. Ye[ah. ]  
42 CLI: [(An' not-)] Temperature changes, (1.5) that's a big one. (0.3) Yeah  
43 NUR: Okay, so with temperature change, (.) what does that trigger? What tends  
44 to happen wh[en you] pay for i- for that-  
45 CLI: [pain ]  
46 NUR: So pain.  
47 (.) [okay, yeah]  
48 CLI: [pain, yeah]  
49 NUR: Yeah, yeah, okay, [yes ]  
50 CLI: [lots] of it [yeah]  
51 NUR: [yeah]  
52 NUR: Okay pain? So, you've really got to consider your environment [and whether]to when=  
53 CLI: [absolutely ]  
54 NUR: =to go [outside,] okay  
55 CLI: [Yes ]  
. ((20 seconds omitted, cancer survivor describes how spending 5 or 10 minutes  
. in an air-conditioned shop, can cause him four hours pain))  
58 NUR: So Ben, it's like you're doing a balancing act.  
59 CLI: Yeah=  
60 NUR: =You're weighing up, is it worth (.) while doing that=  
61 CLI: yep  
62 NUR: =or going out [because of the] ramifications.  
63 CLI: [that's exactly it]  
64 CLI: yeah  
65 NUR: and and that's really tough when [you're needing to do that].  
66 CLI: [( )]  
67 NUR: Yeah yeah, And I can hear you're motivated. You've got this real  
68 motivation to engage with life, with people.

On lines 19 to 28, the cancer survivor shares that he has been unable to play musical instruments because of difficulty using his fingers and hands. He then relays that this inability to use his hands is triggered by temperature changes when he goes outside (lines 37 to 42). After prompting from the nurse counsellor on lines 43 to 44 ("ok, with the temperature change,

*what does that trigger? What tends to happen when you...*) the cancer survivor states the underlying factor is that temperature changes cause him pain. On lines 52 to 54, the nurse counsellor produces an upshot formulation (*“So, you’ve really got to consider your environment and whether to- when to go outside”*). This formulation reframes and creates a version of the cancer survivor’s preceding talk on lines 21 to 50. In presenting the formulation to the cancer survivor, the nurse counsellor gives him the option to agree or disagree with this reframed summary. Work by Heritage and Watson shows that there is a preference for confirmation and acceptance of formulations, as disconfirmation might be seen to jeopardise “the sense of the talk thus far” (Heritage & Watson, 1979).

The formulation produced by the nurse counsellor is accepted by the cancer survivor on line 55 (“Yes”). Notably, in her formulation, the nurse counsellor does not use any of the cancer survivor’s exact words, but rather selects the components of his talk that ostensibly align with her SMS agenda (to determine potential barriers to the cancer survivor undertaking fatigue self-management activities and use this information to inform his fatigue management plan—as indicated by the nurse counsellor’s consultation checklist). Evidently, the nurse counsellor’s use of the word “you’ve” shows that she is attempting to incorporate the cancer survivor’s experience into her formulation. This practice has been recurrently observed in clinical interactions (Antaki, 2008; Heritage & Watson, 1980), and enables the nurse counsellor to reformulate the design and terminology of the cancer survivor’s preceding talk to ostensibly suit her agenda and progress the consultation

Another example of formulation practices being used to focus on matters relevant for fatigue management planning occurs within Fragment 4. On lines 58 to 65, the nurse counsellor produces another formulation in response to the cancer survivor’s temperature-mediated pain (*“So Ben, it’s like you’re doing a balancing act. You’re weighing up, is it worthwhile doing that or going out because of the ramifications and that’s really tough when you’re needing to do that”*). Again, the nurse counsellor uses this formulation to reframe the cancer survivor’s symptoms into a shape suitable for creating his fatigue self-management plan (Antaki, 2008). Further, as with the previous instance, the cancer survivor agrees with the nurse counsellor’s formulation on lines 61 to 63 (*“yep, that’s exactly it”*). This is consistent with evidence that shows formulations generally project agreement, which the speaker must either actively provide (as seen on lines 49 and 53-55) or combat in the next turn (Heritage and Watson, 1979; Antaki, 2008).

## Using formulations to close down matters not relevant for fatigue self-management planning

The previous section showed how nurse counsellors used formulations to sustain talk that is ostensibly relevant in co-creating the cancer survivor's fatigue self-management plan. When providing specific symptom support (such as support for CRF), there are situations where a clinician may need to refocus conversations to maintain focus on the primary agenda of fatigue support. This section demonstrates how formulations can be used to momentarily redirect talk that is not ostensibly relevant (at least, not at the moment) in the creation of the fatigue management plan; and subsequently progress the conversation in direction that aligns with the agenda of providing SMS for fatigue.

### **Fragment 5 [NC1CS1/ 19:55]**

Like Fragment 4, at this point in the session the nurse counsellor is attempting to determine potential barriers or facilitators to the cancer survivor undertaking fatigue self-management activities, to inform the creation of goals for his fatigue self-management plan. Prior to the beginning of this fragment, the cancer survivor has relayed to the nurse that "it doesn't matter whether it has been a good day or a bad day, I must complete something" (data not shown). The cancer survivor explains that he writes lists for himself that consist of tasks that he must complete each day. He describes that these daily lists used to be "big" but he "found that would just make [him] depressed" as he couldn't complete everything. Directly prior to the beginning of Fragment 5, the cancer survivor has recounted that something as simple as cleaning his fish tank which is 15 min work, is difficult for him and no matter how hard he tries he just cannot do it.

01 CLI: I just can't do it, I can't.  
02 NUR: And I wonder if, (0.3) let's say for instance, myself or someone who's close  
03 to you was to see that list and see what you've achieved, that we would notice  
04 that uhh (0.2) you know, given (.) what you're going through, what you've  
05 experienced and the impact of all of this, that (.) that was actually really  
06 significant what you achieved in your day.  
07 CLI: Yea:h  
08 NUR: But I can hear what you're saying=  
09 CLI: Yeah  
10 NUR: =at the same time it's it's at times. It can be: (0.5), I guess, confronting  
11 for you (.) or: uh=  
12 CLI: It can be yeah  
13 NUR: =or disappointing or-  
14 . ((18 seconds omitted. The cancer survivor mentions that the 'simple' tasks he tries  
15 . to undertake are no longer "getting done". This causes him to feel that he didn't  
16 . contribute or achieve anything.))  
17 CLI: it's sort of like each day is worth nothing.  
18 NUR: mmhmm  
19 CLI: I didn't achieve anything. I didn't (1.0) I dunno I guess I didn't  
20 contribute.  
21 NUR: mmm mmm  
22 CLI: I dunno (1.0) um  
23 NUR: mmm whereas- whereas, at the same time, I can uh really hear that those lists  
24 have been really helpful=  
25 CLI: oh yeah  
26 NUR: =because they give you a goal. And sometimes small achievable=

27 CLI: Yeah  
28 NUR: =tasks and goals are most helpful.  
29 CLI: Yep

On lines 8 to 13 the nurse counsellor begins a formulation, and in doing so reframes the cancer survivor's description of his frustration (*"I just cant do it, I cant."*, line 1) into *"But I can hear what you're saying at the same time, I guess it can be confronting for you or disappointing"*. In this instance the nurse counsellor uses her formulation to acknowledge the cancer survivor's distress and redefine a topic of concern to both parties – that the client is frustrated at not being able to complete daily tasks and that this is confronting for him. As with the previous fragment, the nurse counsellor's use of the phrases 'you're saying' and 'confronting for you' demonstrates attentiveness to the cancer survivor's talk and incorporates his experience into her formulation. The cancer survivor subsequently accepts this formulation on line 12 (*"it can be yeah"*); however, he continues to voice frustration at not being able to undertake what he considers to be simple tasks (e.g., *"it's sort of like each day is worth nothing... I didn't achieve anything... I didn't contribute" ... "sometimes I'll look at what I achieved and just think it's so pathetic"*, line 17, lines 19-20). Instead of immediately launching into an inquiry of the cancer survivor's comments, the nurse counsellor continues the formulation she began on line 8, and focuses on the identified facilitator (*"whereas, at the same time, I can really hear that those lists have been really helpful, ... because they give you a goal. And sometimes small achievable tasks are most helpful"*, lines 23-24; lines 26-28). The cancer survivor's account of his apprehensions is valuable to the nurse counsellor as it provides insight into how the fatigue is impacting his quality of life (Berger, 2019). As the nurse counsellor has already acknowledged and noted the cancer survivor's apprehensions in her formulation on lines 8 to 13, she uses the remainder of her formulation to momentarily close that direction of talk as spending extra time discerning it (during this history taking stage), is not ostensibly useful to the creation of the fatigue management plan. Notably, the cancer survivor agrees with the nurse counsellor's formulation (on lines 25, 27, 29) and does not continue with his talk about his perceived inability to cope, which subsequently allows the conversation to progress in a different direction towards the intended goal of the consultation and allows the nurse counsellor to continue providing support for CRF.

This 'conversation management' (i.e., the technique of effectively managing the flow and direction of communication) was particularly useful for nurse counsellor's to obtain a comprehensive view of the cancer survivor's fatigue first (i.e., determining his fatigue severity; fatigue interference on daily living; risk factors for fatigue occurrence; presenting characteristics; self-management capabilities; etc.) and then still have the time to collaboratively provide solutions to matters raised. Moreover, when conducting her

formulation, the nurse counsellor does not completely dismiss the cancer survivor's concerns but addresses his apprehensions at later stages in the consultation. For instance, later in the session she offers counselling support, refers the cancer survivor to external psychological services, and also considers his frustrations when creating goals for his fatigue management plan. Antaki (2008) describes this practice as '*formulating the trouble away*' and suggested that its purpose was to keep a client's descriptions 'non-therapizable' until the assessment stage of a session was complete. Similarly, in this instance the nurse counsellor is using her formulations to control the flow and progress of the consultation by redirecting certain avenues of talk, and choosing the parts of the cancer survivors talk that ostensibly aligns with her agenda of providing fatigue SMS (e.g., setting small realistic goals gives the cancer survivor a sense of achievement); while seemingly being attentive to something in the cancer survivor's own words ("*I always look to make sure to put a line through at least one [list item], And that way I feel like I've done something*" [data not shown]). Analysis of the entire data corpus found that in consultations where this 'conversation management' did not occur, it appeared nurse counsellors often became overwhelmed with cancer survivor recounts (e.g., extended personal accounts about family life and upcoming holidays; prolonged treatment-related talk about chemotherapy and/or opinions on other past their medical teams etc.), which left insufficient time for the provision of supportive management strategies and action planning. This fragment demonstrates how the nurse counsellor used formulation practices to maintain focus on fatigue support provision, allowing her the time to acknowledge the other themes or activities that arise in the consultation in a more productive way.

## **Discussion**

This research responds to the need for evidence-based explanations of how SMS practices for CRF can be, or have been integrated and delivered in clinical care at the interactional level. This study is the first attempt to identify, in detail, the communicative practices used by nurse counsellors and cancer survivors during real-life SMS sessions for CRF. Overall, this study presents two observable practices nurse counsellors use in their work with cancer survivors to provide SMS for CRF: (1) introducing the agenda at the outset of the consultation, and (2) formulations (see Figure 13).

SMS encounters in cancer care are particularly complex as the organisation of supportive care visits and tasks are generally unfamiliar to cancer survivors, meaning they must navigate the challenges of understanding what a clinician is doing and what is expected of them (i.e., what to say and when) (Sterponi et al., 2019). In their recent realist review on factors influencing clinician engagement in SMS, Kantilal and colleagues (2022) identified that in order for productive SMS to occur, clinicians and patients must be clear about their respective roles in

self-management and create a sense of shared responsibility. The findings of this conversation analysis study offer a potential resolution to this complexity by identifying that in instances where clinicians focus discussion on fatigue SMS through clearly introducing the agenda of the consultation at the outset, cancer survivors have a clear understanding of their role, and the tasks and goals of a session. Further, the analysis indicated that managing expectations in this manner produced shared alignment, consequently strengthening the clinician-cancer survivor collaborative partnership. Studies have shown that lack of explanation or poor management of expectations can hinder patient understanding of treatment; and can result in a lack of consensus between clinicians and cancer survivors, as well as therapeutic failure (Ardito & Rabellino, 2011; DiMatteo, 1998; Ha & Longnecker, 2010). Fitzpatrick and colleagues (2006) provide further insight into the mechanisms of a collaborative partnership in their own qualitative study where they identify that establishing shared understanding of therapeutic tasks and goals in the early stages of support provision, produces an upward spiral which launches cancer survivors into an exploratory process that supports more productive therapeutic work (Fitzpatrick et al., 2006). This is consistent with qualitative findings which indicated that cancer survivors often withhold information (i.e., reporting of CRF severity and CRF impact on daily living) from their health care teams if they feel they are rushed or if they perceive there is little time to discuss CRF with their treating clinician (Jones et al., 2021).

Sterponi and colleagues suggest several other significant complexities of self-management encounters in cancer care; 1) much of the supportive care tasks conducted during a consultation depends on information that the clinician acquires from the cancer survivor during the course of the session, and as such support tasks are unpredictable; 2) the extent of attention to be devoted to each support task cannot be fully determined in advance but requires clinicians to exercise ongoing judgement; and 3) the timeframe of supportive care encounters are generally limited (Sterponi et al., 2019). Qualitative research on CRF support provision has demonstrated that clinicians often attempt to bypass these challenges by not responding at all to patient inquires or accounts they consider irrelevant in an attempt to provide quick support, and may even avoiding initiating CRF support discussions with their patients altogether (Bootsma et al., 2020; Borneman et al., 2011; Jones et al., 2021; Jones et al., 2020). This contributes to cancer survivors feeling misunderstood and discouraged to discuss CRF with their healthcare teams, and has been shown to contribute to the breakdown of the patient-provider partnership that is essential to successfully manage CRF (Bootsma et al., 2020; Jones et al., 2021). This conversation analysis study makes a significant contribution in addressing the above challenges, by identifying that employing formulation practices allows clinicians to: select ostensibly useful parts of a cancer survivor's accounts as they occur and

reframe them into a shape suitable for supportive tasks whilst remaining attentive; maintain a focus on matters relevant for support tasks and self-management fatigue planning; tie divergent conversation back to support for CRF; and subsequently provide support within limited time frames. During the provision of symptom support, there may be several instances where clinicians need to redirect and refocus conversations to ensure productive and timely supportive care is provided; formulations act to facilitate this process in a less abrupt manner compared the other reported methods above. As suggested by Antaki (2008), closing, or redirecting conversation using formulation techniques “promotes the sense that one has listened to the other speaker and has extracted something that they themselves might have said” and allows clinicians to maintain respectful and attentive communication.

## **Limitations and Strengths**

This study analysed interactions between cancer survivors and specialist nurses who have received training in supportive care counselling procedures. Notably, not all health professionals are readily trained in this practice. As such, a limitation of this work is that it did not observe the extent to which clinicians who are not specialist trained can operationalise these practices (i.e., introducing the agenda at the outset, producing formulations) successfully. Despite this, these findings have significant implications for research and training. For example, while beginning clinical interactions with open-ended question formats can sometimes be valuable to solicit a patient’s chief complaint (e.g., in a primary care consultation) (Robinson et al., 2016), the analysis indicated that in situations that are task-focused and that have a specific agenda – such as in SMS consultation – opening with broad questions can be problematic as these question types can communicate different things; and thus can be understood, and responded to, differently (Robinson, 2006). This is also supported by findings from Jones and colleagues’ recent qualitative study in which cancer survivors reported that being asked general, open-ended questions was insufficient when discussing CRF with their healthcare teams (Jones et al., 2021). Several studies have indicated that fostering communication and consultation skills can improve clinician confidence in engaging cancer survivors in support discussions about symptom self-management (Kantilal et al., 2022). This conversation analytic study is an initial step in identifying the required training to facilitate this process.

## **Conclusions**

A breakdown of clinician-provider partnerships (i.e., not identifying shared responsibility) has been identified as a significant barrier to the translation of CRF management strategies to clinical practice and contributes to the underreporting and under-management of CRF (Jones et al., 2021; Kantilal et al., 2022), (as cancer survivors are discouraged to report their fatigue

to their health teams). During supportive care sessions, where fatigue management is being targeted, clinicians should focus discussion on fatigue SMS early, by clearly introducing the agenda from the outset of the consultation and asking for client agreement. Continually formulating or summarising patient's talk allows clinicians to maintain a focus on matters relevant for self-management fatigue planning; tie divergent conversation back to support for CRF; and subsequently provide support within limited time frames.



## **6.0 DISCUSSION AND CONCLUSIONS**

### **Chapter Introduction**

This doctoral thesis has explored the efficacy of support programs for CRF management, and identified the components of effective SMS interventions (Study 1); developed a best practice clinical framework that outlined the essential support practices needed for health professionals to successfully support cancer survivors with their fatigue (Study 2); and analysed how SMS can be delivered in clinical practice at an interactional level (Study 3). The doctoral thesis contributes to understanding and enhancing self-management behaviours, CRF, and SMS. The doctoral thesis also addresses several national health and research priorities (e.g., the establishment of SMS CRF best practices, investigation of SMS communication practices and techniques and consultation skills) and has the potential to impact the education and training of the health workforce, improve the adoption of fatigue management behaviours by cancer survivors, and ultimately reduce CRF severity and improve cancer survivor quality of life. This final chapter synthesises the key research findings from the three studies that comprise this doctoral thesis. This chapter also outlines the significance and contributions of this program of research, possible directions for future research, and overall conclusions that can be made from the doctoral thesis.

### **Overview, Key Research Findings, and Implications**

#### **Establishment of CRF SMS Best Practices**

Cancer survivor self-management is focal in the management of CRF; thus, the importance of empowering survivors to self-manage through SMS cannot be overstated. The literature review presented in Chapter 1 emphasised that evidence-based fatigue management strategies are rarely implemented in practice, with CRF remaining undertreated and underreported. Additionally, cancer survivors routinely report they feel discouraged by their health care teams and that they receive inadequate management support. Health professionals report they do not have confidence in providing fatigue SMS to cancer survivors and have called for clear guidance in this area (Hilarius, 2011). Unfortunately, little work had been done to understand the components of SMS for CRF. Inconsistencies in self-management conceptualisations and terminologies, along with limited identification of CRF SMS strategies hinder the synthesis, advancement, uptake, and translation of CRF self-management strategies to practice. The systematic review (Study 1) presented in Chapter 3, is the first published study to identify potentially optimal SMS intervention features and components that are associated with improved CRF and behavioural outcomes. This original contribution to knowledge is unique in that it presented a definitive concept of comprehensive SMS for fatigue and examined the impact of SMS practices on the adoption of fatigue self-management behaviours, as well as CRF severity – an important factor that is often

overlooked. The examination of behavioural outcomes in Study 1 was particularly important because SMS interventions for CRF target cancer survivor behaviour change and support the reduction of fatigue severity through behavioural mechanisms.

Study 1 identified several factors that potentially influence the effectiveness of a fatigue SMS program. Most notably, the review found that studies in which SMS was delivered after cancer treatment, in one-on-one formats, facilitated by health professionals, while incorporating at least one in-person (i.e., face-to-face) contact most frequently reported positive effects on CRF and behavioural outcomes. Additionally, studies which reported the provision of additional training to intervention facilitators most frequently reported positive intervention effects for both CRF and associated fatigue management behavioural outcomes (including self-efficacy to undertake fatigue self-management behaviours). Findings from Study 1 highlighted that guidance and prioritisation of SMS clinical strategies are needed to (1) ensure health professionals have the required CRF SMS capabilities; and (2) to enable the sustained translation of CRF management strategies into practice – a finding that is consistent with key action areas emphasised in national research and health priorities.

The Australian Government identified education and training of SMS as a national health priority, and emphasised the importance of equipping the health workforce with support capabilities. Key national action areas include embedding self-management as core learning, developing health professional roles and practices to better support self-management, and implementing evaluation mechanisms to assess SMS across health services (Australian Health Ministers' Advisory Council, 2017; Nichols et al., 2020). Additionally, the Clinical Oncology Society of Australia (COSA) recently identified the top research priorities for cancer survivorship in Australia. Their report clearly outlined intervention development for CRF among the top three physiological outcome priorities; and the development, implementation, and dissemination of self-management as top health service priority (Crawford-Williams et al., 2022).

The CRF SMS Practice Framework presented in Chapter 4 (Study 2: Modified Delphi Study) makes a significant contribution to the progress of the priorities and key action areas described above. The modified Delphi study was the first published research to develop and clearly define the core practices needed for health professionals to deliver SMS to cancer survivors experiencing CRF; a widely acknowledged critical action point that has not been addressed until now (Australian Health Ministers' Advisory Council, 2017; Howell et al., 2017; Nichols et al., 2020; Rimmer, Sharp, & on behalf of Ways Ahead study team, 2021). Rimmer and colleagues (2021) recently emphasised the importance of defining the core components of SMS programs to ensure the mechanisms of the support are understood and that

implementation is replicable (Rimmer, Sharp, & on behalf of Ways Ahead study team, 2021). Notably, the CRF SMS Practice Framework not only presents key components, it also considers the complex nature of CRF SMS, by conceptualising support as an active process that requires an essential set of collaborative-and partnership building strategies, knowledge, and practices. As mentioned by some panel members in the modified Delphi study, the identification of best practices promotes consistent and evidenced-based approaches to CRF care, as clinicians can use the practice framework as a reference tool for support strategies, recommendations, and information, which can promote continuous learning – another one of the key priority areas highlighted above. Further, the establishment of key practices can streamline the implementation process (Agbejule et al., 2021) and promote best practice, as clinicians who are knowledgeable of support practices are more likely to conduct support conversations with their patients (Kantilal et al., 2022). Additionally, the practice framework has functionality for several different users across a variety of settings, including health professionals, program evaluators; clinical leaders and educators; cancer consumers; clinical researchers; and intervention developers (see Table 7).

### **Exploration of how SMS Practice Could Be Delivered in Clinical Care**

Although a best practice framework is useful, it is also equally important to explore the implementation of a framework in the real-world. This doctoral thesis therefore incorporates research designed to understand how SMS for CRF was accomplished by health professionals in clinical practice and potentially provide insight into where to direct efforts to ensure clinical practice meets best practice recommendations. In the modified Delphi study presented in Chapter 4, some clinician panel participants expressed hesitancy around the feasibility of delivering the established best practice support items in clinical settings. Clinicians questioned how support discussions (e.g., identifying barriers and facilitators to client self-management, providing coping strategies, goal setting, etc.), and creation of goals would occur in real-life clinical practice. Chapter 5 presented a conversation analysis study (Study 3) that provided insight into how SMS CRF practices have been executed in clinical care in a specific local setting (T-CRF SMS Clinic) and provided an opportunity to examine communication practices of SMS in more detail and highlight communication techniques – another national health policy action area. The literature review in Chapter 1 and the Flinders SMS Capability Framework introduced in Chapter 2, highlighted how successful adoption of self-management CRF behaviours by cancer survivors (e.g., dietary changes, increased physical activity, etc.) is greatly dependant on the quality of clinician-survivor interaction and the effective provision of efficacious SMS strategies. Australian policymakers have emphasised the importance of equipping the health workforce with effective communication techniques to support patient self-management. Policy and research priorities stipulate the

need for further investigation and clarification of how communication could be optimised when providing support to cancer survivors (Australian Health Ministers' Advisory Council, 2017; Crawford-Williams et al., 2022). Kantilal and colleagues' recent review emphasised this when they highlighted that the communication, mutual trust, and shared responsibility between clinicians and patients, as well as the presence of sound clinician consultation skills, are key factors influencing whether health professionals engage in SMS tasks and conversations with their patients (Kantilal et al., 2022). The conversation analysis study (Study 3) presented in Chapter 5, generated direct observational evidence for understanding the communication practices used by cancer nurse counsellors when providing SMS to cancer survivors experiencing CRF, and is the first study to examine the impact of these practices within consultations. Findings from Study 3 demonstrated that in instances where clinicians focus discussion on fatigue SMS through clearly introducing the agenda of the consultation at the outset, cancer survivors have a clear understanding of their role, and the tasks and goals of a session. Additionally, study findings suggest that using formulation practices could allow clinicians to maintain a focus on fatigue during consultations and potentially provide support for fatigue in limited time frames. The conversation analytic study contributes to a limited evidence base by providing much needed insight into the communicative practices of clinicians providing SMS for CRF which can support recommendations for future training and practice; contribute to identifying effective strategies for discussing CRF and successfully initiating and maintaining supportive discussions; and support efforts to improve outcomes for cancer survivors.

## **Limitations**

Limitations of each study (Studies 1 – 3) have been presented in their respective chapters. This limitations section presents overarching limitations of the doctoral thesis.

### **Exclusion of Concurrent Symptoms and Psychological Outcomes**

The absence of reporting psychological outcomes in addition to CRF and behavioural outcomes in Study 1, is a potential limitation of this doctoral thesis. It is well reported that symptoms often do not occur alone, and can present as symptom clusters. Psychological outcomes such as depression and anxiety are known to contribute to and potentially exacerbate CRF and impede self-management, forming a complex interplay between these factors. This doctoral thesis took an *a priori* decision to focus on CRF as an unresolved, complex, debilitating symptom experienced by cancer survivors. For future research, including data on concurrent symptoms including psychological outcomes alongside the measured outcomes would have been beneficial. The inclusion of measures could have provided valuable insights into the understanding of CRF SMS. Future studies should consider

incorporating comprehensive assessments of psychological outcomes to capture the multifaceted nature of CRF and its potential comorbidities, thereby enhancing the overall understanding of the condition and its management.

### **Specialised Settings**

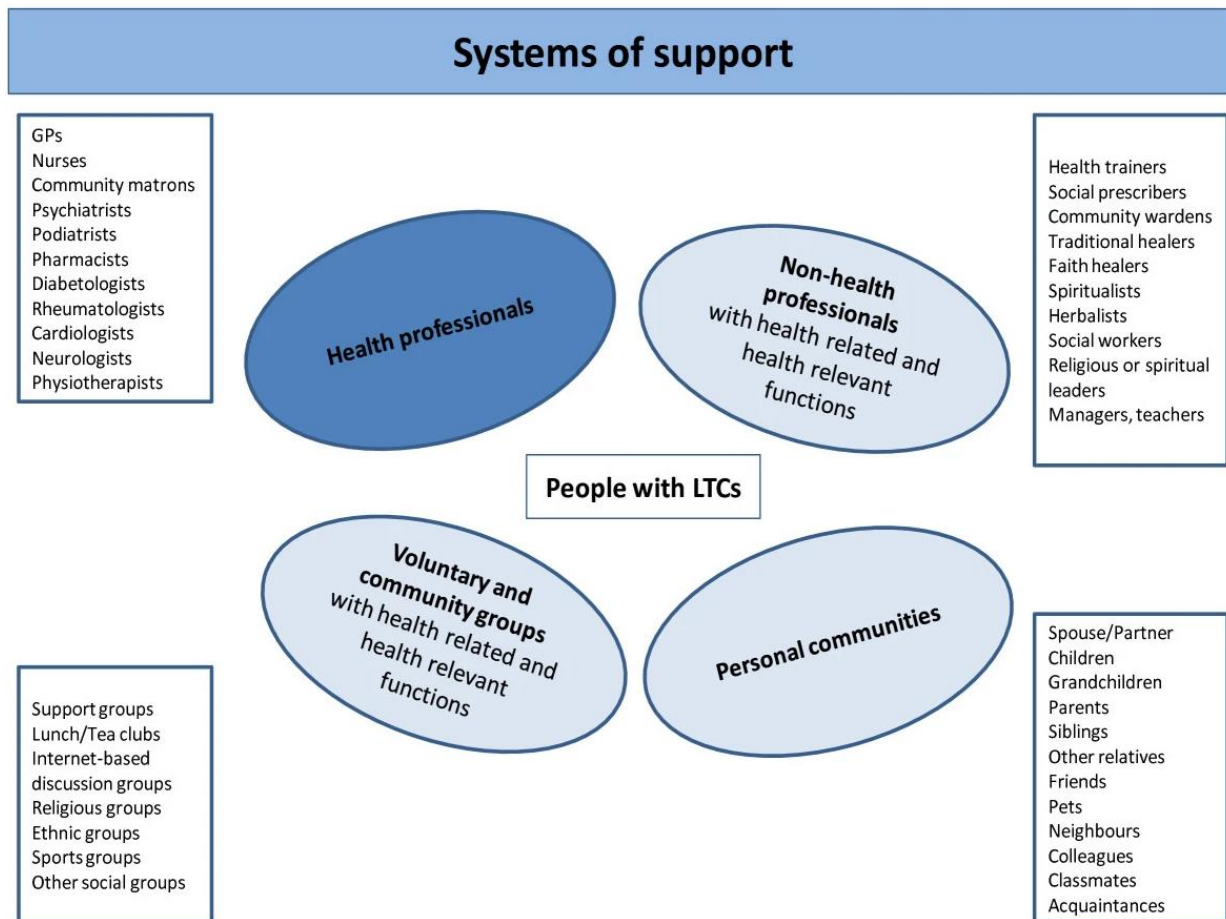
The high international representation within the panel of the modified Delphi study may pose a potential risk to the specificity and contextual relevance of the CRF SMS Practice Framework within the Australian setting. While the broad global applicability of the study findings is valuable, it may result in a trade-off with the depth of impact on the local context. Another limitation was that Study 3 assessed CRF SMS in a specific CRF-focused setting by nurse counsellors with extensive experience in counselling. It is worth reflecting on the suitability of the framework to other settings such as busy routine care environments like primary care or hospital settings that are non-specialist fatigue clinics. The effectiveness and feasibility of implementing the framework in these diverse contexts may present challenges and require further investigation. Factors such as resource availability, staff expertise, and workflow dynamics could significantly impact the practicality and outcomes of implementing the framework outside the specialised CRF clinic. Thus, it is crucial to acknowledge that the generalisability and adaptability of the framework to different clinical settings might be limited, warranting additional research to evaluate its feasibility and efficacy in these non-specialist environments.

### **Focus on the Health Professional System of Support**

The exclusive focus on only health professional SMS could be considered an overarching limitation of this doctoral thesis. So far, this research has emphasised the importance of the clinician-survivor relationship in improving the ability of cancer survivors to adapt health behaviours and manage their CRF. Both the FCF and the CCM introduced in Chapter 2, assert that improved health outcomes are dependent on productive interactions between patients and their health care team, and perceived self-efficacy is highlighted as a significant factor underpinning the effectiveness of CRF self-management behaviours, as well as several self-management theories and models (Chan et al., 2016; Foster & Fenlon, 2011; Girgis, 2020; Hoffman et al., 2009; Lawn & Battersby, 2009; Wagner et al., 1996). Although, these understandings of self-management have strong theoretical basis and empirical support, they do not take into consideration systems of support beyond survivor and health professional interactions (Mills et al., 2017; Vassilev et al., 2010). In fact, a frequent criticism is that current understandings of SMS are often constructed from the health provider point of view, and are driven by biomedical outcomes (e.g., the adoption of healthy behaviours – exercise) that are often thought to be as a result of an individual's motivation or self-efficacy (Rogers et al.,

2011). Further, in traditional theories, factors such as the contexts, resources, practices, priorities, and networks of cancer survivors (which are impacted by wider determinants of health) are often not acknowledged (Koetsenruijter et al., 2014; Vassilev et al., 2010). The exploration of such factors are important, as they provide a comprehensive insight into how self-management is actually completed by individuals in the context of their everyday lives, and allows for SMS strategies and interventions to be better targeted for sustained individual completion (Vassilev et al., 2010).

There is increased recognition of the need to move beyond the sole focus on health professionals, and consider the social systems of support of individuals (also referred to a 'communities of practice' and 'systems of support') - in the self-management of long-term conditions (Koetsenruijter et al., 2014; Mills et al., 2017; Rogers et al., 2011; Thoits, 2011; Vassilev et al., 2010). Moreover, evidence has shown that SMS programs which actively engage patients in social relationships, in particular personal (e.g., family, friends) and community (e.g. social support groups) systems of support, and address the context in which a patient's life and illness are enacted, are well received and lead to sustained change in the management of chronic conditions (Kendall et al., 2012). Further, as most survivor self-management occurs outside of clinical health care settings, social systems of support outside of the health professional (see Figure 13) are integral and cannot be ignored (Rogers et al., 2011). The current doctoral thesis provides important understanding of aspects of how chronic conditions are managed but cannot provide comprehensive understanding of such a complex phenomenon.



**Figure 13:** Systems of Support (Rogers et al., 2011)

## Future Directions

### Research for Contextual Evidence

Several avenues for future research have been identified from this doctoral thesis. One of the key points for future work is the need to contextualise the CRF SMS Practice Framework to allow for successful implementation into routine care. Puddy and Wilkins' present a model that offers a way of conceptualising evidence in three overlapping components, the best available research evidence; experiential evidence; and contextual evidence (Puddy & Wilkins, 2011). These components are defined as follows:

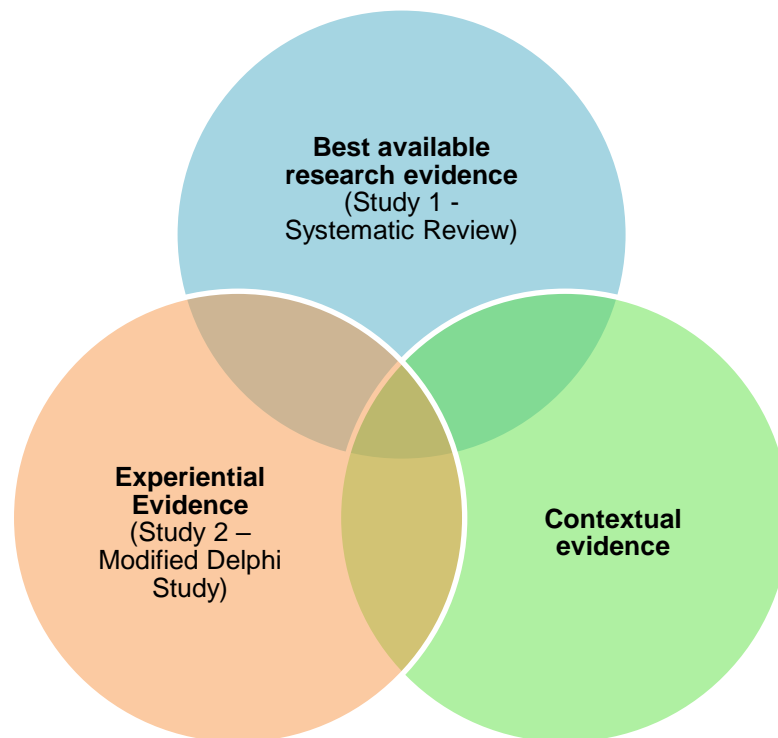
- **Best available research evidence** is based on empirical studies or research reviews in which data has been collected, analysed, and documented (*e.g., systematic review and synthesis of RCTs on the effectiveness of support programs for CRF*).
- **Experiential evidence** is based on an expert's long-term engagement in a field, offering insights into what has worked, what seems to work, and other knowledge and expertise that can sometimes be understood, without being stated (*e.g., consultation*).

*with cancer consumers; health professionals who have experience in cancer care; fatigue researchers and supportive cancer researchers, via modified Delphi study).*

- **Contextual evidence** is based on information about whether a strategy or practice is perceived as useful, relevant, feasible to implement and is acceptable to specific groups.

This doctoral thesis incorporates these tenets of evidence to inform the practice framework (see Figure 14). Although the development of the practice framework integrated feedback on usability from panel participants of the modified Delphi study (Study 2), and the conversation analysis study (Study 3) examined the local context of CRF SMS communication practices in a specific clinical care setting, additional contextual evidence is needed to investigate and support implementation of the practice framework in routine care. As briefly mentioned in Chapter 4, the CRF SMS Practice Framework could be significantly enhanced through additional consultation with key stakeholders. Moreover, contextual evidence could be further honed by conducting primary research evaluations that provide insight on feasibility (i.e., ability to use the practice framework to undertake to SMS tasks given the resources available and the economic, social, geographic, and historical aspects of the current setting); acceptability (i.e., ability for the practice framework to be accepted by the people and decision makers in the current setting); and utility (i.e., whether or not the practice framework is useful or appropriate for the needs of the people in the current setting) (Puddy & Wilkins, 2011).

### **Social Systems of Support**



**Figure 14:** Conceptualising Evidence



SMS for cancer survivors is a multi-level process that involves several essential support systems. A core finding from Study 1 was the need to structure SMS advice and fatigue self-management activities in the context of everyday life. The systematic review conducted for Study 1 found that studies which reported this essential component (i.e., *structuring self-management interventions to align with survivors' 'everyday life'*) most frequently reported reduced participant fatigue and sustained uptake of fatigue management behaviours (Agbejule et al., 2022). This concept was incorporated into the CRF SMS Practice Framework and received positive comments particularly from consumer participants of the modified Delphi study (Appendix 8). Consumer participants reiterated the importance of their personal network as well as other peer support in their perceived confidence to self-manage their CRF. In fact, studies show that a cancer survivor's first response to experiencing CRF is usually communicating their support needs with their personal network (Bootsma et al., 2021). Future qualitative research could examine in more detail the needs, preferences, and views of cancer survivors concerning the support of their CRF, to determine an optimal model of care. Further, future research could explore how voluntary and community groups, non-health professionals, and personal communities are currently involved in CRF management support; could best be recognised, supported, or formally incorporated in support provision; and potentially whether or how these groups could utilize the practice framework to provide supportive care for CRF. By understanding and defining the role of these support networks, SMS for those experiencing CRF can be refined to ensure that cancer survivors truly receive comprehensive support.

## **Conclusions**

The World Health Organization (World Health Organization, 2003) asserts that increasing the effectiveness of clinician SMS will have far greater impact on the health of a population than any improvement in special medical treatments. Enabling health professionals to provide effective SMS for CRF – a symptom that is routinely reported as being unaddressed and unmet – is crucial. This doctoral thesis moves beyond the investigation of intervention effectiveness to the identification, dissemination, and implementation of evidence based CRF self-management strategies into clinical care through the establishment of effective SMS practices.

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# APPENDICES

## Appendix 1: A Systematic Scoping Review of Implementation of Interventions for Cancer-Related Fatigue Management

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## **Title**

# **Bridging the Research to Practice Gap: A Systematic Scoping Review of Implementation of Cancer-Related Fatigue Management**

## **Abstract**

**Background.** Cancer-related fatigue (CRF) is one of the most common and distressing symptoms in people with cancer. Although efficacy of interventions for CRF have been extensively investigated, less has been done to ensure successful translation into routine clinical practice. The aim of this systematic scoping review was to synthesise knowledge surrounding the implementation of CRF interventions, summarise the processes and outcomes of implementation strategies used, and identify opportunities for further research.

**Methods.** PubMed, Cochrane CENTRAL, EMBASE and CINAHL databases were searched (up to December 2020). The Cochrane Effective Practice and Organisation of Care (EPOC) Group taxonomy and the RE-AIM Framework were used to guide the evaluation of implementation strategies and outcomes, respectively.

**Results.** Six studies were included. Three used an implementation framework (PARIHS, KTA, Cullens & Adams' Implementation Guide) to guide implementation. Overall, the implementation strategies used across all studies were reported to have directly resulted in immediate changes at the clinician level (e.g., increased clinician behaviours, self-efficacy, attitudes, knowledge of CRF management). No clear relationship was found between the use of implementation models and the number or type of implementation strategies used. For outcomes, Effectiveness and Implementation were the most highly reported RE-AIM measures followed by Reach then Maintenance. Adoption was the least reported.

**Conclusions.** Despite the high prevalence of CRF and evidence-based interventions for managing CRF, there is limited evidence informing the sustainable implementation of these interventions. This systematic scoping review emphasises the lack of quality CRF implementation studies presently available in the literature leading to a disconnect between effective CRF interventions, routine clinical care, and cancer survivors at present. This review highlights the need for robust study designs guided by established frameworks to methodically design and evaluate the implementation of CRF management interventions in the future.

## **Keywords**

cancer-related fatigue; exercise; implementation science; oncology; physical activity; survivorship

## 1.0 Background

Cancer-related fatigue (CRF) is experienced by over 60% of cancer survivors depending on their cancer diagnosis and associated treatments, with two-thirds reporting severe CRF extending beyond 6 months, and one-third reporting persistent CRF over many years [1]. While CRF is known as one of the most distressing and prevalent symptoms experienced by people with cancer [2, 3], it has no current universal definition, with the National Comprehensive Cancer Network (NCCN) describing it as “a persistent, subjective sense of physical, emotional and/or cognitive exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning” [4]. CRF greatly diminishes patients’ physical, mental, occupational, emotional and social wellbeing during and after treatment [2, 5, 6]. Other than reduced quality of life, CRF can also lead to difficulties in decision making, daily living disruption and an increased dependency on others [7]. Such impacts on quality of life (QoL) have been widely reported by a broad range of cancer survivor populations [4, 6-13].

Various interventions for managing CRF have been investigated. These include physical activity and exercise (e.g., aerobic, resistance), pharmacological interventions (e.g., erythropoietin, methylphenidate, modafinil), psychological interventions (e.g., cognitive behaviour therapy), and integrative therapies (e.g., acupuncture, massage). There is level one evidence [14-18] supporting the benefits of physical activity, exercise and psychological interventions for managing CRF. In a recent meta-analysis, Mustian and colleagues [16] identified that exercise (weighted effect size [WES], 0.30; 95% CI, 0.25–0.36;  $P < .001$ ) and psychological interventions (WES, 0.27; 95% CI, 0.21–0.33;  $P < .001$ ) produced significant moderate positive effects on CRF improvement, with authors suggesting that both management strategies be prescribed as first line therapy. A plethora of research has focused on the efficacy of CRF interventions; however, there is much to learn about how these interventions can be incorporated into healthcare and ‘real-world’ settings.

While the discipline of implementation science is gaining momentum, less than half of interventions found to be effective in disease management and prevention are ever adopted into clinical use and routine practice [19-21]. Over recent years, cancer care and health service leaders are increasingly

concentrating their efforts on facilitating the systematic uptake of research findings into routine care to improve service and patient outcomes [22]. There are numerous systematic reviews on the clinical efficacy of CRF interventions; however, to our knowledge there is no comprehensive review focussing on the implementation of CRF management interventions and programs. To address this gap, this systematic scoping review of the CRF literature was conducted to answer the following key questions: (1) What current efforts have been made to implement CRF interventions in clinical care?; (2) What implementation frameworks, strategies, theories or models have been used when implementing CRF interventions in clinical care?; and (3) What were the outcomes of identified CRF interventions and implementation efforts?

## **2.0 Methods**

This review sought to examine implementation in CRF literature and identify possible knowledge gaps, thus a scoping methodology was adopted [23]. This systematic scoping review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines [24].

### **Eligibility Criteria**

The population for this review were cancer survivors (regardless of age, gender, tumour and treatment type) at any stage of their cancer trajectory that have experienced fatigue as a result of their cancer or cancer treatment. The taxonomy of implementation strategies developed by the Cochrane Effective Practice and Organisation of Care (EPOC) Group [25] were used to determine the definition and inclusion of implementation studies in the review (see Additional File 1). These EPOC implementation strategies were developed for interventions that targeted and produced changes at the healthcare organisation level, healthcare professional level and the health service level and thus were considered relevant for this review.

For inclusion, studies were required to meet the following criteria: 1) have the implementation of an intervention/program/guideline as a primary goal; 2) have cancer-related fatigue as a primary symptom



of interest; 3) incorporate at least one of the EPOC implementation strategies; 4) be published in English; and 5) have full-text available.

No restrictions were placed on types of study designs eligible for inclusion. As the key interest of our systematic scoping review is to describe implementation outcomes of CRF management interventions, we included original research articles (i.e., randomised controlled trials, observational studies, qualitative studies, mixed methods, abstracts, program evaluations) and other grey literature (e.g., evaluations of modules, online programs and institutional/government interventions). Descriptive articles (i.e., commentaries, editorials, recommendation reports/articles) were excluded.

### **Search Strategy**

Four databases (PubMed, Cochrane CENTRAL, EMBASE and CINAHL) were searched (up to December 2020) as outlined in Additional File 2. Free text terms and relevant subject headings (i.e., MeSH, Emtree) for “cancer-related fatigue” (cancer fatigue, fatigue) and “interventions” were used. These terms were also combined with implementation study terms (e.g., “implementation”, “translation”, “program development”, etc.) using the Boolean logic operators (or, and). Reference and citation lists of relevant articles were also hand searched for eligible studies that met the inclusion criteria. Titles and abstracts of articles retrieved from the search strategy were independently screened by two authors (CS, OAA). The same two authors then assessed the eligibility of relevant full-text articles for inclusion in the review. Disagreements were resolved through consensus among the two authors, with a third author (RC) as arbiter where required.

### **Data Extraction**

Data extraction was conducted by one author (OAA) and checked for accuracy by a second author (RC). Key information extracted included: study characteristics (i.e., author, publication year, study design, purpose, participants, sample size); intervention characteristics (i.e., setting, context, model of care, resources used, intervention description); implementation framework or theory used; implementation strategies used; and implementation outcomes. A model or framework was considered specific to implementation if it described the process of translating research into practice, explained the influences

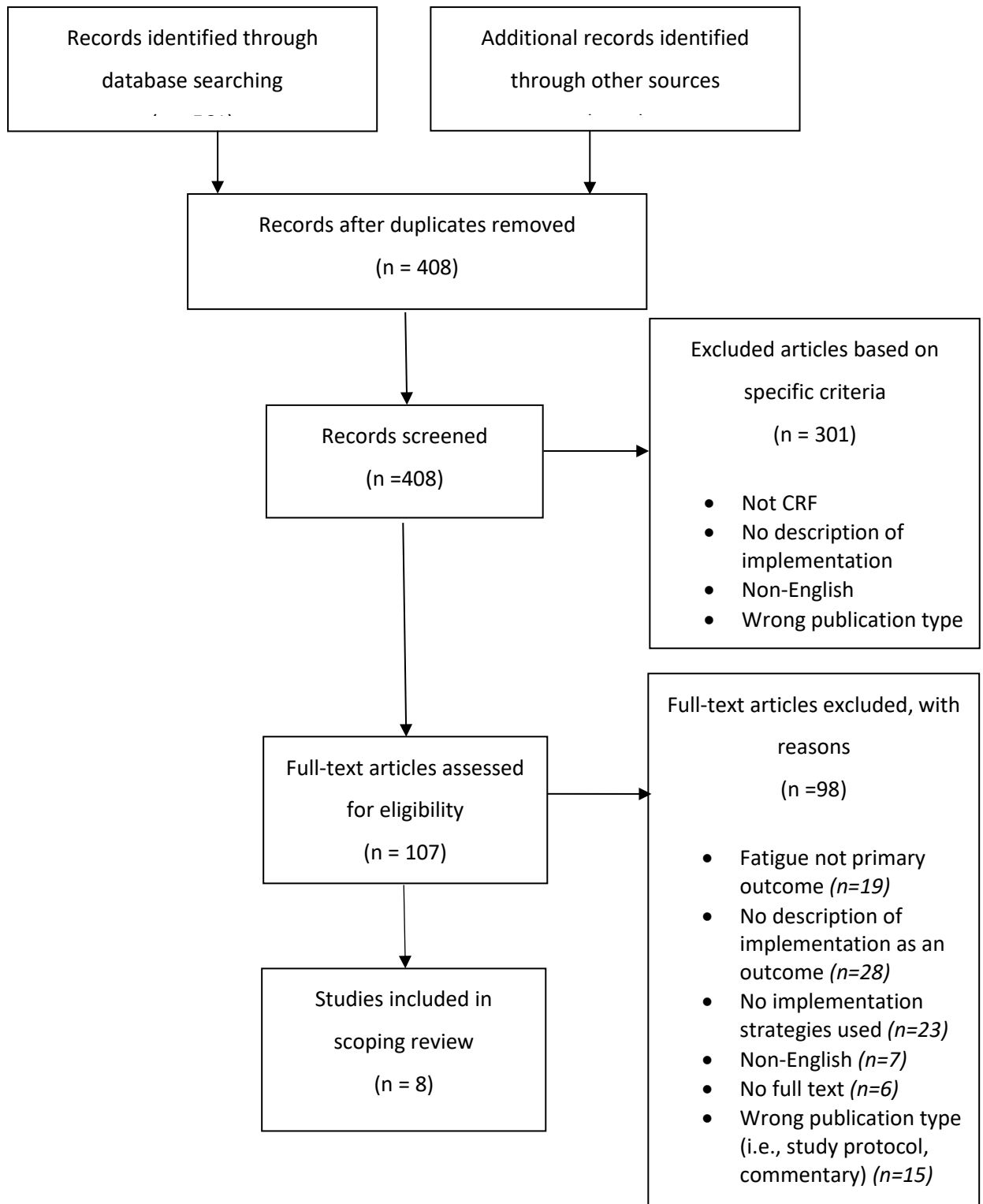
of implementation outcomes, or evaluated implementation processes [26]. Implementation strategies were categorised using the components from the EPOC taxonomy (see Additional File 1).

The RE-AIM framework [27] was used to catalogue the outcomes of strategies, methods or techniques designed to change clinician or patient behaviours related to CRF. RE-AIM was initially developed to balance emphasis on internal and external validity and to expand on assessments of interventions beyond efficacy [28-30]. The RE-AIM dimensions include reach (R), effectiveness/efficacy (E), and maintenance (M)—which operate at the individual-level (i.e., rate or participation, intervention success rate, and endurance of individual behaviour respectively); and adoption (A), implementation (I), and maintenance (M), which focus on the organisation level [31]. In our review, data were extracted using a widely used [28, 30] RE-AIM coding sheet for systematic reviews published on the RE-AIM website (<http://www.re-aim.org/resources-and-tools/asures-and-checklists/> - Additional File 3). Due to the heterogeneity of included studies, a narrative synthesis was conducted. As the purpose of this review was to provide an overview of existing evidence regardless of methodological quality or risk of bias, no quality assessment was conducted, consistent with the PRISMA-ScR guidelines.

### **3.0 Results**

Database searches resulted in 561 potentially eligible records. Of these, eight articles representing six implementation studies [32-37] met the inclusion criteria and were included in the review (See PRISMA Flow Chart: Figure 1).

**Figure 1: PRISMA Flow Diagram**



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

## **Characteristics of Included Studies and Programs**

Included studies are described in Table 1. Of the six studies included, three were conducted in the USA [34, 36, 37], two in China [32, 35], and one in Canada [33]. Study design varied and consisted of one clinical audit implementation study [32], one qualitative program evaluation [37], three pre-test, post-test single group observation studies [33, 35, 36], and one longitudinal 3-group quasi-experimental comparative study [34]. Three studies [32, 33, 35] examined the impact of implementation efforts on the adoption of CRF evidenced-based guidelines, of which two [32, 33] reported the impact of implementation strategies at the organisational and health professional level, and one [35] described the impact of implementation efforts on oncology nurses and patients. The remaining three studies [34, 36, 37] investigated the efficacy of CRF interventions implemented at the patient level. Participants in each of the three efficacy studies [34, 36, 37] had mixed tumour types (i.e., breast, colon, lung, gastrointestinal, prostate, ovarian, uterine, myeloma, non-Hodgkin and Hodgkin lymphoma cancers). CRF interventions described in these three studies were physical activity and exercise [36], clinician and patient education [34], or combined exercise and education [37]. Of the two studies with education components [34, 37], only ‘information giving’ education strategies were described (e.g., information sessions, printed material). Types of physical activity described were aerobic exercise (e.g., walking, treadmill, Nu-Step), resistance training (e.g., resistance bands), balance and stretching, yoga and aquatic exercises [36, 37]. Of the three studies that implemented CRF interventions [34, 36, 37], two [34, 36] reported the impact of CRF interventions on patient fatigue outcomes (e.g., reduced fatigue).

## **Implementation Models and Frameworks**

Only three of six studies were informed by an implementation framework or model. Huether and colleagues [36] utilised Cullens and Adams’ Implementation Strategies for Best Practice Guide. Jones and colleagues [33] used the Knowledge to Action (KTA) implementation framework; and Tian and colleagues [35] used the Promoting Action on Research Implementation in Health Services (PARIHS) framework to guide dissemination and implementation of CRF guidelines into clinical practice.

## **Implementation Strategies**

Distinct EPOC implementation strategies used by all included studies are recorded in Table 1.

### *Educational Meetings and Materials*

Coaching and training strategies were the most used strategies (five of six studies) [32-36] to promote uptake of CRF interventions. Health professional education was delivered in the form of regular staff meetings, staff training sessions and workshops, formal presentations, unit in-services, role-play sessions (i.e., participation in mock fatigue assessments & patient education sessions) and print materials (i.e., 'pocket' fatigue guidelines & tip sheets, flipcharts, newsletters, education booklets). Education content across each study varied but generally included background information on fatigue, fatigue management, fatigue assessment procedures and tools, and referral processes.

### *Local Opinion Leaders and Stakeholder Engagement*

Stakeholder engagement were used in five of six studies [32, 33, 35-37]. Stakeholder groups commonly included clinicians (i.e., psychiatrists, radiation and medical oncologists, physical therapists, surgeons, professors, specialist nurses), cancer survivors, research staff (i.e., research assistants, postdoctoral fellows), and community support professionals. The use of a key opinion leader was described in only one study [35], engaging a nurse who trained and persuaded fellow clinicians to accept implementation efforts.

### *Use of Clinical Guidelines and Local Consensus Processes*

Three studies [36-38] focused efforts on implementing existing clinical fatigue guidelines, including the National Comprehensive Cancer Network (NCCN) Fatigue Guidelines [32, 34] and the Canadian Association of Psychosocial Oncology (CAPO) guidelines for CRF [33]. Tian and colleagues developed and implemented the Clinical Practice Guideline: Nursing Care of Cancer-Related Fatigue in Adults with Cancers [35], whereas Jones and colleagues specifically described the adaptation of guidelines to the local context after stakeholder consensus [33].

### *Audit and Feedback*

Specific audit and feedback strategies were described in two studies [32, 35]. One study [35] described periodic audit completion rounds on nursing units, and routine discussions with staff to gather concerns, challenges, suggestions and distribute feedback; however, study authors did not report the specific details of audit content. The second study [32] described health professional training; fatigue screening at patient admission; fatigue screening at regular intervals throughout care; delivery of comprehensive fatigue assessments; and the provision of management strategies (i.e., physical activity and other strategies) to patients as components that were audited. In addition, interviews with patients and reviewed patient records were used to measure clinician compliance with audit components. A third study did [36] report the use of audit and feedback strategies, however they did not specify processes in further detail.

### *Managerial Supervision and Managing Performance*

Managerial supervision and monitoring of performance strategies were utilised in two studies [32, 36] in the form of regular reporting to senior leaders, routine communication with nurses, and ongoing monitoring of staff to ensure program compliance. Wang and colleagues [32] reported that intervention leaders worked within the nursing unit to monitor nursing practice to ensure adequate nurse education on CRF, nurse provision of CRF assessment upon patient admission, and nurse delivery of patient education for CRF management strategies (i.e., physical activity, and other strategies). Unfortunately, Huether and colleagues [36] reported using managerial supervision and monitoring of performance strategies but did not provide specific detail on performance outcomes. *'Continuous Quality*

### *Improvement*

Continuous quality improvement strategies were described by three studies [35-37] and generally involved protocol revisions and program modification based on clinician or patient feedback. Of these studies, the 'Energy Through Motion' CRF program [36] reported the formation of a dedicated quality improvement program; however, details of this quality improvement program were not provided.

### *Tailored Interventions*

Four studies [32-35], described tailored interventions that were based on assessments of barriers to change. Wang and colleagues [32] conducted a clinical audit to determine CRF management barriers; Borneman and colleagues [34] identified barriers at the patient, professional and system level during the first phase of their quasi-experimental study; Tian and colleagues [35] identified barriers and facilitators through focus group discussions, surveys and observation; and Jones and colleagues [33] conducted semi-structured focus group interviews with stakeholder groups. Common barriers identified were lack of CRF knowledge, inconsistent application of CRF guidelines, insufficient knowledge of CRF screening and assessment, resistant attitudes towards program adoption, busy environments, heavy workloads, and time restrictions.

### *Reminders*

Only one study [36] reported the regular use of practice reminders to reinforce the intervention to staff members. Reminders were distributed by the project leader through intervention ‘tips of the week’; however, the distribution method used (e.g., newsletter, text, email) remains unclear.

### *Organisational Culture*

Efforts to change organisational culture were reported across all studies [32-37] using practical methods including the formation of fatigue specific referral and clinical feedback systems; creation, and incorporation of CRF assessment flowcharts and assessment tools; addition of fatigue management processes to organisation protocol; and the development of CRF information documentation for both staff and patients.

**Table 1:** Summary of Included Articles

Author, year [Program name], country	Study design /Setting/ Sample Size	Purpose	Participants	Models of Care	Resources Used/ Described	Intervention/ Program Description	Implementation Model/ Framework/ Theories
Abbott et al. 2017 [65] & Huether et al., 2016 [40] / Energy Through Motion ©/Iowa United States	Pre-, post-test single group/ Ambulatory / (n=39) Pre-, post-test single group / 2 Survivorship clinics/ (n=50)	Feasibility (Abbott et al., 2017) Effectiveness (Huether et al., 2016)	Adult Cancer Survivors	Nurse-led survivorship clinics Home-based exercise	Activity trackers, Resistance Bands, Verbal instruction, Printed material (i.e., exercise & calorie guides), Pedometers, Activity logs, Bottle	3-month physical activity program that incorporated education, a specialised kit (including info on PA benefits, exercise equipment, sleep strategies logbook, home workouts) and ongoing patient support. The program also included an intricate text message system provide information and encouragement and promote adherence.	(Cullen & Adams, 2002) Implementation Strategies for Best Practice Guide
<p style="text-align: center;"><b>EPOC Implementation Strategies</b></p> <p><u>System/health professional level</u>  <b>Reminders:</b> update practice reminders provided by project leader to regularly reinforce the program.  <b>Local Opinion leaders:</b> DNP student, clinical nurse specialist, nurse practitioners informed content and development.  <b>Continuous Quality Improvement:</b> Senior leaders, existing and new team members were regularly updated on intervention progress. • Dedicated quality improvement program. • Protocol revisions based on feedback from clinicians, patients, or family.  <b>Managerial supervision &amp; Monitoring Performance:</b> Regular reports to senior leaders.  <b>Interprofessional Education &amp; Educational meetings:</b> Presentations on evidence on CRF, physical activity and the Energy Through Motion program at staff meetings, unit in-services,  <b>Educational materials:</b> pocket guides provided for clinicians</p>					<p style="text-align: center;"><b>Outcomes</b></p> <p><u>Effectiveness</u></p> <ul style="list-style-type: none"> <li>• Results <ul style="list-style-type: none"> <li>○ <b>Fatigue:</b> Decreased by an average of 2 points compared to an increase of 0.69 in usual care arm (p=0.0006)</li> <li>○ <b>Activity Levels:</b> Increased activity levels by a mean of 2.59 points (p=0.0016) compared to usual care (decreased levels by a mean of 1.07)</li> <li>○ <b>QOL:</b> Improved in all measured areas from 1.24-2.41 points (0-10 scale) compared to decrease (0.69 – 1.14 points) in usual care.</li> <li>○ <b>Program evaluation:</b> Participants reported that the program was helpful and beneficial. Connecting activity trackers to the computer and follow-along activity videos considered least helpful (Information videos also reported as not used regularly).</li> </ul> </li> <li>• Percent attrition: 10%</li> </ul> <p><u>Implementation</u></p> <ul style="list-style-type: none"> <li>• <b>Completion rate:</b> 90%</li> </ul> <p><u>Maintenance (Setting Level)</u>  Program still maintained at the University of Iowa Holden Comprehensive Cancer Centre</p>		



Author, year [Program name], country	Study design /Setting/ Sample Size	Purpose	Participants	Models of Care	Resources Used/ Described	Intervention/ Program Description	Implementation Model/ Framework/ Theories
Borneman et al., 2010 [66] & 2011 [38]/ [Passport to Comfort]/ California, United States	Quasi-experimental comparative study/Ambulatory/ (Phase 1 [usual care] n=83, Phase 2 [intervention] n=104, Phase 3 [Dissemination] n=93)	Phase 1 & 2: Effectiveness  Phase 3: Dissemination	Patients with breast, colon, lung and prostate cancer (at least 1 month after diagnosis).	Nurse-led	Teaching Packet consisting of written educational materials.	Phase 1, 2: Psycho-educational intervention. Each patient received 4 (approx. 60min) educational sessions as well as written information material or 'tip' sheets in a 'teaching packet'. Tip sheets provided education on exercise, nutrition, emotional issues and sleep disturbance. During sessions, information on pain assessment, fatigue assessment and fatigue management was provided. A month after last educational session participants received bi-weekly follow-up phone calls every 2 weeks for 3 months.	None Described
<p style="text-align: center;">EPOC Implementation Strategies:</p> <p><u>System/ Health Professional Level</u>  <b>Local Consensus Processes &amp; Clinical Guidelines:</b> Intervention informed by the National Comprehensive Cancer Network (NCCN). A 'Patient Pain Knowledge Tool' was created based on NCCN pain guidelines.  <b>Educational Meetings &amp; Material:</b> Regular meetings with nurses. • Pain and fatigue presentations by national experts to oncologists and nurse practitioners. • Monthly newsletter to practitioners for ongoing education and communication. • Internal Advisory Board met quarterly to gain clinician input from researchers involved in the intervention.  <b>Organisational Culture (Phase 3):</b> Pain and fatigue education provided to all clinicians at a total of 38 in-services. • Pain and fatigue information provided at key meetings. • Routine fatigue assessment added to outpatient clinic vital sign flow sheet. • Increased referrals to supportive care departments for pain and fatigue. • Patient education materials were translated into Spanish. • Patient education materials made available on employee Intranet. • Advocacy posters placed around clinic to remind staff and patients to discuss fatigue. •  <b>Audit and feedback:</b> Clinical feedback reports completed for patients and provided to MDs and NPs based on chart audits with specific feedback for pain and fatigue management.  <b>Tailored interventions:</b> Strategies created to address identified patient, professional and system barriers.</p>					<p style="text-align: center;">Outcomes</p> <p><u>Reach</u></p> <ul style="list-style-type: none"> <li>• <b>Participation rate</b> (Phase 3): 93%</li> </ul> <p><u>Effectiveness</u></p> <ul style="list-style-type: none"> <li>• Phase 1 &amp; 2: <b>Fatigue</b> - fatigue management barriers were significantly higher in the usual care group than in the intervention group. The usual care group had significantly more fatigue (beta = -0.155).</li> <li>• Phase 3: <b>Fatigue</b> - Significant immediate and sustained effects were shown on the Fatigue Barriers Scale (FBS) for the intervention group. The intervention group demonstrated a significant delayed effect in Physical QOL – maintained baseline levels of QOL throughout the study when we would normally expect a decrease in QOL. Statistically significant differences between QOL measures were small.</li> </ul> <p><u>Maintenance (Individual)</u></p> <ul style="list-style-type: none"> <li>• (2-month follow-up) Attrition rate: 32.5%</li> </ul>		

Author, year [Program name], country	Study design /Setting/ Sample Size	Purpose	Participants	Models of Care	Resources Used/ Described	Intervention/ Program Description	Implementation Model/ Framework/ Theories
Jones et al., 2020 [37]/ Canada	Prospective Cohort/(n=18)	Implementation Intervention  Acceptability and Feasibility	Healthcare professional and community support workers	N/A	Flipchart/Checklist– summarised guidelines, screening, and assessment information.	A one-time in person 2-hour training session offered to health care practitioners and community support providers about the CAPO CRF guidelines. First hour provided information on practice gaps reported in literature, CAPO CRF guidelines, communication skills and motivational interviewing principles. Second hour involved role-play and group discussions.	Knowledge to Action (KTA) Model
<p style="text-align: center;">EPOC Implementation Strategies</p> <p><b>Clinical Guidelines:</b> Canadian Association of Psychosocial Oncology (CAPO) guidelines for CRF used to inform education sessions.</p> <p><b>Local Consensus Processes:</b> Clinical guidelines adapted to the Ottawa context after consensus amongst stakeholders.</p> <p><b>Local opinion leaders &amp; Tailored Intervention:</b> Focus interviews and program development with stakeholder groups (patients, health care professionals and community support professionals, pedagogy expert) to identify barriers to change; subsequent strategies then created.</p> <p><b>Educational materials:</b> All participants provided with a flipchart that contains information on assessing and managing fatigue.</p>					<p style="text-align: center;">Outcomes</p> <p><u>Reach</u> <b>Participation Rate:</b> 90%</p> <p><u>Implementation Impact</u></p> <ul style="list-style-type: none"> <li>• Program was effective in increasing knowledge, self-efficacy and intent to apply guidelines.</li> <li>• <b>CRF Knowledge:</b> <math>-3.959(14)</math>, <math>p = 0.001</math> with a large effect size (<math>d = 0.98</math>).</li> <li>• <b>Self-Efficacy in CRF Assessment</b> (<math>t = 2.621(13)</math>, <math>p = 0.021</math>) with a large effect size (<math>d = 0.88</math>).</li> <li>• <b>Self-efficacy to intervene for CRF</b> (<math>t = 2.924(13)</math>, <math>p = 0.012</math>) with a large effect size (<math>d = 1.13</math>).</li> <li>• <b>Intent to apply Clinical Guidelines in Practice:</b> <math>t = 4.786(13)</math>, <math>p = 0.000</math> with a large effect size (<math>d = 1.35</math>).</li> <li>• <b>Feasibility:</b> mean satisfaction score (<math>52.27 \pm 6.97</math> out of 60 points maximum).</li> </ul> <p><u>Implementation</u> <b>Completion Rate:</b> 88.9%</p>		

Author, year [Program name], country	Study design /Setting/ Sample Size	Purpose	Participants	Models of Care	Resources Used/ Described	Intervention/ Program Description	Implementation Model/ Framework/ Theories
Tian et. al 2017 [39]/ China	Pre-test, post-test/ Radiotherapy Unit & Medical Oncology Unit/N/A	Implementation – Intervention  Translating guidelines into practice	Nursing Staff	N/A	Nursing record chart, CRF education booklet, CRF quality control checklist	Study outlined the creation of a ‘CRF Nursing Guideline’ using a steering group (consisting of clinical experts). The resulting guidelines were implemented into practice through an evidenced-based project utilising training and education for nurses, changes to nursing procedures (screening and assessment and quality review) and the provision of staff resources. Impact of the project was measured at the organisational, staff and patient level.	The Promoting Action on Research Implementation in Health Services (PARIHS) framework
<p style="text-align: center;">EPOC Implementation Strategies:</p> <p><u>System/health professional level</u>  <b>Continuous Quality Improvement &amp; Audit and Feedback:</b> Feedback and suggestions periodically collected to determine whether further specific training or modification (to nursing procedure) was required.  <b>Educational materials:</b> CRF Education booklet and other training print materials given to nursing staff.  <b>Educational meetings:</b> Training courses on CRF nursing care were established, including elementary training on evidence-based nursing practice and specific training on CRF nursing care. Seminars on evidence-based practice concerning CRF management.  <b>Clinical Practice Guidelines/ Local Consensus Processes:</b> The “Clinical Practice Guideline: Nursing Care of Cancer-Related Fatigue in Adults with Cancer” was developed by interventionists.  <b>Local opinion leaders:</b> Creation of a steering group (six directors from nursing, medical oncology, radiotherapy, Traditional Chinese Medicine, Psychiatry departments). ● Opinion leader identified to change nurse negative opinion of the project, train other nurses and act as a role model for fellow clinicians. ● Integration of existing staff into facilitation team.  <b>Tailored Intervention:</b> Initial focus groups and discussions conducted to identify barriers to change. Subsequent strategies then created.</p>					<p style="text-align: center;">Outcomes</p> <p><u>Implementation Impact</u></p> <ul style="list-style-type: none"> <li>● Nurse Outcomes: After implementation of the project, knowledge, attitudes, and behaviour scores were all higher than at baseline.</li> <li>● Patient Outcomes: <ul style="list-style-type: none"> <li>○ No differences were detected between the baseline and final scores of the “self-efficacy questionnaire for CRF management” (SQFM) scale.</li> <li>○ Patients adopted more effective CRF management strategies (previously just rested to alleviate fatigue)</li> <li>○ CRF scores lower after intervention than prior to intervention [5.59(2.09) vs. 6.50 (1.90); t = 2.22, p = 0.04].</li> </ul> </li> </ul>		

Author, year [Program name], country	Study design /Setting/ Sample Size	Purpose	Participants	Models of Care	Resources Used/ Described	Intervention/ Program Description	Implementation Model/ Framework/ Theories
Van Gerpen & Becker, 2013 [41]/ [LifeSpring]/ United States	Program Evaluation Article /Wellness Centre/N/A	Program Evaluation	Adult Cancer Survivors	Physical therapist and exercise physiologist led	Resistance Bands T-shirts w/LifeSpring logo Written Hand out materials Snacks Balloons (for release at graduation) Exercise equipment (dumbbells, machines)	Exercise and education program. 12-week program consisting of a bi-weekly exercise session and a weekly education session. Exercise component consists of: 20-30-minutes of aerobic exercise (5-min intervals of stationary bike, treadmill, walking on the indoor track, recumbent stepper (Nu-SteP), or upper-body ergometer) and 20-30-minutes of group exercises (resistance training, balance/flexibility/stretching exercises, aquatic exercises and relaxation, Pilates or BODYFLOW™ exercises). Educational sessions are led by content experts and include topics such as exercise and cancer, healing, communication and coping, spirituality sleep.	None Described
<p style="text-align: center;">EPOC Implementation Strategies:</p> <p><u>System/Health Professional Level</u>  <b>Local Opinion leaders:</b> Program development by physical therapist, medical and radiation oncologists, general surgeons, nurses, cancer survivors. • Phone interviews with intervention leaders from other programs to provide additional insight on recruitment, retention, program design education session topics, screening tools, etc.  <b>Continuous Quality Improvement:</b> Program was modified to include all cancer types (originally only breast cancer survivors) after results from initial program evaluation. Sessions were limited to 12 participants after previous larger class sizes caused challenges in providing individualised support.</p>					<p style="text-align: center;">Outcomes</p> <p><u>Effectiveness/ Efficacy</u>  Participants reported improvements in their fatigue, pain, sleep disturbances, depression, and quality of life, (demonstrated from their pre-, mid-, and post program scores).</p> <ul style="list-style-type: none"> <li>• Fatigue: [5.58 (2.11) vs. 3.55 (1.86); p &lt; 0.0001]</li> <li>• Sleep [4.77 (2.5) vs. 3.26 (2.27); p &lt; 0.0001],</li> <li>• Quality of life [3.63 (2.27) vs. 2.08 (1.86); p &lt; 0.0001],</li> <li>• Pain [2.52 (2.31) vs. 1.85 (1.85); p &lt; 0.001],</li> <li>• Depression [2.72 (2.21) vs. 1.65 (1.49); p &lt; 0.0001].</li> </ul> <p><u>Implementation</u>  <b>Participation/Attendance Rates:</b> 80%. From 2007 to approx. 2013: 182 participated in program and 152 completed the program</p> <p><u>Maintenance (Setting Level)</u>  Program still maintained at the Bryan Health Medical Centre</p>		

Author, year [Program name], country	Study design /Setting/ Sample Size	Purpose	Participants	Models of Care	Resources Used/ Described	Intervention/ Program Description	Implementation Model/ Framework/ Theories
Wang et al., 2018 [36]/ China	Clinical Audit/ Hospital/ N/A	Implementation Project	Nursing Staff	N/A	Educational materials	This article first determined the current state of CRF management in the oncology department by undertaking an initial audit. Strategies (listed below) were then implemented to improve practice and address the barriers identified. A follow-up audit was conducted to evaluate the impact of changes made.	None described. Researchers used the JBI Getting Research into Practice (GRiP) tool to identify barriers and practice gaps.
EPOC Implementation Strategies					Outcomes		
<p><b>Local Opinion Leaders:</b> Routine communication with stakeholders to inform strategy development and promote good clinical practice.</p> <p><b>Clinical Guidelines:</b> Content of all educational materials derived from the NCCN CRF guidelines.</p> <p><b>Organisational Culture &amp; Educational materials:</b> Information brochures and posters about CRF management strategies developed for patients and staff. • Flow chart detailing CRF assessment steps created and displayed in nursing unit. • Paper-based CRF assessment tools (including BFI) created and distributed for use.</p> <p><b>Educational meetings:</b> Formal 2-hr education sessions on CRF background, management and assessment delivered to all nurses. • ‘Practice fatigue assessments’ and patient education sessions completed by nurses (under supervision).</p> <p><b>Monitoring Performance &amp; Managerial Supervision:</b> Ongoing discussions, communication, and monitoring of nurses to ensure compliance.</p> <p><b>Tailored interventions:</b> Clinical audit conducted to address barriers to change. • Procedures adjusted to account for changes in environment, workload and time restrictions (i.e., reallocation of work tasks, management support, time management via prioritisation of work tasks, balancing resources).</p>					<p><u>Implementation Impact</u></p> <p>Compliance with best practice audit criteria (compliance rates) -</p> <ul style="list-style-type: none"> <li>• Health professional received education and training: Baseline audit – <b>0%</b> Follow up audit - <b>97%</b></li> <li>• CRF assessment upon admission and at regular intervals throughout care: Baseline audit – <b>0%</b> Follow up audit - <b>86%</b></li> <li>• Focused assessment of fatigue undertaken in patients who screen positively: Baseline audit – <b>0%</b> Follow up audit - <b>64%</b></li> <li>• Patient education about physical activities: Baseline audit – <b>3%</b>, Follow up audit - <b>78%</b></li> <li>• Patient informed about the strategies to manage cancer related fatigue: Baseline audit – <b>0%</b> Follow up audit - <b>83%</b></li> </ul>		

Abbreviations: **BFI** = Brief Fatigue Inventory; **CAPO** = Canadian Association for Psychosocial Oncology; **CRF** = Cancer-related Fatigue; **DNP** = Doctor of Nursing Practice; **JBI** = Joanna Briggs Institute; **MD** = Doctor of Medicine; **NCCN** = National Comprehensive Cancer Network; **N/A**= Not applicable; **NP** = nurse practitioner; **PA**=physical activity; **QOL** = Quality of Li

## **Implementation and Intervention Outcomes (RE-AIM)**

Implementation outcomes of the included studies are outlined in Table and Additional File 3. Overall, Effectiveness and Implementation were the most highly reported dimensions followed by Reach. Adoption and Maintenance were the least reported dimensions.

### **Reach of CRF interventions**

Reach is defined as the number, proportion and representativeness of individuals who are willing to participate in a given initiative or intervention [31]. Descriptions of target population (including demographic information), inclusion criteria and sample size were reported in five [33-37] of six studies. Only one study [35] reported the representativeness or characteristics of participants and non-participants by comparing the sample with broader populations. Program participation rate was reported by two studies [33, 34].

### **Efficacy of CRF interventions**

Efficacy describes the impact of CRF interventions on identified outcomes (e.g., fatigue). Fatigue and behavioural outcome measures were reported in four of six studies [34-37]. Of these studies, all reported reduced CRF severity as a result of the intervention. The ‘Energy Through Motion’ CRF intervention [36] resulted in decreased fatigue severity by an average of two points compared to an increase of 0.69 points in the usual care arm ( $p=0.0006$ ). Pre- and post-program scores from Van Gerpen and Becker’s ‘LifeSpring’ CRF intervention [37] demonstrated statistically significant improvements in fatigue (5.58 (SD 2.11) vs. 3.55 (SD 1.86);  $p < 0.0001$ ). Tian and colleagues’ [35] also produced lower patient CRF scores after their CRF intervention ( $p = 0.04$ ). Lastly, the ‘Passport to Comfort’ CRF intervention [34] produced significant and beneficial effects on fatigue barriers ( $p=0.001$ ) and patient fatigue management knowledge ( $p=0.002$ ). No studies reported on cost-effectiveness.

### **Adoption (setting and staff level) of CRF implementation efforts**

Adoption is defined as the number, proportion, and representativeness of settings and intervention agents who are willing to initiate a program [31]. Indicators for adoption were the least reported

outcomes in the included studies. Further, indicators such as the description of targeted locations, inclusion/exclusion criteria of settings and staff, method to identify settings and staff, setting and staff participation rate, representativeness of staff and settings, number of staff participating in intervention delivery, and measures of intervention cost were not reported by any study.

## **Implementation**

According to Glasgow and colleagues [31], implementation at the setting level refers to the cost of implementation, and whether the intervention was delivered as intended. At the individual level, implementation refers to clients' use of the intervention and implementation strategies. Intervention completion rates were reported by four studies [32, 33, 36, 37] and ranged from 80 to 90%. No study described methods to ensure fidelity of the intervention. Additionally, only the 'Energy Through Motion' CRF program [36] detailed the ongoing implementation cost of the intervention (intervention kits valued at \$21.75 USD per patient).

Results of implementation efforts varied across all studies. Implementation strategies utilised in Wang and colleagues' study [32] resulted in increases in nurse CRF education, nurse assessment of patient CRF upon admission and at regular intervals throughout treatment, and nurse provision of patient education on exercise and other management strategies for CRF. Jones and colleagues [33] reported that their two-hour health and community professional training session resulted in large to very large increases in clinician CRF knowledge ( $d=0.98$ ), self-efficacy in CRF assessment ( $d=0.88$ ), self-efficacy to intervene for CRF ( $d=1.13$ ), and intent to apply CRF guidelines ( $d=1.35$ ). Tian and colleagues [35] dissemination of CRF guidelines led to increased clinician knowledge, attitude and CRF management behaviours, and the increased adoption of effective CRF management strategies amongst patients. Borneman and colleagues [36] strategies to address professional and system barriers (e.g., formal fatigue presentations to staff, monthly newsletters, ongoing meetings with nurse practitioners) resulted in organisational change (e.g., routine fatigue assessment added to outpatient clinic sheet, increased supportive care referrals). Although Huether and colleagues [36] and Van Gerpen and Becker [37] described the use of implementation strategies in their respective programs, outcomes of their implementation efforts were not reported.

## **Maintenance of CRF interventions and implementation efforts**

Maintenance is defined as the extent to which individual behaviour is sustained six months or more after the intervention; and whether a program or policy is institutionalised as part of routine organisational practice [31]. Maintenance indicators at both the individual and setting level were not fully reported in any study and only partially reported across four of the six studies [34-37]. Borneman and colleagues [34] reported individual follow-up and attrition (three months) after program completion; however, did not provide follow-up data at  $\geq 6$  months post-intervention Tian and colleagues [35] stated that innovations and strategies developed from their implementation efforts were maintained for two months after project completion, but were discontinued due to lack of staff time and funding. Borneman and colleagues [34] noted their dissemination of the intervention was conducted at the study institution and that plans were underway to disseminate the intervention into other community centres.

At the time of writing this review, the ‘LifeSpring’ CRF intervention described in Van Gerpen and Becker’s evaluation [37] is currently maintained and institutionalised at the US Bryan Health Medical Center. Additionally, the ‘Energy Through Motion’ CRF intervention [36] appears to be institutionalised at survivorship clinics offered by the University of Iowa Holden Comprehensive Cancer Centre in the United States; however, little detail of the current program and its integration can be found. None of the studies provided details on costs associated with maintenance, however Van Gerpen and colleagues [37] state that ongoing funding for the program was provided by the medical centre’s foundation, and Huether and colleagues report that after project completion of the ‘Energy Through Motion’ CRF intervention, “continuation of funding for patient supplies was obtained through requests from a regular benefactor of the cancer centre” [36].

## **4.0 Discussion**

Efforts to sustainably implement evidenced-based CRF management strategies into routine clinical care are urgently needed, owing to the high incidence, prevalence, and burden of CRF in cancer survivors severely impacting health-related quality of life [1]. Despite established CRF management strategies



[1, 16], sustainable models of care connecting cancer survivors to effective CRF interventions have yet to be satisfactorily investigated [38]. Our systematic scoping review was able to identify only six studies evaluating the implementation of interventions designed for individuals experiencing CRF. Further, all studies had limited external validity and lacked methodological rigor (e.g., poor reporting of exclusion criteria, study design, data analysis; limited to no follow-up periods; absence of frameworks and theories to guide implementation, etc).

Only three studies used specific implementation models to guide the dissemination process. When applied accurately, implementation theories and frameworks have been shown to enhance dissemination into practice by improving interpretability of study findings and increasing the use of essential implementation strategies [27]. Given only three studies adopted an implementation framework in our review, it is difficult to establish which model is the most helpful for future CRF implementation.

Despite limited use of implementation models, a range of strategies were used across included studies. While most studies in this review demonstrated immediate changes at the clinician, organisational and patient level through their use of various implementation strategies, it was difficult to determine the impact (and impact strength) of individual strategies on implementation outcomes. Further research to identify the preferred strategy from clinicians, patients, and other stakeholders in CRF interventions is likely to be helpful in ascertaining the usefulness, relevance, and effectiveness of specific implementations strategies that will improve implementation efforts [39].

Maintenance and Adoption were the least reported RE-AIM indicators, while Reach, Effectiveness, and Implementation were highly reported across the studies. For all domain indicators, reporting was exceptionally higher for aspects of internal validity (e.g., inclusion criteria, sample size) than external validity (e.g., representativeness of participants, description of settings and staff, intervention fidelity). This is consistent with previous reviews of health interventions across a variety of populations [32, 40-43]. Of note, the level of reporting on Adoption was poor with indicators at the staff and setting level amongst the lowest reported. Details of intervention settings and delivery staff are critical as they allow for the assessment of intervention applicability (and its effect) to different conditions [43]. In five of six included studies, intervention facilitators were employed solely to deliver the CRF intervention or

implementation effort, and often had high levels of specific training and supervision, a situation which is not indicative of “real-life practice”. Thus, to assist the replication and translation of CRF guidelines and management interventions into routine practice; information regarding intervention setting and staff characteristics, and level of staff skill and training is vital.

Cost was another implementation outcome that was under-reported yet is essential when establishing sustainable models of care for cancer survivors. Cost effectiveness, including start-up and ongoing costs of intervention delivery, have been identified as key factors in determining the translation of research findings into practice [44]. However, these costs were rarely reported, with only the ‘Energy Through Motion’ CRF intervention providing an explicit cost of intervention materials (\$21.75 USD per patient) [36]. Cost concerns are associated with reduced stakeholder willingness to implement evidenced-based interventions and represent the most significant barrier to evidenced-based practice implementation and program sustainability [45-47]. Reporting costs in future implementation efforts for CRF management is critical.

Assessment of intervention maintenance and sustainability has been identified as a neglected area in clinical research [40-43, 48] with results of this review in agreement. Across all studies, the same common barriers to program continuation were reported: lack of clinician knowledge and skills in the management of CRF, shortage of clinician human resources, lack of program and staff funding, and lack of clinician time. These barriers have been repeatedly highlighted across the CRF literature [49-51]. Berger and Mooney [51] emphasise the lack of access to, and re-imburement for, integrated supportive cancer programs and services remains the largest challenge to effectively implementing CRF guidelines into routine clinical practice. Further, they conclude that without additional time and reimbursement, clinicians cannot be expected to adequately provide effective or targeted clinical care to individuals experiencing CRF.

### **Implications for Future Research and Practice**

Implementation research in CRF management is severely lacking, highlighting the need for focussed research in this area. In Box. 1, we provide key findings and recommendations of our systematic scoping review. Although feasibility, acceptability and effectiveness outcomes are widely reported across CRF

literature, a greater focus on other pertinent implementation outcomes such as adoption and program maintenance are paramount to translate CRF guidelines and interventions into real-world settings. While we acknowledge that these studies have different aims, and may not comprehensively cover all dimensions outlined in the RE-AIM framework, it is suggested that CRF implementation studies incorporate several stepwise iterative phases to provide opportunities to trial, assess and refine elements; determine resource needs and costs; and gather evidence of implementation impact [49].

Most studies included in this review described CRF implementation at the health professional level, or in acute health care settings. However, the physical, psychological, and psychosocial needs of cancer survivors after active treatment require continuous long-term support which is often only provided by primary and community health care teams [52]. As such, there is a need to extend CRF implementation and translation efforts to community and primary care settings where they will be more accessible to larger population of cancer survivors in the community.

#### Box .1 Key Findings and Implications for Future Research and Practice

##### Future research should:

- put greater emphasis on reporting aspects of external validity such as representativeness, setting characteristics, staff level characteristics, and implementation cost.
- be underpinned or guided by an implementation framework.
- utilise rigorous pragmatic designs with adequately powered samples and longer follow-up periods.
- report the impact of implementation at the system, health professional and cancer survivor level.

##### Intervention developers should:

- consider sources of ongoing funding and endeavour to use existing resources (staff, equipment, infrastructure, etc.) to deliver implementation efforts.

##### Clinical leaders should:

- endeavour to build clinician awareness and knowledge of evidenced-based CRF management and assessment strategies through the provision of educational training and resources.
- seek regular engagement with clinical staff and relevant stakeholder groups to identify potential/existing enablers or barriers to clinical change and to tailor implementation efforts to specific contexts.
- place emphasis on the allocation of clinician resources within settings, the provision of time management support to clinicians (e.g., reallocation of work tasks, adjustment of procedures to fit clinician schedule, adjustment of clinician schedule to fit procedures) and the identification of ‘clinical champions’ or opinion leaders, to encourage peer behaviour change and compliance with the recommended CRF management and assessment practices.

## **Limitations**

This review has two main limitations. First, the inconsistencies of what constitutes an implementation study (e.g., implementation processes, terminologies, definitions, intention to treat, inclusion/exclusion criteria) made it difficult to detect a distinct relationship between the use of implementation models and strategies, and implementation outcomes. However, this is not unique to our review with similar inconsistencies frequently reported across the implementation science literature [52-54]. Second, our review was limited to studies in English, potentially resulting in some level of publication bias limiting the generalisability of results.

## **5.0 Conclusion**

This systematic scoping review is the first to examine models, strategies, and outcomes of studies reporting on the implementation of interventions for individuals experiencing cancer-related fatigue. Our review found that various implementation strategies have been used to promote uptake of CRF management interventions and guidelines at the organisational, clinician, and patient level. However, lack of consistent reporting of external indicators (e.g., ongoing and start-up costs of intervention, setting and staff representativeness) and factors such as lack of clinician time, insufficient clinician and intervention funding, and unsustainable maintenance costs, are potential barriers to study translatability and CRF program implementation. This review emphasises the absence of quality CRF implementation studies and highlights the pertinent need for more robust, theory driven implementation studies to bridge this important knowledge-practice gap.

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#### Additional File Legend

**Additional File 1:** Modified EPOC Implementation Strategies

**Additional File 2:** Search Strategy

**Additional File 3:** RE-AIM Indicators & Reporting of RE-AIM Indicators Across all Included Studies



## Additional File 1: Modified EPOC Implementation Strategies

STRATEGY	CRITERIA
Organisational culture	Did the intervention utilise any strategies to change organisational culture?
Audit and Feedback	Is performance feedback provided in either a verbal, written or electronic format? Are recommendations for clinical action provided?
Communities of practice	Does the intervention utilise communities in practice? (Groups of people with a common interest who deepen their knowledge and expertise in an area by interacting on an ongoing basis)
Continuous Quality Improvement	Does the article or intervention describe/undertake any iterative processes to review and improve care? (This can include the involvement of healthcare teams, analysis of a process or system, a structured process improvement method or problem-solving approach, and use of data analysis to assess changes).
Monitoring the performance of the delivery of healthcare	Is the intervention/program/ service routinely monitored. Has it been compared with an external standard?
Educational games	Does the intervention use games as an educational strategy to improve standards of care
Educational materials	Does the article or intervention describe/ incorporate the distribution of knowledge and educational materials to support clinical care? For example, this may be facilitated by the internet, learning critical appraisal skills; skills for electronic retrieval of information, diagnostic formulation; question formulation, etc.
Educational meetings	Does the intervention or article describe or use courses, workshops, conferences or other educational meetings?
Educational outreach visit, or academic detailing	Does the article/ intervention describe or utilise personal visits by a trained person to facilitators/intervention participants/ in their own settings (to provide information with the aim of changing practice).
Clinical Practice Guidelines/ Local Consensus Processes	Is the development of the intervention informed by any clinical practice guidelines, frameworks or models? Does the article promote the implementation of clinical guidelines? Was there any formal or informal consensus process to choose or adapt guidelines for use?
Inter-professional Education	Does the intervention use/provide/incorporate continued education of health professionals?
Local opinion leaders	Were local opinion leaders identified and used to inform intervention development and to promote good clinical practice?
Patient-mediated interventions	Was the intervention informed by information provided by patients (survey, interview, other patient interactions)?
Managerial supervision	Does the article/ intervention incorporate routine supervision visits with health?
Routine patient reported outcomes	Does the article or intervention describe/allow for the facilitation of frequent routine patient reported outcome measures (e.g., logbook recording fatigue severity, impact on QOL, etc.)?
Reminders	Does the intervention use or describe any manual or computerised mechanisms that prompt individuals to perform an action?
Tailored interventions	Is the intervention based off any assessment of barriers to change? Was the intervention informed by any assessments like interviews or surveys?

### Summary of EPOC Modifications

- Implementation strategies put into question format to assist screening process.
- EPOC taxonomy contains more items. Only the taxonomy relevant to the study were included (see summary of EPOC modifications)

The following strategies were not included as they were not considered relevant to the study (outside the scope of the study or a different scope of the study): Public release of performance data, Clinical incident reporting and the “Interventions targeted at specific types of practice, conditions or settings” section.

## Additional File 2: Search Strategy

### CINAHL

1. (MH "Systems Implementation") OR (MH "Program Implementation") OR (MH "Implementation Science") OR (MH "Program Development") [53,225]
2. TI ( implement\* OR disseminat\* OR translat\* OR ("Systems Implementation") OR ("Program Implementation") OR ("Implementation Science") OR (Program Development) ) OR AB ( implement\* OR disseminat\* OR translat\* OR ("Systems Implementation") OR ("Program Implementation") OR ("Implementation Science") OR ("Program Development") ) [266,712]
3. S1 OR S2 [299,074]
4. (MM "Cancer Fatigue") [959]
5. (MH "Cancer Fatigue") [1,590]
6. TI ( ("cancer fatigue" OR "cancer related fatigue" OR cancer related fatigue) ) OR AB ( ("cancer fatigue" OR "cancer related fatigue" OR cancer related fatigue) ) [1,380]
7. S4 OR S5 OR S6 [2,435]
8. (S3 AND S7) **[159]**

### EMBASE

1. 'implementation science'/exp [1510]
2. implement\*:ab,ti OR translat\*:ab,ti OR 'program development':ab,ti [1,060,964]
3. #1 OR #2 1,061,142]
4. 'cancer fatigue'/exp/mj [1,226]
5. 'cancer fatigue'/exp [3,179]
6. 'cancer fatigue':ab,ti OR 'cancer related fatigue':ab,ti [2,270]
7. #4 OR #5 OR #6 [4,395]
8. #3 AND #7 **[251]**

### COCHRANE LIBRARY

1. MeSH descriptor: [Implementation Science] explode all trees [34]
2. MeSH descriptor: [Health Plan Implementation] explode all trees [176]
3. MeSH descriptor: [Translational Medical Research] explode all trees [116]
4. MeSH descriptor: [Program Development] explode all trees [710]
5. (implement\* OR translation OR "program development"):ti,ab,kw [42,849]
6. ("cancer related fatigue" OR "cancer fatigue"):ti,ab,kw [1,016]
7. (#1 OR #2 OR #3 OR #5) AND #6 **[52]**

PUBMED: (((("implementation science"[MeSH Terms] OR "translational medical research"[MeSH Terms] OR "program development"[MeSH Terms] OR knowledge translation[MeSH Terms] OR health plan implementation[MeSH Terms] OR (implement\*[Title/Abstract]) OR (translation[Title/Abstract]))) AND ((("cancer fatigue"[Title/Abstract]) OR "cancer related fatigue"[Title/Abstract])) **[99]**

## Additional File 3: RE-AIM Indicators & Reporting of RE-AIM Indicators Across all Included Studies

<b>REACH</b>	
<b>R1. Described Target Population &amp; Demographics</b>	A brief description of the broader target population & Gender, age, educational attainment, occupation, SES, behavioural outcomes
<b>R2. Method to Identify Target Population</b>	Describe the process by which the target population was identified for participation in the study.
<b>R3. Recruitment Strategies</b>	Describe the methods used to recruit participants into the study.
<b>R4. Inclusion Criteria</b>	Description of inclusion criteria for individual participants
<b>R5. Exclusion Criteria</b>	Description of exclusion criteria for individual participants
<b>R6. Representativeness of participants</b>	Comparison of characteristics (% females, mean age, age range...) between participants and non-participants
<b>R7. # Eligible &amp; Invited (exposed) to Recruitment</b>	The total number of eligible participants contacted for participation.
<b>R8. Sample Size</b>	The number of people who agree to participate
<b>R9. Participation Rate</b>	Sample size divided by the target population denominator
<b>R10. Cost of Recruitment</b>	The cost of recruitment can reflect monetary and/or time units.
<b>EFFICACY / EFFECTIVENESS</b>	
<b>E1. Measures and results for post-intervention assessment</b>	Description of outcome measures
<b>E2. Intention-to-treat analysis utilised</b>	Analysing participants in the groups in which they were randomised regardless of adherence
<b>E3. Imputation procedure</b>	Description of imputation procedure used for Intention-to-treat analysis
<b>E4. Quality of Life measure included</b>	Description of use and results for QoL
<b>E5. Measure of satisfaction with / acceptability of programme</b>	Description of included measures regarding satisfaction and acceptability
<b>E6. Cost Effectiveness</b>	Code as reported if specific mention and amounts are provided for the cost of the intervention.
<b>E7. Effects at follow-up</b>	At least one follow-up assessment (after post-intervention assessment) included
<b>E8. Attrition at program completion</b>	Description of type and % of attrition
<b>ADOPTION</b>	
<b>A1. Setting Adoption rate</b>	The proportion of sites eligible and contacted that participated.
<b>A2. Description of Targeted Location</b>	Characteristics that would be considered an ideal location for the intervention.
<b>A3. Inclusion/Exclusion Criteria of Setting</b>	Description of eligibility criteria for settings
<b>A4. Description of Intervention Location</b>	The explicit statement of characteristics of the location of the intervention
<b>A5. Method to Identify Setting</b>	Describe the process by which the location was identified for participation in the study
<b>A6. Average # of Persons Served Per Setting</b>	Calculated average number of participants at each site.
<b>A7. Staff Participation Rate</b>	The proportion of the staff that was eligible and contacted and participated

<b>A8. Method to Identify Target Delivery Agent</b>	Describe the process by which the target delivery agent was identified for participation in the study.
<b>A9. Description of Delivery Agent</b>	Characteristics of Staff
<b>A10. Level of Expertise of Delivery Agent</b>	Description of expertise (e.g. training) of delivery agents
<b>A11. Inclusion/Exclusion Criteria of Delivery Agent</b>	The explicit statement of characteristics of the delivery agents that were used to determine if a potential delivery agent is eligible to participate.
<b>A12. Measures of Cost Adoption</b>	Description of costs for intervention set-up
<b>IMPLEMENTATION</b>	
<b>I1. Theories</b>	Explicit statement of theories or principles used to develop the intervention
<b>I2. Intervention Number of Contacts</b>	Total number of encounters with participants
<b>I3. Timing of Contacts</b>	Describe when the intervention contacts occur over the course of the intervention.
<b>I4. Duration of contacts</b>	Length of each intervention contact
<b>I5. Extent to which intervention was delivered as intended</b>	Description of individual adherence, compliance, attendance and/or staff adherence
<b>I6. Consistency of intervention delivery</b>	Description of consistency across staff, time, settings and subgroups of participants
<b>I7. Participant Attendance/ Completion rates</b>	The proportion of the intervention that the participants received, on average.
<b>I8. Costs of delivery (ongoing costs)</b>	Description of costs (time, money)
<b>MAINTENANCE</b>	
<b>M1. Assessed outcomes ≥ 6 months</b>	Follow-up periods ≥ 6 months post-intervention
<b>M2. Drop-out rate to last follow-up</b>	% drop-out (if follow-up assessment ≥ 6 months)
<b>M3. Current status of programme</b>	Description of current status after end of study
<b>M4. Use of qualitative methods to measure individual or organisational level maintenance</b>	
<b>M5. Is the program still in place</b>	Description of program continuation after completion of the research study.
<b>M6. Adaptations made</b>	Description of adaptations made to foster sustainability of programme
<b>M7. Costs of maintenance</b>	Description of costs (money, time) related to sustainability of programme

## Reporting of RE-AIM Indicators Across all Included Studies

	REACH										EFFECTIVENESS							ADOPTION												IMPLEMENTATION								MAINTENANCE						
	R1	R2	R3	R4	R5	R6	R7	R8	R9	R10	E1	E2	E3	E4	E5	E6	E7	A1	A2	A3	A4	A5	A6	A7	A8	A9	A10	A11	A12	I1	I2	I3	I4	I5	I6	I7	I8	M1	M2	M3	M4	M5	M6	M7
Abbott et al. 2017 & Huether et al., 2016	+	-	+	+	+	-	-	+	-	-	+	-	-	+	+	-	+	+	-	-	+	-	-	-	-	+	+	-	-	+	+	+	+	-	+	+	+	-	-	+	-	Y	-	-
Borneman et al., 2010 & 2011	+	-	-	+	-	-	-,+	+	-,+	-	+	-	+	+	-	-	+, -	-	-	-	+	-	+	-	-	+	+	-	-	-	+	+	+	-	-	-	-	-	-	+	-	-	-	-
Jones et al., 2020	+	-	-	+	-	-	-	+	+	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	+	-	-	+	+	+	+	-	-	+	-	-	-	-	-	-	-	-
Tian et. al 2017	+	-	-	+	-	-	-	+	-	-	+	-	-	-	-	-	-	-	-	-	+	-	+	-	-	-	-	-	-	+	-	-	-	-	-	-	-	-	-	+	-	-	-	-
Van Gerpen & Becker, 2013	+	-	+	+	-	-	-	+	-	-	+	-	-	+	+	-	-	-	-	-	-	-	+	-	-	+	+	-	-	-	+	+	+	-	-	+	-	-	-	+	-	Y	+	-
Wang et al., 2018	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	+	-	-	-	-	-	-	-	-	+	-	-	-	-	+	-	-	-	-	-	-	-	-	

(N.A) Not Applicable, (+) reported, (-) not-reported, (Y) yes, (N) no.

## Appendix 2: Population Intervention Comparison Outcome (PICO) Selection Criteria (Study 1)

	Inclusion	Exclusion
Participants	<p>Cancer survivors (regardless of age, gender, tumour &amp; treatment type) at any stage of their cancer trajectory that experience fatigue.</p> <p>Self-described self-management interventions OR self-management models including at least one of the following intervention components:</p> <ul style="list-style-type: none"> <li>• information about cancer-related fatigue and/its management</li> <li>• information about managing psychosocial consequences of illness</li> <li>• information about available social support resources and navigating transitions</li> <li>• provision of /agreement on goal setting and specific clinical action plans and/or urgent problems</li> <li>• regular clinical review</li> <li>• monitoring of condition with feedback</li> <li>• practical support with adherence (medication or behavioural)</li> <li>• provision of equipment</li> <li>• provision of access to advice or support when needed</li> <li>• training rehearsal to communicate with healthcare professionals</li> <li>• training rehearsal for lifestyle adaptations and for everyday activities</li> <li>• training rehearsal for psychological strategies</li> <li>• social support</li> <li>• lifestyle advice and support</li> </ul>	<p>No intervention or any intervention other than those specified in the inclusion criteria.</p>
Control	<p>No intervention, a clearly defined usual or standard care or an alternative intervention.</p>	
Outcomes	<p>Must include one of the following primary outcomes:</p> <p>Primary:</p> <ol style="list-style-type: none"> <li>1. Fatigue (Severity, Interference, Distress)</li> </ol> <p>Secondary:</p> <ol style="list-style-type: none"> <li>1. Behavioural Outcomes (e.g., physical activity, diet, exercise, sleep, fatigue management self-efficacy, other self-efficacy outcomes - cancer self-efficacy, general self-efficacy, physical self-efficacy, etc)</li> </ol>	<p>Lack of at least one relevant pre-specified outcome</p>
Study Design	<p>Randomised controlled trials</p>	<p>Studies reporting non-randomised studies.</p>

## Appendix 3: Search Strategy SMS Systematic Review (Study 1) - Updated 20/06/2021

### Search Strategy for CINAHL

1. TI ( "self manage\*" OR "self care" OR "self efficacy" OR "self medication" OR "self admin\*" OR "self concept" OR "self help" OR "self monitor\*" OR "symptom management" ) OR AB ( "self manage\*" OR "self care" OR "self efficacy" OR "self medication" OR "self admin\*" OR "self concept" OR "self help" OR "self monitor\*" OR "symptom management" ) OR (MH "Self-Management") OR (MH "Self Care") OR (MH "Self-Efficacy") OR (MH "Self Concept") OR (MH "Self Administration" (MH "Self-Management") OR (MH "Self Care") OR (MH "Self-Efficacy") OR (MH "Self Concept") OR (MH "Self Administration"))
2. TI ( "cancer fatigue" OR "cancer related fatigue" OR "cancer-related fatigue") OR AB ( "cancer fatigue" OR "cancer related fatigue" OR "cancer-related fatigue") OR (MM "Cancer Fatigue") OR (MH "Cancer Fatigue") (MM "Cancer Fatigue")
3. TI ( S1 AND S2 ) OR AB ( S1 AND S2 ) **[275]**

### Search Strategy for EMBASE

1. 'self manage\*':ab,ti OR 'self care':ab,ti OR 'self efficacy':ab,ti OR 'self medication':ab,ti OR 'self admin\*':ab,ti OR 'self concept':ab,ti OR 'self monitor\*':ab,ti OR 'self help':ab,ti OR 'self care'/exp
2. 'cancer fatigue':ab,ti OR 'cancer related fatigue':ab,ti OR 'cancer fatigue'/exp/mj OR 'cancer fatigue'/exp
3. #1 AND #2 **[199]**

### Search Strategy for PUBMED

((((((((((("self management"[MeSH Terms] OR "self care"[MeSH Terms]) OR "self administration"[MeSH Terms]) OR "self efficacy"[MeSH Terms]) OR "self medication"[MeSH Terms]) OR "self concept"[MeSH Terms]) OR "self medication"[Title/Abstract]) OR "self management"[Title/Abstract]) OR "self care"[Title/Abstract]) OR "self administration"[Title/Abstract]) OR "self efficacy"[Title/Abstract]) OR "self concept"[Title/Abstract]) OR "self medication"[Title/Abstract]) AND ("cancer fatigue"[Title/Abstract] OR "cancer related fatigue"[Title/Abstract]) **[86]**

### Search Strategy for COCHRANE CENTRAL

1. MeSH descriptor: [Self Medication] explode all trees
2. MeSH descriptor: [Self Efficacy] explode all trees
3. MeSH descriptor: [Self-Management] explode all trees
4. #1 OR #2 OR #3 OR "self management" OR "self care" OR "self efficacy" OR "self medicat\*"
5. "cancer related fatigue" OR "cancer fatigue"
6. #4 AND #5 **[118]**

#### Appendix 4: Summary of Study Characteristics for Systematic Review (Study 1)

Citation & Country	Study Design	Intervention Aim	Population	Cancer Type	Timing	Inclusion Fatigue Cut-off Score	Sample Size	Control Name & Description	Intervention Name & Description	Mode of Delivery	Intervention Delivery agent	Intervention Timing and Duration	# of Self-management Support Taxonomy Components
Abrahams et al., 2017 Netherlands	2-arm RCT	To improve severe fatigue	Severely fatigued breast cancer survivors (who had completed treatment with curative intent at least 3 months prior).	Breast	Post Tx	CIS-FS $\geq$ 35	N=132 INT: 66 CONT :66	Participants placed on 6-month waiting list for F2F CBT, included oncological follow-up examinations and referral for psychosocial care. No restriction on the use of fatigue interventions.	Internet based cognitive behavioural therapy. 3 F2F sessions and 8 web-based treatment modules. 2 initial F2F sessions (goal setting, & treatment plan). Therapists use assessment tools to assess which treatment modules each survivor should complete (minimum of 3). Completion of online modules (Modules 1 and 8 compulsory) – therapists provide feedback answer questions via email/ video consult. Final F2F session (discussion fatigue severity outcomes) after the completion of online modules.	Web-based & F2F  Individual	HP: Licensed cognitive behavioural therapists experienced in working with fatigued cancer survivors.	Max duration 6 months. 2 initial F2F sessions. 8 online modules. Bi-weekly email correspondence from therapists (also option for 2 video calls max).	8
Armes et al., 2007 UK	2-arm RCT	To improve CRF related thoughts and behaviour.	Adult patients with significant fatigue undergoing active chemo.	Any	During Tx	Self-reported fatigue	N=55 INT: 28 CONT:27	Usual care. CRF not assessed routinely & management advice given in an ad hoc manner.	Behaviour oriented intervention that provided cognitive and physical strategies for managing CRF.	F2F  Individual	Research fellow trained to deliver INT using study manual.	6-9 weeks. 3 sessions, 60-min. Delivered every 3 to 4 weeks.	6
Bantum et al, 2014 USA	2-arm RCT	Determine the effectiveness of a web-based behaviour program on fatigue.	Adult cancer survivors who had at completed primary treatment at least 4 weeks prior.	Any	Post Tx	Not assessed	N=303 INT: 156 CONT:147	Waitlist control	Six session online education course/ workshop. 20-25 survivors per cohort (9 cohorts total). Each week of course content includes approx. 30-35 webpages of didactic content. Program content includes skill building, problem solving, action planning to build self-efficacy, etc.	Web-based  Enables group discussion via forums	Peers: Cancer survivors (2 per cohort) with intensive online training about intervention materials and how to respond to user comments and goals	6 weeks. New topic completed weekly	9
Barsevick et al., 2004 USA	2-arm RCT	Evaluate efficacy of energy conservation and activity management on CRF	Adult cancer survivors initiating chemo, RT, or concurrent therapy.	Breast, lung, colorectal, prostate, gynaecologic, bladder, testicular cancer, or lymphoma  (mostly breast)	During Tx	Not assessed	N=396 INT: 200 CONT:196	Attention control. Information on nutrition and healthy diet.	Energy Conservation and Activity Management (ECAM). Three oncology nurse-led telephone sessions. After session 1 participants complete fatigue monitoring journal and assess activity patterns. Journal used to create energy conservation plan in session 2. In session 3 the plan was evaluated and revised.	Telephone  Individual	HP: Oncology nurse with 8 hours of counsellor training and individual case supervision.	Total duration varied, approx. 3 weeks. Three phone sessions during the first 3 weeks of chemo or weeks 3-5 of radiotherapy.  Session 1 & 2: 30 minutes Session 3: 15 minutes	6



Barsevick et al., 2010 USA	2-arm RCT	Evaluate efficacy of energy and sleep enhancement on fatigue and sleep disturbance and functional status in chemo pts.	Adult cancer survivors commencing chemo.	Breast, lung, colorectal, prostate, gynaecologic, bladder, testicular cancer, or lymphoma (mostly breast)	During Tx	Not assessed	N=292 INT:153 CONT:139	Attention control. Information on nutrition and healthy diet	Energy and sleep enhancement. Three oncology nurse-led telephone sessions and a handbook relating to the intervention (consisting of and examples of energy conservation and sleep management strategies) detailing information on CRF, and coping skills.	Telephone Individual	HP: Oncology nurse	Total duration varied. Three phone sessions during the second, third and fourth weeks after chemotherapy.	6
Bennet et al., 2007 USA	2-arm RCT	Evaluate effect of motivational interviewing on increasing self-efficacy, physical activity, aerobic fitness and CRF.	Adult cancer survivors who completed primary treatment at least 6 months prior to enrolment.	Any	Post Tx	Self-reported fatigue	N=56 INT: 28 CONT: 28	Usual care. Maintenance of current physical activities	One initial F2F MI counselling session & 3 subsequent MI phone calls to assist with problem solving.	F2F & Telephone Individual	HP: Physical activity counsellor with 8hrs group training and 6hrs individual training in MI by an experienced MI trainer.	4.5 months. One 30- min counselling session. 20 min telephone call at 2 weeks, 2 months, and 4.5 months after initial F2F session.	5
Bruggeman-Everts et al., 2017 Netherlands	3-arm RCT	To reduce chronic cancer related fatigue	Adult participants who had completed curative treatment at least 3 months prior	Any	Post-Tx (hormonal treatment allowed)	CIS-FS $\geq$ 35	N=167 AAF: 62 eMBCT:55 CONT: 50	Active control. Psychoeducation. Received automatic 'no-reply' emails detailing possible causes of fatigue and information on sleep hygiene, energy balance and coping with worry.	Trial investigating the effectiveness of 2 web-based interventions: Ambulant Activity Feedback therapy (AAF) – (physical activity coaching) and electronic Mindfulness-based Cognitive Therapy eMBCT. <b>AAF:</b> ambulant activity coaching system, supported weekly by a physiotherapist through email. Participants work to achieve personal goals created in collaboration with the physiotherapist. Patients have access to real-time feedback, can monitor their past personal activity, gain access to their activity pattern, and then increase/ balance daily activity to improve energy levels. <b>eMBCT:</b> psychologist guided online program that provides audio mindfulness exercises and information about a different mindfulness exercise each week. Patients can write down their experiences in a log following their exercises which a therapist then responds to weekly.	Web-based Individual	<u>HP</u> eMBCT: psychologist (provided guidance remotely).  AAF: home based physiotherapist	AAF: 3hrs per week for nine weeks  eMBCT: 4hrs per week for nine weeks	8
Chan et al., 2011 China	2-arm RCT	Examine effectiveness of psychoeducation	Stage III or IV Lung cancer survivors	Lung (III-IV)	During Tx	Not assessed	N=140 INT: 70 CONT: 70	Usual care. 5-7 min briefing of radiotherapy procedure and	Psychoeducational intervention consisting of education sessions on symptom management and	F2F Unclear if group or individual	HP: Registered nurses with at least 2 years of clinical	4 weeks. 40-min education delivered one week prior to	6

		on intervention on anxiety, breathlessness and fatigue	aged 16 years and older who were scheduled to receive palliative RT.					skin care side effects; and optional group talk session on general care	progressive muscle relaxation coaching.		experience. 2-day training session on INT and progressive muscle relaxation provided.	commencing RT, and repeated three weeks after beginning RT.	
Dodd et al., 2010 USA	3-arm RCT	Evaluate effectiveness of home-based exercise on CRF management.	Adult female cancer survivors beginning chemo treatment.	Breast, colorectal, ovarian	Group 1 (INT): During & Post Tx  Group 2: Post Tx	Not assessed	N= 119 (Group 1): 44 (Group 2): 36 CONT: 39	Usual Care. No exercise prescription.	Pro-Self Fatigue Control Program. Home-based exercise training intervention consisting of three main components: CRF knowledge, self-management skills to manage CRF, coaching to support the continuation of positive behaviours. Included a tailored exercise prescription that was adjusted through weekly follow-up phone calls. Group 1: INT provided before & after chemo	Home based  Individual	Unclear – nurse?	Group 1: 1 year Group 2: 6 months	6
Donnelly et al., 2011 UK	2-arm pilot RCT	Evaluate efficacy of a physical activity behavioural change intervention in managing CRF among gynaecological cancer survivors	Adult gynaecological cancer survivors currently undergoing treatment or post-treatment (<3 years of diagnosis)	Gynaecological cancer (stage I-III)	Post Tx	Moderate (4-6) or severe (7-10) on a scale from 1 to 10	N=33 INT=16 CONT=17	Usual care (not specified).	Home-based physical activity intervention (walking and strengthening exercises). Consisted of initial physiotherapist consultation, subsequent weekly phone calls and a final F2F consultation.	F2F & Telephone  Individual	Unclear – Physiotherapist?	12 weeks. At least 5 times a week (30 minutes)	7
Fillion et al., 2008 Canada	2-arm RCT	Effectiveness of stress-management and psychoeducation program on fatigue, energy level and QOL	Adult female breast cancer survivors who had completed treatment at least 2 years prior	Breast	Post Tx	Not assessed	N=87 INT:44 CONT:43	Usual care. General information	Stress management psychoeducation and supervised physical activity. Participants also given home-based relaxation assignments for stress/fatigue management.	F2F & Home-based  Group	HP: Kinesiologist or research nurse supervised walking training.  2 oncology nurses delivered psychoeducation sessions.  (Trained & supervised by a health psychologist in CBT – 10hours & 6hours reading)	4 weeks. 4 weekly group meetings of 2.5hrs and one telephone booster session (5–15 min)	8
Foster et al., 2016 UK	2-arm RCT	Increase self-efficacy to manage CRF	Adult patients experiencing CRF who have completed primary treatment at least 5 years prior	Any	Post Tx	≥ 4 on an 11-point rating scale	N=163 INT: 83 CONT: 76	Usual Care. Fatigue education leaflet	Self-management support web program. Five sessions (1. Intro. 2. Goal setting. 3. Exercise, diet, sleep, work, home. 4. Thought & feelings. 5. Talking to others). Additional activities: patient stories (video & text) used to provide examples of CRF management; links to relaxation and mindfulness	Web-based  Individual	Self-directed (online)	Participants given 6-week access. Five (2 compulsory, 3 non-compulsory), 30-min sessions, delivered weekly.	7

									training and information on financial support.				
Freeman et al., 2015 USA	3-arm RCT	Evaluate the benefit of imagery-based education on QOL	Adult breast cancer survivors a least 6 weeks post treatment	Breast	Post Tx	Not assessed	N= 118 Live Delivery: 48 Telemed: 23 CONT:47	Waitlist control	Imagery-based group behavioural intervention. First 4 sessions separated into three modules consisting of didactic education, group interaction and guided imagery. Brief 10 min weekly phone calls to encourage home-based practice (continued for 3 months post treatment). Study compared live and telemedicine deliveries of intervention.	F2F or telemedicine  Group	HP: Licensed professional counsellor, and a family medicine physician	5 weeks. Five 4hr sessions delivered weekly.	6
Galiano-Castillo et al., 2016 Spain	2-arm RCT	To improve adverse effects in breast cancer survivors.	Adult female breast cancer survivors who had completed adjuvant therapy	Breast (I-III A)	Post Tx	Not assessed	N=81 INT: 40 CONT: 41	Usual care-written exercise information	Internet-based exercise program tailored to each participant. Each program session consisted of warm-up, resistance & aerobic training, and cool-down. Program staff monitored participant performance and feedback remotely.	Telemedicine  Web-based  Individual	Unclear: e-cuidate research staff?	8 weeks. Three 90-min training sessions per week (non-consecutive days)	5
Godino et al., 2006 Spain	2-arm RCT	Investigate the impact and satisfaction of a nursing education program on fatigue severity	Gastric and Colon cancer survivors between 30 and 75 years – before, during and after chemotherapy treatment	Gastric & Colon	Post and During Tx	Not assessed	N=40 INT: 23 CONT: 17	Usual care. Written information	Patient education program that included training, counselling, and educational materials.	F2F  Individual	HP: Oncology nurses	Three sessions. Session 1 – first cycle of chemo, session 2, second cycle of chemo, session 3, 1-month after treatment.	4
Gokal et al., 2015 UK	2-arm RCT	To improve psychosocial health outcomes among breast cancer patients	Breast cancer survivors aged 18 to 75 about to commence chemo.	Breast (I-III)	During Tx	Not assessed	N=50 INT: 25 CONT: 25	Usual care (not specified)	Home-based walking intervention consisting of moderate intensity walking and guidance recommendations (intervention booklet).	Home-based  Individual	Unclear – research staff?	12 weeks	4
Golsteijn et al., 2018 Netherlands	2-arm RCT	To increase physical activity in prostate and colorectal survivors.	Adult prostate and colorectal cancer survivors undergoing curative treatment or who have completed primary treatment up to a year prior.	Prostate & Colorectal	During and Post Tx	Not assessed	N=510 INT: 266 CONT:244	Waitlist control	Computer-tailored physical activity program. Participants received physical activity advice (via a secure website and mail) automatically generated from a message library, questionnaire data and computer data-driven decision rules. Also had access to interactive content on website comprising of home exercise instruction videos, expert consultation with physical therapist, discussion groups, and other background information.	Web-based  Individual	No delivery agent: guidance automatically generated using computer decision making	3-4 months. Three computer-tailored advice messages delivered each month. Three sessions.	6
Gregoire et al., 2020 Belgium	2-arm RCT	To improve fatigue and associated symptoms	Adult cancer survivors who have completed active treatment	Any	Post Tx	(Score of at least 4 out of 10 on 1 of these 6 items: physical	N=95 INT: 48 CONT: 47	Waitlist control (received intervention 4 months later).	Group intervention combining self-care and self-hypnosis. 8 sessions comprising of relaxation exercises, information and 15-min self-hypnosis (under therapist	F2F  Group	HP: Anaesthetist and an international expert in hypnosis.	8-week duration. 8 Weekly, 2-hour sessions.	4

			since less than a year.			fatigue, moral fatigue, depression, anxiety, fear of recurrence, ruminations)			supervision) at the end of each session. Participants completed self-care tasks at home in between sessions.				
Hoffman et al., 2017 USA	2-arm pilot RCT	To improve self-efficacy for fatigue self-management	NSCLC survivors at least 21 years old who were undergoing primary care surgery	NSCLC	During Tx	Not assessed	N=87 INT: 47 CONT:40	Usual care standard medical care from health care providers	Perceived self-efficacy - enhancing (PSE) CRF self-management education. Content based on the NCCN CRF guidelines. Nurse home visit scheduled when pt. ready to begin exercise. Exercise program conducted at home via Nintendo Wii Fit Plus (nurse installed console at participants home) and involved incremental increase of walking minutes to result in 30 minutes of walking per day by end of the intervention. Balance exercises also completed 5 days a week. Nurse adjusted exercise prescription each week.	F2F & Phone Home- based  Individual	HP: Primary registered nurse	6 weeks duration. End goal to achieve 30 min of walking for 5 days during the week.	8
Johns et al 2015 USA	2-arm pilot RCT	Examine efficacy of mindfulness-based stress reduction for CRF	Adult cancer survivors who reported CRF for longer than 8 week and were at least 3 months post treatment.	Any	Post Tx	FSI $\geq$ 4	N=35 INT: 18 CONT: 17	Waitlist control	Mindfulness based stress reduction. Guided training during class and through audio recordings outside of class on mindfulness meditation practices (i.e., body scan, sitting meditation, hatha yoga, walking meditation, and compassion meditation). Brief psychoeducation related to CRF.	F2F  Group	HP: Instructor with 6 years MSBR teaching experience (MSBR Teacher Certification)	7 weeks. 2hrs each week.	6
Johns et al., 2016 USA	2-arm pilot RCT	Examine efficacy of mindfulness-based stress reduction for CRF compared to an active comparator	Adult breast and colorectal patients with non-metastatic disease more than 3 months and less than 5 years post-treatment (RT, chemo) experiencing severe fatigue.	Breast & Colorectal I (Stages 0-III)	Post Tx	FSI $\geq$ 4	N=71 INT:35 CONT:36	Attention Control. Psychoeducational support. 8-week group class 2hr weekly. Education on fatigue management, group discussion weekly readings.	Mindfulness based stress reduction. Guided training during class and through audio recordings outside of class on mindfulness meditation practices (i.e., body scan, sitting meditation, hatha yoga, walking meditation, and compassion meditation). Brief psychoeducation related to CRF.	F2F  Group	HP: Physician and a doctoral-level clinical health psychologist with 9 and 3 years of MBSR teaching experience, respectively.	8 weeks. 2hrs each week.	7
Johnston et al., 2011 USA	2-arm pilot RCT	To relieve CRF	Breast cancer survivors between 18 and 65 who had completed	Breast	Post Tx	BFI $\geq$ 4	N=13 INT: 6 CONT: 7	Usual care. Received normal practice from their personal physicians which included	Education + acupuncture. Education component involved teaching patients self-care techniques alongside an eight-session program that involved administering acupuncture. Acupuncture	F2F  Individual	HP: Acupuncturist with over 10 years of cancer experience.	8 weeks. 4-weekly self-care sessions. 8 weekly acupuncture sessions.	6

			primary treatment and were cancer free.					pharmacological and non-pharmacologic options.	administered according to STRICTA Acupuncture protocol. Participants also received usual care.				
Lam et al., 2018 China	2-arm RCT	To promote physical activity, reduce fatigue, enhance self-efficacy muscle strength and QOL in children with cancer	Individuals aged 9-18 years diagnosed with cancer within previous 2-months	Any	During Tx	Not assessed	N=70 INT: 37 CONT: 33	Attention control: 15-minute health education talk, medical follow up, home visits mimicking the INT, & placebo INT activities (playing chess/cards, diet & influenza advice).	Integrated physical programme with 28 home visits from nurse coaches over a 6-month period. Coaches provided physical activity management strategies and health information.	F2F, Home visit  Individual	HP student: Nursing student (n=16) (enrolled in bachelor's degree year 2 or above. Attended a 1-day training workshop and were required to pass 2 exams).	6-months. Coaches visited their assigned participants twice per week for the first 4 weeks, and then once per week for 20 weeks. Each visit = 1hr.	5
Lee 2014 South Korea	2-arm pilot RCT	To promote exercise and dietary behaviours for breast cancer survivors.	Adult breast cancer survivors who completed cancer within 12 months prior and were diagnosed within 2 months prior	Breast (0-III)	Post Tx	Not assessed	N=59 INT: 30 CONT: 29	Attention Control: 50pg educational booklet on exercise and diet	Web-based self-management exercise and diet intervention. 5 modules comprising of exercise and dietary education, assessments, action planning and automatic feedback.	Web-based  Individual	Self-directed (no interaction with any health professionals)	12 weeks. Pts encouraged to access the platform twice weekly.	5
Li et al., 2018 Hong Kong/ China	2-arm RCT	To promote physical activity, reduce fatigue and enhance self-efficacy	Cancer survivors aged 9-16 years who had completed cancer treatment at least 6-months previously	Any	Post Tx	FS-C $\geq$ 25	N=222 INT: 117 CONT:105	Attention control. 4 days engaged in different leisure activities organised by a community centre over a 6-month period (e.g., cartoons, chess, handcraft, health education on influenza and diet, theme parks, museums)	Adventure-based training program conducted at campsite. Comprised a 40-min briefing session covers brief health education components, and adventure activities with increasing levels of difficulty.	F2F Group (12 participants session)	HP: 2 adventure-based trainers & registered nurse	4 separate training days delivered 2 months apart (2 weeks after randomisation and at 2, 4 and 6 months)	2
Mooney et al., 2016 Canada	2-arm RCT	To reduce chemo related symptoms	Adult cancer survivor beginning a course of chemo (excl. concurrent RT)	Any	During Tx	Not assessed	N=358 INT: 180 CONT:178	Attention control. Enhanced usual care – Automated telephone interactive voice response symptom reporting system without nurse care. Reminded to call practitioner for concerns.	Telephone-based interactive voice response system included daily home monitoring of chemo symptoms with nurse provider alerts for poorly controlled symptoms. System used patient-reported data to provide tailored automated algorithm-based self-care management messages. Messages comprised of coaching content based on symptom severity level and other habits. Poorly managed symptoms (fatigue at level	Telephone based symptom reporting system  Individual	HP: Nurse practitioner & automated service	Symptoms reported daily during chemo for mean of 77 days	5

									≥4/10 for 3 days) triggered calls from nurses who then provided more intensive care.				
Naraphong et al., 2015 Thailand	2-arm pilot RCT	To improve fatigue related symptoms (fatigue, symptom distress, physical fitness, sleep, mood disturbance)	Adult female breast cancer survivors receiving adjuvant chemo	Breast	During Tx	Not assessed	N=23 INT: 11 CONT: 12	Attention control. Typical support services provided through the cancer centre, plus 2 booklets on 'general issues about breast cancer' and self-care activities for chemo, DVD on self-care after breast surgery & weekly phone calls.	Program comprised of exercise interventions tailored to relevant to Thai physical activities. 12-week self-directed culturally sensitive exercise program. Initial training session included and an exercise kit containing written instructional materials, a pedometer, and exercise logs. Subsequent intervention sessions were scheduled during regular clinic visits.	F2F Individual	Not recorded who provided exercise prescription  Peer: Family member invited as a coach to help the participant identify appropriate activities, self-directed	12 weeks. Initial session 45min, subsequent sessions 30-40min.  Weekly phone calls to monitor progress	6
Purcell et al, 2010 Australia	Factorial RCT (4-arm RCT)	Reduce severity of fatigue in RT pts.	Adult cancer survivors scheduled for 20 or more days of curative RT.	Any	During Tx	Not assessed	N=110 Group 1 (Pre- and post-RFES): 27 Group 2 (Pre-RFES): 28 Group 3 (Post-RFES): 27 Group 4 (No RFES): 28	Usual care. One-on-one verbal nursing education & flyer on generic fatigue information.	Radiotherapy fatigue education and support (RFES). Content on RT processes, treatment side effects, and behavioural strategies to reduce fatigue. Education delivered via PPT presentation 1 week prior to RT planning and/or 1-2 weeks after RT completion.	F2F Group	HP: Nurse	60min education session.	5
Ream et al., 2006 UK	2-arm RCT	Evaluate a supportive/educative approach to managing CRF	Cancer survivors aged 18-70 due to commence first cycle of chemo	Non-Hodgkin's lymphoma, gastrointestinal, non-small cell lung, colorectal, breast, or unknown primary cancer.	During Tx	Not assessed	N=103 INT: 48 CONT: 55	Usual care. Assessment of fatigue and education provided in ad hoc manner.	Assessment/monitoring of fatigue; education on fatigue; coaching in self-care; and provision of emotional support. Self-care counselling on energy conservation and management of activity and functioning.	F2F, Home visit Individual	HP: Cancer nurse with counselling qualifications and CRF knowledge	Intervention provided over the first three treatment cycles (3 months).	7
Ream et al., 2015 UK	2-arm pilot RCT	Reduce fatigue severity	Adult cancer survivors scheduled for first course of intravenous chemo	Breast, colorectal, lymphoma	During Tx	Moderate fatigue or higher (NCCN definition - a score of 4 or above on a numeric rating scale from 1 to 10	N=44 INT: 23 CONT: 21	Usual care-screening for fatigue, limited self-care advice and referral.	Resource pack containing 'Coping with Fatigue' booklet, fatigue diary & handbook. Motivational interviewing delivered via telephone.	Telephone Individual	HP: Cancer Nurse received 10-week module on motivational interviewing	Three calls delivered over 3 treatment cycles. First call approx. 40min, final two calls 20min	6

Reif et al., 2013 Germany	2-arm RCT	To reduce perceived fatigue in cancer survivors	Adult cancer survivors diagnosed with malignant tumours (excl. brain cancer pts.) who have completed active treatment.	Malignant cancers excl. brain metastases	Post Tx	Moderate (4-6) or severe (7-10) on a scale from 0 to 10 (NCCN CRF guidelines)	N=261 INT: 132 CONT:129	Waitlist control	Patient education program. Content included information on causes and fatigue management, time, energy, and sleep management, coping with emotions and adopting appropriate management strategies.	F2F Group (groups of 8)	HP: Nurses and psychologists (authors note the intervention can be carried out by any HP). Trainers attended 2-day workshop.	6 weeks. 6 sessions, 90min each delivered weekly.	7
Ritterband et al., 2012 USA	2-arm pilot RCT	To improve insomnia in cancer survivors	Cancer survivors aged 21 or older, in remission at least 1 month post treatment	Any	Post Tx	Self-reported experiences of fatigue (no questionnaire)	N=28 INT: 14 CONT: 14	Waitlist control	Internet CBT program with education on sleep hygiene, sleep restriction stimulus control, and relapse prevention. Program incorporates tailored feedback.	Web-based Individual	Unclear. 'research staff'	Can be completed over 6-9 weeks. 6 modules (approx. 45-60min to complete)	8
Sandler et al., 2017 Australia	2-arm RCT	To improve post-cancer fatigue	Breast & colon cancer survivors who have completed primary treatment between 3 and 12 months prior	Breast & colon	Post Tx	SOMA $\geq$ 3	N=46 INT: 22 CONT: 24	Attention control. Education package comprising of written CBT booklet & and single session with exercise physiologist and clinical psychologist	CBT and graded exercise therapy program. Comprised of 5 consultations with exercise physiologist and 6-8 sessions with a clinical psychologist. Compulsory modules on activity pacing, graded exercise therapy, sleep-wake cycle management, neurocognitive disturbance management. Optional modules on coping enhancement, and depression and anxiety management.	F2F Individual	HP: Exercise physiologist Clinical psychologist	12 weeks	10
Savard et al., 2005 Canada	2-arm RCT	To improve chronic insomnia	Adult female breast cancer survivors with insomnia (caused/aggravated by cancer) who had completed primary treatment at least 1 month prior	Breast (I-III)	Post Tx	Not assessed	N=57 INT: 27 CONT: 30	Waitlist control	CBT program that combined the use of stimulus control, sleep restriction, cognitive therapy, sleep hygiene, and fatigue management.  Multimodal approach combined behavioural, cognitive, and educational strategies.	F2F Group	HP: Master-level psychologist (experience with INT protocol).	8 weeks. 8 sessions approx. 90 min delivered weekly	5
Schjolberg et al, 2014 Norway	2-arm RCT	To manage fatigue in women with early breast cancer	Adult female cancer survivors who had completed a form of curative treatment for early-stage breast cancer	Breast (I-II)	Post Tx	NRS $\geq$ 2.5	N = 160 INT: 79 CONT: 81	Usual care. Standard F2F care (info on general issues associated with living with cancer) provided by nurses and radiotherapists in outpatient clinic	Educational intervention to improve knowledge and skills. PPT presentation, patient booklet, group discussions. Education comprised of strategies to reduce fatigue, promote balance between activity, guide energy conservation and promote restorative activities.	F2F Group (approx. 10 per group)	HP: 2 cancer nurses experienced in education.	3 weeks. Three 2hr sessions delivered weekly	6

Smith et al., 2019 USA	2-arm RCT	To manage pain and associated symptoms in cancer survivors	Adult breast cancer survivors with chronic pain	Breast	During & Post Tx  Any time point	Not assessed	N=89 INT:37 CONT: 52	Waitlist control	Online symptom self-management curriculum. Comprises of online videos, cognitive reframing exercises, mind-body exercises, compulsory online introductory group meeting.	Web-based  Individual (one online group meeting)	Self-directed – asynchronous. Live online group meeting led by master's level therapist	10 weeks. 10 online sessions delivered weekly	1
Spahn et al., 2013 Germany	2-arm RCT	To improve chronic fatigue symptoms of women with stage I-III breast cancer	Adult female breast cancer survivors who have completed primary treatment at least 3 months prior.	Breast (I-III A)	Post Tx	>40mm on 100mm VAS	N=64 INT: 32 CONT: 32	Attention control – home based walking treatment	Walking treatment and multimodal mind-body medicine treatment (MMMT) program. MMTT included nutrition counselling, relaxation exercises, physical exercises, stress reduction, cognitive restructuring, and hydrotherapy. Supervises walking sessions.	F2F Group (10 -20 per group)	HP: Sports therapist delivered walking sessions	10 weeks. 10 walking sessions and one 6-hr mind body session completed weekly.	5
Stanton et al., 2005 USA	3-arm RCT	To improve fatigue, energy and cancer specific distress.	Adult female breast cancer survivors 6 weeks post-surgery	Breast (I-II)	Post Tx	Not assessed	N=558 INT 1:187 INT 2: 184 CONT:187	Usual care – 43pg 1994 National Cancer Institute- Facing <i>Forward</i> publication	INT 1: Videotape – 23 min film addressing re-entry challenges in four life domains: physical health, emotional well-being, interpersonal relations, and life perspectives.  INT 2: psychoeducational counselling. One F2F and one telephone session incorporating a review of pt. cancer-related concerns in four domains, setting, action planning, Video tape (INT 1), 60pg manual.	INT 1: self-directed, video  INT 2: F2F, telephone  Individual	HP: Trained cancer educators (social worker, psychologist) masters or PhD level education received full day training session (guided by INT manual).	<u>INT 2</u> F2F session: 80min; telephone session: 30 min (delivered 2 weeks after F2F session)	6
Steel et al., 2016 USA	2-arm RCT	To reduce depression, pain, fatigue in an advanced cancer population	Advanced cancer survivors and family caregivers aged at least 21 years	hepatocellular, gallbladder, neuroendocrine, pancreatic carcinoma, cholangiocarcinoma, or other primary cancers that had metastasized to the liver	Post Tx	Not specified – <i>authors expected survivors would experience symptoms over the course of the INT</i>	N=261 INT: 144 CONT:117	'Enhanced usual care. Usual care provided by medical care + contact by care-coordinator & appropriate referral if symptoms for pain and depression were high	Web-based stepped collaborative care intervention comprising of psychoeducational website & collaborative care coordinator. Coordinator provided CBT, and recommendation for symptom management. Website included symptom tracking, symptom info, diary taking, peer chat room, audio-visual library, resource library.	Web-based, Telephone & F2F  Individual	HP: Therapist trained in CBT and with experience in cancer care (master's or PhD level)	6 months. Telephone contact with care coordinator fortnightly, F2F contact every 2 months.	7
Vallerand et al., 2017 Canada	2-arm RCT (phase II)	Increase aerobic exercise behaviour in haematologic cancer survivors	haematologic cancer survivors aged 18-80	leukaemia, non-Hodgkin lymphoma, Hodgkin	Unclear	Not assessed	N=51 INT: 26 CONT: 25	Attention control. Self-directed exercise (Canada's Physical Activity	Exercise telephone counselling. Consisting of exercise prescription, physical activity guidelines and counselling sessions incorporating action planning, goal setting, coping	Telephone  Individual	Unclear	12 weeks. Weekly telephone counselling sessions.	7



		(content on fatigue)		lymphoma				guideline + exercise goal (60-300min/week of weekly moderate-to-vigorous aerobic exercise)	planning, self-monitoring, and self-regulation activities.				
Van der Lee et al., 2012 Netherlands	2-arm RCT	Reduce severe chronic fatigue in cancer survivors	Adult cancer survivors who had completed treatment at least 1 year prior.	Any	Post Tx	CIS-FS $\geq$ 35	N=100 INT: 72 CONT: 28	Waitlist control	Mindfulness-based cognitive therapy (MBCT). Comprised of information on the stress-coping model, and strategies for coping with pain and fatigue, recognising unpleasant experiences, coping with negative emotions and communication.	F2F Group	HP: Therapist. Had received mindfulness-based stress reduction training courses with Kabat Zinn	9 weeks. Eight weekly sessions of 2.5 h and one 6h session, plus one 2.5 h follow-up session 2 months after the ninth session. Total hrs 28.5h.	6
Van Waart et al., 2015 Netherlands	3-arm RCT	To maintain or enhance physical fitness and minimise fatigue in patients undergoing adjuvant chemo.	Adult cancer survivors scheduled to undergo chemo.	Breast, colon cancer	During Tx	Not assessed	N=230 OnTrack: 76 Onco-Move: 77 CONT: 77	Usual care. Varied depending on hospital setting. Did not involve exercise	Onco-Move. Low intensity home-based physical activity program. OnTrack - moderate-to-high intensity, combined resistance and aerobic exercise program supervised by physical therapists.	Onco-Move: Home based Individual  OnTrack- F2F, individual	HP Onco-Move specially trained nurses  OnTrack: specially trained physical; therapist	From first cycle of chemo to 3 weeks after last chemo cycle. Onco-Move: 30 min of physical activity per day, 5 days per week.  OnTrack: 2 60min sessions per week.	3
Van Weert et al., 2010 Netherlands	3-arm RCT	To reduce cancer related fatigue	Adult cancer survivors who received treatment at least 3 months prior	Any	Post Tx	Reporting increased fatigue to physician	N=213 (PT+CBT) :76 PT: 71 CONT: 66	Waitlist control	Rehabilitation program. PT: 24 hrs of individual physical training and 24hrs of group sports & activities. Training based on pt. goals. Information on exercise & fatigue provided.  PT+CBT: Physical training combined with CBT. See above for PT component. CBT consisted of information and coping strategies for stress, exercise, physiology, and relaxation. Problem solving, goals setting, decision making skills taught.	PT: F2F Individual, Group  CBT: F2F Individual	HP PT: 2 physical therapists with cancer survivor experience.  CBT: 2 psychologists  Trained with a manual.	12 weeks. PT: 2 times per week for 1hr.  CBT: once a week, 2 hours per session	7
Vargas et al., 2014 USA	2-arm RCT	To improve sleep quality and fatigue	Adult female early breast cancer survivors who had undergone lumpectomy or mastectomy	Breast (I-III)	During Tx	Not assessed	N=240 INT: 120 CONT:120	Attention control. Standard care + 1 day 6h psycho-education session	Cognitive behavioural stress management (CBSM) program comprising of didactic presentations, instruction in CBT techniques and relaxation exercises, and home practice exercises in participant workbook.	F2F Group (up to 8)	Unclear	10 weeks. Ten 2hr sessions delivered weekly.	3
Wang et al., 2011 Taiwan	2-arm RCT	To improve fatigue QOL, sleep disturbances,	Female cancer survivors aged 18 to	Breast (I-II)	During Tx	Not assessed	N=72 INT: 35 CONT: 37	Usual care – not specified	Low-to-moderate intensity walking program. Incorporated heart rate ring monitor, pedometer, weekly phone call,	F2F, phone Individual	HP: Nurses	6 weeks. Sessions and phone calls delivery weekly.	6

		exercise self-efficacy, exercise capacity and exercise behaviours	72 with early breast cancer who had undergone surgery and were scheduled for chemo						meetings & exercise diary, and a role model story.				
Wangnum et al., 2013 Thailand	2-arm RCT	To improve fatigue	Lung cancer survivors aged between 45 and 65 years who had received at least one round of 47 platinum-based chemo	Lung (III-IV)	During Tx	Not assessed	N=60 INT: 30 CONT: 30	Unclear if usual care. Cancer nurse provided service & information. Pts received 30min training on how to exercise during chemo sessions, and instructions to take home and review.	Multidisciplinary education program in self-care fatigue. Sessions comprised of breathing exercises, physical activity coaching and exercises, nutritional assessment and advice and information & exercises for coping with depression.	F2F Individual	HP: Physical therapist, nutritionist, psychological nurse	9 weeks. Four F2F sessions delivered every three weeks. Session 1 was approx. 90min and remaining three sessions were 60min each.	7
Willems et al., 2017a & 2017b Netherlands	2-arm RCT	To manage psychosocial and lifestyle-related issues	Adult cancer survivors who had completed primary treatment at least 4 weeks prior, but longer than 56 weeks.	Any	Post Tx	Not assessed	N=518 INT: 265 CONT:253	Waitlist control	Web-based psychosocial education program. 8 modules covering return to work, fatigue, anxiety and depression, social relationships and intimacy issues, physical activity, diet, and smoking cessation.	Web-based Individual	Self-directed online	Given access to the program for 6 months.	9
Yates et al., 2005 Australia	2-arm RCT	To improve CRF	Adult female breast cancer survivors commencing adjuvant chemo.	Breast (I-II)	During Tx	Not assessed	N=110 INT: 57 CONT: 53	Attention control. General cancer education sessions with oncology nurse. One F2F session, two telephone sessions. Delivered weekly.	Fatigue psychoeducational support program. Identification of pt. needs and coping strategies provided accordingly. Preparation of fatigue management plan/ Patient booklet (published by Oncology Nursing Society) to supplement sessions.	F2F. telephone Individual	HP: Nurses	3 weeks. Three 10-20min sessions delivered weekly. Session 1 F2F, Session 2&3 via telephone.	7
Yun et al., 2012 South Korea	2-arm RCT	To improve CRF	Cancer survivors aged 20 to 65 years who have completed primary treatment within the past 24 months	Any (I-III)	Post Tx	BFI ≥ 4 (moderate-severe fatigue)	N=273 INT: 136 CONT:137	Waitlist control	Internet-based education CRF program based on NCCN program guidelines that covered a general introduction to CRF energy conservation, physical activity, nutrition, sleep hygiene, pain control, and distress management.	Web-based Individual	Self-directed	12 weeks.	8
Zhang et al., 2018 China	2-arm RCT	Reduce fatigue severity	Female ovarian cancer survivors between 18-	Ovarian	During Tx	Moderate (4-6) or severe (7-10) on a scale from 0 to 10	N=72 INT: 36 CONT: 36	Usual care. Drug education, balanced diet recommendation, education on	Nurse-led home-based exercise and cognitive behavioural therapy. Comprising of online CBT sessions, self-help education manual, exercise	F2F, web-based, telephone, home based	HP: 5 nurses with master's level education received INT and CBT training	12 weeks. 12 online CBT sessions delivered once weekly (approx.	9

			80 years who had completed surgery and were receiving adjuvant chemo.			(NCCN CRF guidelines)		chemo for ovarian cancer.	education manual, telephone counselling on fatigue information and exercise methods. Option to receive online interventions at home in or clinic.	Individual	from specialist cancer nurse with over 10 years' experience in gynaecology.	1hr). Weekly nurse telephone for exercise component.	
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**Abbreviations:** BFI – brief fatigue inventory; CBT – cognitive behavioural therapy; Chemo – chemotherapy; CIS-FS – Checklist of individual strength fatigue severity subscale; CONT – control; F2F – face-to-face; FS-C – Fatigue scale-child; FSI – fatigue symptom inventory; HP – health professional; INT – intervention; NCCN – national comprehensive cancer network; NRS – numeric rating scale; pg. – page; PPT – Microsoft PowerPoint; PT – physical training; Pts. – patients; QOL – quality of life; RCT – randomised controlled trial; RT – radiation therapy; SOMA – somatic fatigue subscale; Telemed – telemedicine; Tx – treatment; VAS – visual analogue scale.

## Appendix 5: Risk of Bias for each Included Study (Study 1)

	D1	D2	D3	D4	D5	Overall
Abrahams 2017	+	+	+	!	+	!
Armes 2007	-	!	+	!	!	-
Bantum 2014	!	+	!	!	!	!
Barsevick 2004	+	!	+	!	!	!
Barsevick 2010	!	!	-	!	!	-
Bennet 2007	+	!	+	!	!	!
Bruggeman-Everts 2017	-	!	-	!	!	-
Chan 2011	!	!	!	!	!	!
Dodd 2010	+	+	+	!	+	!
Donnelly 2011	+	!	+	!	!	!
Fillion 2008	-	+	!	!	+	-
Foster 2016	+	!	!	!	!	!
Freeman 2015	+	+	!	!	+	!
Galiano-Castillo 2016	-	-	!	!	!	-
Godino 2006	!	!	!	!	!	!
Gokal 2015	!	+	-	!	+	-
Golsteijn 2018	+	+	!	!	+	!
Gregoire 2020	+	!	!	!	!	!
Hoffman 2017	!	+	+	!	+	!
Johns 2015	+	!	!	!	+	!
Johns 2016	+	-	!	!	!	-
Johnston 2011	+	+	!	+	+	!
Lam 2018	+	!	+	!	!	!
Lee 2014	+	!	!	+	!	!
Li 2014	+	!	!	-	-	-
Mooney 2016	+	!	!	+	!	!

- + Low risk
- ! Some concerns
- High risk

- D1 Randomisation process
- D2 Deviations from the intended interventions
- D3 Missing outcome data
- D4 Measurement of the outcome
- D5 Selection of the reported result

Naraphong 2015	+	-	!	!	+	-
Purcell 2010	+	!	!	-	!	-
Ream 2006	!	-	!	!	!	-
Ream 2015	+	+	!	!	+	!
Reif 2013	-	!	+	!	!	-
Ritterband 2012	+	!	+	+	!	!
Sandler 2017	!	!	-	!	!	-
Savard 2005	!	-	-	!	-	-
Schjollberg 2014	!	-	-	!	!	-
Smith 2019	+	!	+	!	!	!
Spahn 2013	+	-	-	!	!	-
Stanton et al 2005	+	!	-	!	!	-
Steel et al., 2016	+	!	+	!	!	!
Vallerand 2017	!	!	-	!	!	-
Van der Lee 2012	!	!	!	!	!	!
Van Waart 2015	+	!	!	!	!	!
Van Weert 2010	+	!	-	+	!	-
Vargas 2014	!	-	!	!	!	-
Wang 2011	!	-	-	!	!	-
Wangnum 2013	+	+	!	!	+	!
Willems 2017a & 2017b	+	+	!	!	+	!
Yates 2005	+	-	!	+	!	-
Yun 2012	+	!	!	!	!	!
Zhang 2018	+	!	!	!	!	!

## Appendix 6: SMS Taxonomy Components in each study (Study 1)

Study	1. Information about CRF and/its management	2. Information about managing psychosocial consequences of illness.	3. Information about available social support resources and navigating transitions.	4. Provision of /agreement on goal setting and specific clinical action plans and/or urgent problems.	5. Regular clinical review.	6. Monitoring of condition with feedback.	7. Practical support with adherence (medication or behavioural)	8. Provision of equipment	9. Provision of access to advice or support when needed	10. Training rehearsal to communicate with healthcare professionals	11. Training rehearsal for lifestyle adaptations and for everyday activities	12. Training rehearsal for psychological strategies	13. Social support	14. Lifestyle advice and support	# of SMS taxonomy components per study
Abrahams 2017	✓	✓		✓						✓	✓	✓	✓	✓	8
Armes 2007	✓			✓		✓					✓	✓		✓	6
Bantum 2014	✓	✓		✓		✓	✓			✓		✓	✓	✓	9
Barsevick 2004	✓			✓		✓	✓				✓			✓	6
Barsevick 2010	✓			✓		✓	✓				✓			✓	6
Bennet 2007				✓	✓		✓				✓			✓	5
Bruggeman-Everts 2017	✓	✓		✓	✓	✓	✓					✓		✓	8
Chan 2011	✓	✓					✓				✓	✓		✓	6
Dodd 2010	✓				✓	✓	✓				✓			✓	6
Donnelly 2011				✓	✓	✓	✓				✓	✓		✓	7
Fillion 2008	✓	✓		✓		✓	✓				✓	✓		✓	8
Foster 2016	✓	✓		✓		✓	✓						✓	✓	7
Freeman 2015					✓	✓	✓				✓	✓	✓		6
Galiano-Castillo 2016						✓	✓		✓		✓			✓	5
Godino 2006	✓					✓	✓							✓	4
Gokal 2015				✓			✓				✓			✓	4
Golsteijn 2018				✓		✓	✓				✓		✓	✓	6
Gregoire 2020		✓									✓	✓		✓	4
Hoffman 2017	✓			✓	✓	✓	✓	✓			✓			✓	8
Johns 2015	✓	✓					✓				✓	✓		✓	6
Johns 2016	✓	✓					✓				✓	✓	✓	✓	7
Johnston 2011	✓	✓		✓		✓						✓		✓	6
Lam 2018				✓			✓				✓	✓		✓	5
Lee 2014				✓		✓	✓				✓			✓	5
Li 2014											✓			✓	2
Mooney 2016					✓	✓			✓		✓			✓	5
Naraphong 2015				✓		✓	✓				✓		✓	✓	6
Purcell 2010	✓			✓			✓					✓		✓	5
Ream 2006	✓				✓	✓	✓				✓	✓		✓	7
Ream 2015	✓		✓	✓	✓		✓							✓	6
Reif 2012	✓	✓					✓				✓	✓	✓	✓	7
Ritterband 2012	✓	✓		✓		✓	✓				✓	✓		✓	8
Sandler 2017	✓	✓		✓	✓	✓	✓		✓		✓	✓		✓	10
Savard 2005	✓	✓									✓	✓		✓	5
Schjolberg 2014	✓			✓	✓						✓		✓	✓	6
Smith 2019												✓			1
Spahn 2013		✓			✓						✓	✓		✓	5
Stanton et al 2005		✓	✓	✓								✓	✓	✓	6
Steel et al., 2016	✓	✓			✓		✓		✓			✓	✓	✓	7
Vallerand 2017	✓			✓			✓			✓	✓		✓	✓	7
Van der Lee 2012	✓	✓									✓	✓	✓	✓	6
Van Waart 2015							✓				✓			✓	3
Van Weert 2010	✓			✓		✓	✓				✓	✓		✓	7
Vargas 2014		✓									✓	✓			3
Wang 2011				✓	✓		✓				✓		✓	✓	6
Wangnum 2013	✓			✓	✓	✓	✓					✓		✓	7
Willems 2017a & 2017b	✓	✓	✓	✓						✓	✓	✓	✓	✓	9
Yates 2005	✓	✓		✓		✓				✓		✓		✓	7

Yun 2012	✓	✓				✓			✓		✓	✓	✓	✓	8
Zhang 2018	✓	✓		✓	✓	✓	✓		✓			✓		✓	9
<b>Total # of studies</b>	<b>32</b>	<b>23</b>	<b>3</b>	<b>30</b>	<b>16</b>	<b>26</b>	<b>34</b>	<b>1</b>	<b>6</b>	<b>5</b>	<b>37</b>	<b>31</b>	<b>16</b>	<b>46</b>	

## Appendix 7: Reported outcomes of included studies, post-intervention, and follow-up (Study 1)

Study name	Type of study, INT vs CONT length	Relevant outcome measures	Immediate post-intervention results	Follow-up	Post intervention follow-up results
Abrahams 2017	2-arm RCT: Internet CBT (ICBT) vs waiting list for CBT, varied – max duration 6 months	Fatigue severity (CIS-FIS)	Lower fatigue scores in ICBT (MD 11.5; 95%CI 7.7-15.3, p<.0001). Large INT effect size (Cohen's d = 1.0).	No follow-up assessment completed	N/A
Armes 2007	2-arm RCT: behaviour intervention vs usual care, 9-12 weeks	Fatigue severity (VAS-F), fatigue-related distress (FOM), physical functioning (EORTC-QLQc30)	Sig. lower fatigue severity (MD: -15.9; 95%CI 2-29.8, p=0.03) and higher physical functioning (MD: 19.7;95%CI: -30.2 to -9.2; p=0.001) in behaviour intervention. No sig. difference between groups for fatigue-related distress (U test score: 183; p=0.25).	9 months post-recruitment; 6-7 months post-CTX (? post INT)	No sig. difference between groups for fatigue-related distress (U test score: 149; p=0.90) or fatigue severity (MD: -17.1; 95%CI: -1.5 to 35.7; p=0.07). Higher physical function in behaviour intervention (MD: 17.1; 95%CI: -31.7 to -2.5; p=0.02).
Bantum 2014	2-arm RCT delayed treatment design: online education vs waitlist control, 6 weeks	Fatigue severity (BFI), exercise (Godin Exercise questionnaire), fruit/vegetable intake (Block Food Frequency questionnaire)	Treatment effect was not sig. (p=0.56, effect size 0.17) for fatigue severity.  No sig. effect on fruit/vegetable intake (p=0.24, effect size= 0.21), strenuous or moderate aerobic exercise (p=0.45, effect size 0.29), moderate aerobic exercise (p=0.49, effect size= 0.10), mild aerobic exercise (p=0.28, effect size= 0.10).  Increased strenuous exercise (p=0.01, effect size 0.36) and stretching exercise (p=0.01, effect size 0.12) compared to control.	No follow-up assessment completed	N/A
Barsevick 2004	2-arm RCT: energy conservation and activity management vs attention control, varied	Fatigue impact (GFS), fatigue intensity (POMS-F), physical and mental fatigue (SCFS-P)	ECAM group experienced a greater decrease in fatigue impact, intensity, and physical and mental fatigue over time compared with the control group (GFS: F= 4.5; p < 0.01) (POM-F: F=3.7.	No follow-up assessment completed	N/A



	according to chemo schedule		p<0.05), (SCFS-P: F=3.1. p<0.05) respectively.		
Barsevick 2010	2-arm RCT: energy sleep enhancement vs attention control, varied according to chemo schedule	Fatigue severity(GFS, POMS-F)	No sig. group-by-time effects for fatigue severity (GFS: F=0.02; p>0.005; & POMS-F: F=0.47; p>0.05).	No follow-up assessment completed	N/A
Bennet 2007	2-arm RCT: motivational interviewing vs usual care, 4.5 months	Fatigue (Schwartz Cancer Fatigue Scale), <u>Physical Activity (CHAMPS Physical Activity questionnaire)</u> , <u>Self-Efficacy for physical activity (6-item questionnaire)</u>	Not measured.	1.5 months post INT	No sig. difference between INT and CONT for fatigue (d=0.14) and aerobic fitness (d=0.09).  High-efficacy individuals in INT increased their physical activity levels faster over 6 months than did low-efficacy individuals in the intervention group (B = 121.35, p= 0.05).  In the control group, self-efficacy did not affect levels of physical activity.
Bruggeman-Everts 2017	3-arm RCT: ambulant feedback therapy (AAF) vs electronic mindfulness therapy (eMBCT) vs ambulant physical activity coaching vs psychoeducational educational emails, 9 weeks.	Fatigue Severity (CIS-FS)	Specific results not reported.	3 months post INT	Fatigue severity decreased sig. more in the AAF and eMBCT groups compared to the psychoeducational control group over time.  No sig. difference between AAF and eMBCT.
Chan 2011	2-arm RCT: psychoeducation vs usual care (radiotherapy effects education); 4 weeks	Fatigue severity (Revised PFS - Chinese ver.)	Lower fatigue severity in INT. Sig. between-group difference (p=0.011) in the pattern of change in fatigue, with a small effect size (partial eta squared = 0.033).	(?) 3 months post baseline (? post INT)	No sig. difference was found in the pattern of change in fatigue overtime (baseline to 3 months post INT) (p=0.034).
Dodd 2010	3-arm RCT: exercise during & after cancer treatment vs exercise after cancer treatment	Fatigue severity (PFS)	Results not reported.	Group 1: (6 months post INT/treatme	The linear change in fatigue severity over time by group showed no sig. differences (p=0.084) among the groups.

	vs usual care, varied between groups.			nt completion)	
Donnelly 2011	2-arm pilot RCT: home based physical activity program vs usual care (not specified), 12 weeks	Fatigue severity (MFSI-SF), Clinically sig. fatigue measure (FACIT-F)	Sig. decrease in fatigue severity with INT (MFSI-SF) ( $p=0.046$ ; Cohen's $d=0.13$ ). No between-group differences for FACIT-F fatigue severity ( $p=0.34$ ).	6 months post INT	Sig. decrease in fatigue severity with INT (MFSI-SF) ( $p=0.01$ ; Cohen's $d=0.20$ ). No between-group differences for FACIT-F fatigue severity ( $p=0.10$ ).
Fillion 2008	2-arm RCT: group stress management and psychoeducation vs usual care (general information), 4 weeks	Fatigue severity (MFI), Energy Level (POMS-Vigor Scale), Fitness (VO2 Max)	Sig. between group difference for fatigue severity ( $p=0.03$ , Cohen's $d = 0.49$ ), and energy level ( $p=0.01$ , Cohen's $d = 0.58$ ) No sig. between group difference in fitness.	3 months post INT	No sig. fatigue effect over time. No sig between-group difference for fatigue severity, energy level and fitness.
Foster 2016	2-arm RCT: web-based intervention vs leaflet, 6 weeks	Fatigue severity (BFI), perceived self-efficacy for fatigue self-management (PSEFSM questionnaire, CS-SES), QOL (FACT-G, PWI, PHQ-9)	No sig. differences between groups noted for all outcomes; near-significant improvement between groups in fatigue self-efficacy ( $p = 0.09$ ).	3 months post baseline (? post INT)	No sig. differences between groups noted for all outcomes; between-group difference in fatigue self-efficacy decreased becoming negligible.
Freeman 2015	3-arm RCT: live imagery-based behavioural program (LD) vs telemedicine imagery based behavioural program (TD) vs waitlist control, 5 weeks	Fatigue severity (FACIT-F)	Participants in LD and TD reported sig. less severe fatigue than waitlist ( $p<0.01$ ). No differences between LD and TD groups on any outcome measure.	3 months post treatment completion (? post INT)	No effect on fatigue severity over time.
Galiano-Castillo 2016	2-arm RCT: Internet-based exercise program vs usual care (written exercise) inf, 8 weeks.	Fatigue severity (PFS – revised, Spanish ver.)	Improved total fatigue severity in INT vs CONT ( $p<0.001$ ; Cohen's $d= -0.89$ , 95%CI - 1.30 to -0.48). Large effect size.	6 months post INT	Improved total fatigue severity in INT vs CONT ( $p=0.002$ ; Cohen's $d=0.74$ , 95%CI -1.19 to -0.29). Moderate effect size.

Godino 2006	2-arm RCT: patient education program vs written information, 3 weeks	Fatigue severity (FACT-F)	Lower fatigue severity in INT (mean score $121 \pm 25$ ) compared to CONT (mean score $105 \pm 13$ ) clinically sig. however, findings not statistically sig. due to small sample size ( $p > 0.05$ ).	No follow-up assessment completed	N/A
Gokal 2015	2-arm RCT: home-based walking vs usual care (not specified), 12 weeks	Fatigue severity (FACT-F), Physical activity (General Practice Physical Activity Questionnaire & Yamax SW-200 Pedometer)	Sig. reduction in fatigue severity in INT vs CONT over time ( $F(1,48) = 5.77$ , $p = 0.02$ ). Sig. improvement in perceived levels of physical activity in INT vs CONT ( $\chi^2(3, N=50) = 17.15$ , $p = 0.001$ ).	No follow-up assessment completed	N/A
Golsteijn 2018	2-arm RCT: computer-tailored physical activity program vs waitlist control, 3-4 months	Fatigue severity (CIS-F), Physical activity: moderate-to-vigorous physical activity (MVPA) and days $\geq 30$ min physical activity (SQUASH, ActiGraph GT3X-BT)	Sig. decreased fatigue severity in INT vs CONT ( $B = -3.57$ , $p = 0.02$ ). Sig. improvement physical activity in terms of both MVPA ( $B = 133.55$ , $p = 0.04$ ) and days with at least 30 min of physical activity ( $B = 0.86$ , $p < .001$ ) in INT vs CONT.	2 months post INT	INT had a sig. decrease in fatigue severity in comparison to CONT ( $B = -4.16$ , $p = 0.009$ )  Sig. improvements in physical activity (MVPA: $B = 267.17$ , $p < .001$ ; Days $\geq 30$ min physical activity: $B = 0.98$ , $p < .001$ ). ActiGraph assessed MVPA also increased significantly (MVPA: $B = 44.60$ , $p = 0.006$ ), whereas the increase in ActiGraph assessed days $\geq 30$ min PA was borderline significant ( $B = 0.38$ , $p = 0.05$ ).
Gregoire 2020	2-arm RCT: Self-care and self-hypnosis vs waitlist control, 8 weeks	Fatigue severity (MFI), Physical Activity (Garmin Vivoactive HR, self-reported number of physical activity hours per week)	All dimensions of fatigue (MFI-20) sig. improved in INT: general fatigue ( $p < 0.001$ , Cohen's $d = 0.67$ ); physical fatigue ( $p < 0.001$ , Cohen's $d = 0.60$ ); mental fatigue ( $p < 0.001$ , Cohen's $d = 0.65$ ); lack of activity ( $p < 0.001$ , Cohen's $d = 0.67$ ); and lack of motivation ( $p = 0.002$ , Cohen's $d = 0.54$ ). No sig. differences for physical activity (steps/day or hrs/wk).	No follow-up assessment completed	N/A

Hoffman 2017	2-arm pilot RCT: Perceived self-efficacy - enhancing (PSE) CRF self-management education vs usual care (standard medical care from health care providers), 6 weeks	Fatigue severity (BFI), perceived self-efficacy (PSE) for fatigue self-management (PEFSM), CRF Self-management behaviours -walking & balance – (weekly diary that included prescription and activities completed), PSE for walking duration (Survey), Fatigability – fatigue with activity (6-minute walk test – 6MWT)	<p>Sig. improvement in fatigue severity, sig. between-group difference [t (42) = -9.3, p&lt;.001; 95% CI -4.0 to -2.6; Cohen's d = 1.7].</p> <p>PSE for CRF self-management: sig. difference between groups [t (41.8) = 7.4, p&lt;.001; 95% CI 2.0 to 3.5; d = 1.3]</p> <p>PSE Walking: sig. difference between groups [t (52.2) = 4.3; p&lt;.001; 95% CI 14 to 39; d = 0.8].</p> <p>PSE for Balance: sig. difference between groups at week 6 [t (46.9) = 4.1; p&lt;.001; 95% CI 6.6 to 19.5; d = 0.7].</p> <p>CRF self-management walking and balance exercise: increase in walking and balance exercise behaviours.</p> <p>Fatigability: sig. difference between the INT and CONT group's fatigue during the 6MWT [t (50.9) = -9.3, p&lt;.001; 95% CI -3.3 to -2.1; d = 1.8)</p>	No follow-up assessment completed	N/A
Johns 2015	2-arm pilot RCT: mindfulness-based stress reduction (MSBR) vs waitlist control, 7 weeks	Fatigue severity, interference, & frequency (FSI)	MBSR group demonstrated sig. greater improvement than CONT in fatigue interference p<0.001 Cohen's d =-1.43, fatigue severity p<0.001 Cohen's d= -1.55, fatigue frequency p<0.001 Cohen's d=-1.08	6 months post INT	MBSR group demonstrated sig. greater improvement than CONT in fatigue interference p<0.001 Cohen's d=-1.34, fatigue severity p<0.001 Cohen's d=-1.54, fatigue frequency p<0.001 Cohen's d=-1.22
Johns 2016	2-arm pilot RCT: mindfulness-based stress reduction (MSBR) vs psychoeducation 8 weeks	Fatigue interference, fatigue severity, fatigue global improvement (FSI -	No sig. between-group differences for fatigue interference or fatigue severity. Fatigue global improvement: MBSR participants were significantly more	6 months post INT	No sig. between-group differences for fatigue interference, fatigue severity or fatigue global improvement.

		Fatigue Symptom Inventory scale)	likely than PES participants [58.8 vs. 34.3 %, respectively; $\chi^2 (1) = 4.176, p = 0.041$ ] to report their CRF as being moderately to completely better		
Johnston 2011	2-arm pilot RCT: Education + acupuncture vs usual care (standard care from physicians), 8 weeks	Fatigue severity (BFI)	INT had clinically sig. 2.38-point greater reduction in fatigue severity (90% CI: 0.586 to 5.014; $p=0.08$ ; Cohen's $d = 1.85$ ). Not statistically sig. due to small sample size	No follow-up assessment completed	N/A
Lam 2018	2-arm pilot RCT: Integrated physical adventure programme vs various leisure activities, 6 months	Fatigue severity (Fatigue Scale - Chinese ver.), physical activity levels (CUHK-PARCY), physical activity Self-efficacy (PASE)	Sig. lower fatigue severity ( $p<0.001$ ), and higher physical activity self-efficacy ( $p<0.001$ ) in INT than CONT.  Physical Activity levels: not measured at this timepoint.	3 months post INT	Sig. lower fatigue severity ( $p=0.010$ , eta squared= 0.09) and higher levels of physical activity self-efficacy ( $p=0.004$ , eta squared =0.11) in INT. Sig. higher physical activity levels in INT ( $p=0.003$ , eta squared = 0.12)
Lee 2014	2-arm pilot RCT: diet and exercise web program vs 50-page booklet	Fatigue severity (BFI-K: Korean ver.), exercise & intake of fruit and veg. (exercise & dietary diaries), stage of change (Motivational readiness questionnaire: non-validated)), perceived self-efficacy (Non-validated study questionnaire)	Sig. improvement in fatigue severity ( $p = 0.032$ ), higher stage of change for exercise ( $p < 0.0001$ ) and fruit & veg consumption ( $p = 0.029$ ) in INT. Sig. increase in self-efficacy for exercise management ( $p = 0.024$ ) and to increase F&V intake ( $p = 0.023$ ). Sig. increase in moderate intensity aerobic exercise for at least 150 min per week ( $p < 0.0001$ ) and eating 5 servings of F&V per day ( $p = 0.001$ ) in INT vs CONT.	No follow-up assessment completed	N/A
Li 2014	2-arm RCT: adventure camp vs attention control (leisure	Fatigue severity (FS-C - Chinese ver.), physical activity	No sig. difference between INT and CONT for fatigue severity ( $p=0.09$ ).	6 months post INT	Sig. main effects for the INT on all outcomes; INT had lower levels of fatigue severity ( $p<0.001$ ), higher levels of

	activities), 4 days over six months	levels (CUHK-PARCY), self-efficacy (PA-SE)	Sig. higher physical activity levels ( $p<0.01$ ) and self-efficacy ( $p<0.01$ ) in INT vs CONT.		physical activity ( $p<0.001$ ), and self-efficacy ( $p<0.001$ ).
Mooney 2016	2-arm RCT: Telephone-based interactive voice symptom reporting system with nurse care vs interactive voice symptom reporting system w/o nurse care, mean 77 days	Fatigue severity (measure not specified; NRS scale 1-10)	Sig. less fatigue severity in intervention (MD: -0.685, $p<0.001$ ).	No follow up assessment completed	N/A
Naraphong 2015	2-arm pilot RCT: walking exercise vs information, 12 weeks	Fatigue severity (PFS-R), Physical Fitness 12-MWT (12-min walk test).	Non sig. improvement in fatigue severity in INT vs CONT (no sig. group or time effects differences for fatigue ( $\beta = -0.00$ , $p= 0.15$ )).  Sig. higher physical fitness over time in INT vs CONT ( $t = 2.28$ , $p = 0.04$ ).	No follow up assessment completed	N/A
Purcell 2010	4-arm RCT: pre- & post-radiotherapy fatigue education and support (RFES) vs pre-RFES vs post-RFES, vs usual care (no RFES), 60 min RFES session	Fatigue severity (MFI), Physical activity (IPAQ- SF), leisure & self-care activity participation (FAI)	No form of RFES achieved sig. reduction in fatigue severity, or the improvement physical activity or leisure and self-care activities.	6 weeks post-RT (? post INT)	No sig. treatment effects on fatigue severity, physical activity, and leisure & self-care activities from the complete RFES programme analysis compared to usual care. Pre-RFES group had sig. increase in vigorous activity ( $p<0.01$ ) compared to no pre-RFES, post-RFES sig. increase in walking $p<0.05$ ) compared to no post-RFES.
Ream 2006	2-arm RCT: fatigue education and management counselling vs usual care (ad hoc fatigue assessment), 3 chemo cycles (3 months).	Fatigue severity, distress caused by fatigue, disruption to work/chores by fatigue, disruption to pastimes/hobbies, (4 study VAS questionnaire – non-	Global mean fatigue score sig. lower in INT ( $p<0.04$ , $ES=0.18$ ). No stat. sig. difference in fatigue severity ( $p=0.19$ ) or disruption to work/chores caused by fatigue ( $p=0.10$ ).	No follow-up assessment completed	N/A

		validated), global mean fatigue score	Sig. lower associated distress ( $p < 0.01$ ), and disruption to hobbies ( $p = 0.02$ ) caused by fatigue.		
Ream 2015	2-arm pilot RCT: motivational interviewing vs usual care, varied depending on chemo cycle (3 cycles)	Fatigue intensity (BFI), fatigue distress (FDS), fatigue self-efficacy (questionnaire)	Improvement in fatigue intensity (ES=0.18; 95% CI: -0.57 to 0.93), fatigue distress (ES=0.62; 95% CI: 0.11 to 1.13), fatigue self-efficacy (ES= -0.34 ; 95% CI : -1.10 to 0.71).	No follow-up assessment completed	N/A
Reif 2013	2-arm RCT: fatigue information and management education vs waitlist control, 6 weeks	Fatigue severity (Fatigue assessment questionnaire - FAQ); general self-efficacy (General self-efficacy scale); exercise self-efficacy (Physical exercise self-efficacy scale), physical activity (FFKA); fatigue knowledge (non-validated fatigue knowledge test [F-WT] -created for study)	Comparison with waitlist control not reported.	6 months post INT	Sig. reduction in fatigue severity ( $F = 76.510$ , $p < 0.001$ , $\eta^2 = 0.248$ ) in INT over time. Sig. improvements in general self-efficacy ( $F = 27.680$ , $p < 0.001$ , $\eta^2 = 0.107$ ), exercise self-efficacy ( $F = 49.230$ , $p < 0.001$ , $\eta^2 = 0.175$ ), physical activity ( $F = 8.036$ , $p < 0.001$ , $\eta^2 = 0.033$ ), and fatigue knowledge ( $F = 55.157$ , $p < 0.001$ , $\eta^2 = 0.192$ ).
Ritterband 2012	2-arm pilot RCT: internet CBT program vs waitlist control, 6-9 weeks	Overall fatigue severity (MFSI-SF) and general, mental, emotional, and physical fatigue subscales.	Sig. improvements in overall fatigue severity ( $F_{1,26} = 13.88$ ; $p < 0.01$ , $d = 1.16$ ), general fatigue ( $F_{1,26} = 9.46$ ; $p < 0.01$ , $d = 0.91$ ), mental fatigue ( $F_{1,26} = 8.65$ ; $p < 0.01$ , $d = 0.66$ ).  No sig. improvement in emotional ( $F_{1,26} = 3.44$ ; $p = 0.08$ , $d = 0.77$ ) and	No follow-up assessment completed	N/A

			physical fatigue ( $F_{1,26}=2.83$ ; $p=0.11$ , $d=0.47$ ).		
Sandler 2017	2-arm RCT: CBT and exercise program vs education and single exercise session, 12 weeks	Fatigue severity (SOMA), Physical activity (IPAQ)	Sig. fatigue improvement in fatigue severity in INT compared to CONT [(M= 2.55, SD = 3.77; $t(36) = -2.56$ ) vs (M= 0.10; SD =2.55)]; $p < 0.05$ between groups.  No sig. difference between groups in physical activity levels ( $p=0.82$ )	3 months post INT	Sig. improvements in fatigue within INT ( $p < 0.05$ ); however, no sig. difference was found in change scores between groups (MD = 1.56; 95% CI: -3.77 to 0.48; $p = 0.13$ ).  No sig. difference between groups in physical activity levels ( $p=0.96$ )
Savard 2005	2-arm RCT: CBT vs waitlist control, 8 weeks	Fatigue severity (MFI-Canadian French ver.)	Sig. lower fatigue severity in INT ( $F_{1,158} = 11.70$ ; $p < 0.001$ )	3-, 6-, & 12-months post INT	No sig. difference between fatigue post-treatment scores at 3-, 6-, or 12-months post INT.
Schjolberg2014	2-arm RCT: CRF education and coping strategies vs usual care – info on general cancer, 3 weeks	Fatigue Severity [FQ – physical, mental, total, chronic - & LFS (lee fatigue)]	No sig. difference in total fatigue, physical fatigue, mental fatigue, chronic fatigue, and Lee fatigue between groups.  No sig. difference within groups for all fatigue measures.	3 months post INT	No sig difference in total fatigue, physical fatigue, mental fatigue, chronic fatigue, and Lee fatigue between groups.  No sig. difference within groups for all fatigue measures.
Smith 2019	2-arm RCT: Online CBT vs waitlist control, 10 weeks	Fatigue severity (FACIT-F), self-efficacy (Self-efficacy for Managing Chronic Disease scale)	Not measured.	4.5 months post INT	Sig. reduction in fatigue severity in INT compared with CONT (ES: 0.46; $p=0.034$ ). INT had a moderate effect on fatigue (Cohen's $d = 0.46$ ).  No sig. difference in improvements in self-efficacy between the INT and CONT ( $p > 0.05$ ).
Spahn 2013	2-arm RCT: walking sessions & mind body exercises vs home-based walking, 10 weeks	Fatigue severity (MFI), unusual fatigue of the <i>last month</i> & unusual	No sig. group differences for any outcome. Clinically sig. reduction in unusual fatigue in last month (31% reduction in both groups).	3 months post INT	No sig. group differences for any outcome. Clinically sig. reduction in unusual fatigue in last month in INT (37% reduction).



		fatigue of the <i>last week</i> (German Fatigue Questionnaire)			
Stanton 2005	3-arm RCT: information video (VID) vs psychoeducational counselling (CTL) vs info booklet (EDU), varied	Fatigue/energy (SF-36)	Not measured.	6, 12 months post recruitment	<u>6 months</u> VID intervention produced a sig. greater improvement in fatigue/energy ( $t_{1, 405}=2.36$ ; $p=0.018$ ), during 6 months than did the CTL. No sig. differences for EDU versus CTL and VID versus EDU. <u>12 months</u> No sig. effects of the intervention on fatigue/energy
Steel 2016	2-arm RCT: web-based collaborative care vs attention control (usual care from medical team), 6 months	Fatigue severity (FACT-F)	Non sig. reduction of fatigue severity with a small effect size (Cohen's $d=0.26$ ) was observed between the INT and attention control arm ( $t(15)=1.80$ , $p=0.09$ ).	No follow-up assessed	N/A
Vallerand 2017	2-arm RCT: exercise telephone counselling vs self-directed exercise, 12 weeks.	Fatigue severity (FACT-F), Aerobic exercise (GLTEQ)	No sig. between-group difference on fatigue severity. Increased weekly aerobic exercise in INT (adjusted mean between group difference ( $p < 0.001$ , Cohen's $d=0.19$ )).	No follow-up assessed	N/A
Van der Lee 2012	2-arm RCT: mindfulness based cognitive therapy vs waitlist control, 9 weeks.	Fatigue Severity (CIS-F)	Sig. lower fatigue severity in INT than waitlist control ( $p<0.001$ ). Effect size for fatigue =0.74	6 months post INT	Follow-up compared with immediate post INT: no sig. difference ( $p=0.20$ ). Follow-up compared with baseline: Sig. less fatigue severity ( $p<0.001$ ).
Van Waart 2015	3-arm RCT: Low intensity home based physical activity (Onco-Move) vs supervised moderate-to-high intensity program (OnTrack) vs Usual care (no prescribed exercise),	Fatigue severity (MFI, Fatigue quality list), Physical fitness (step ramp test, endurance test, physical activity scale for the elderly)	OnTrack reported sig. less general ( $p=0.041$ , $ES=0.29$ ) and physical fatigue ( $p<0.001$ , $ES=0.63$ ), reduced activity ( $p=0.045$ , $ES=0.31$ ), reduced motivation ( $p=0.049$ , $ES=0.34$ ) than usual care; and sig. less physical fatigue ( $p=0.021$ , $ES=0.42$ ) than Onco-Move.	5 months 1 week post INT	No sig. between-group differences for any of the performance-based measures of physical fitness or in self-reported fatigue.

	varied – duration of all chemo cycles		Physical fitness levels were maintained immediately after completion of chemo in OnTrack but declined in usual care and Onco-Move.		
Van Weert 2010	3-arm RCT: physical training (PT) vs PT + cognitive behaviour therapy (CBT) vs waitlist control (WLC), 12 weeks	Fatigue severity (MFI – general fatigue, physical fatigue, mental fatigue, reduced motivation, reduced activation)	Compared to WLC, PT had sig. reduction in 4 domains of fatigue (general mean change: -1.0, $p < 0.01$ ; physical mean change: -2.4, $p < 0.001$ ; mental mean change: -1.6, $p < 0.05$ ; reduced activation mean change: -1.3, $p < 0.05$ ). PT+CBT showed reduction in one fatigue domain only (physical fatigue mean change: -2.7, $p < 0.01$ ). No sig. differences in reduction in fatigue were found between the PT+CBT and PT groups.	No follow-up assessment completed	N/A
Vargas 2014	2-arm RCT: Cognitive behavioural stress management vs psychoeducation, 10 weeks	Fatigue (FSI – fatigue intensity and fatigue-related daytime interference)	Not measured.	3 months & 9 months post INT	No sig difference over time between INT and CONT for fatigue intensity ( $p > 0.30$ , Cohen's $d = 0.37$ ). Sig. lower fatigue-related daytime interference in INT ( $p < 0.05$ , Cohen's $d = 0.48$ )
Wang 2011	2-arm RCT: walking program vs usual care (not specified), 6 weeks	Fatigue severity (FACIT-F), exercise self-efficacy (ESES), exercise behaviour (GLTEQ), exercise capacity (6MWD)	INT had sig. lower fatigue ( $F_{1,60} = 9.74$ , $p = 0.003$ ), improved exercise self-efficacy (results NR), increased exercise behaviour ( $F_{3,180} = 25.53$ , $p < 0.001$ ), and exercise capacity ( $F_{1,63} = 12.01$ , $p = 0.001$ ) compared to CONT over program period.	No follow-up assessment completed	N/A
Wangnum 2013	2-arm RCT: Multidisciplinary education program in self-care fatigue vs nurse	Fatigue severity (PFS), physical fitness (VSAQ), nutritional status (MNA)	Sig. lower fatigue ( $t = 2.15$ , $p = 0.036$ ) and improved nutritional status ( $t = 4.01$ , $p = 0.002$ ) in INT.	No follow-up assessment completed	N/A

	provided information on exercise strategies, 9 weeks		No sig. difference in physical fitness (t=-0.20, p=0.846) between groups.		
Willems 2017a & 2017b	2-arm RCT: Web-based psychosocial education program vs waitlist control, 6-month access to program	Fatigue severity (CIS-F)	Sig. reduction in fatigue severity (B = -4.36, p = 0.020, f2 = 0.013, Cohen's d = 0.21).	12 months post baseline	Non-sig. group differences in fatigue severity.
Yates 2005	2-arm RCT: psychoeducational support program vs general cancer education, 3 weeks	<u>Fatigue management behaviours</u> (study questionnaire non-validated), confidence with managing fatigue (11-point NRS - developed for study), <u>Fatigue experiences</u> (fatigue distress, fatigue severity, fatigue impact-PFS, FACT-F), <u>Cancer self-efficacy</u> (24-item questionnaire -non-validated)	<u>Fatigue Experiences</u> : Sig. lower fatigue at worst (p=0.01), fatigue severity p=0.01), fatigue interference (p=0.01), average fatigue (p=0.02), FACT-F score (p=0.05) in INT. No sig. between group differences for best fatigue, fatigue distress and fatigue now.  <u>Fatigue management behaviours</u> : INT pts. had sig. greater actions recommended to (p=0.01) in the number of treatments recommended. No sig. between group differences for all other fatigue behaviours.	3-4 weeks post INT & 6-12 weeks post INT	<u>Fatigue experiences</u> : No sig between-group differences for all measures of fatigue experiences.  <u>Fatigue management behaviours</u> : No sig. between-group differences for communication with health professionals about fatigue or number of actions taken to manage fatigue. INT pts. had sig. greater actions recommended to (p=0.02) in the number of treatments recommended.  <u>Confidence with managing fatigue</u> : no sig. between group differences in baseline to post INT change scores (all time points).  <u>Cancer self-efficacy</u> : no sig. effect of INT (at all time points).
Yun 2012	2-arm RCT: internet-based education vs waitlist control, 12 weeks	Fatigue (BFI, FSS) – global fatigue, fatigue severity, fatigue interference.	INT had sig. greater decrease in global fatigue (p=0.001, Cohen's d=0.29), fatigue severity (p=0.008, Cohen's d=0.21), and fatigue interference scores (p=0.001, Cohen's d=0.29) of BFI, and in the total score of FSS.	No follow-up assessment completed	N/A

			Among patients who had moderate or greater fatigue at baseline, the INT group had clinically more meaningful improvement than CONT in BFI global score, worst fatigue, and FSS score.		
Zhang 2018	2-arm RCT: Nurse-led home-based exercise and cognitive behavioural therapy vs usual care (drug, diet chemo education), 12 weeks	Fatigue severity (PFS-Chinese ver.)	Lower total (t/Z=-2.558, p=0.011), behavioural (t/Z=-4.978, p<0.001), sensory (t/Z=-2.709, p=0.007), and cognitive fatigue (t/Z=-2.147, p=0.036) in INT vs CONT. No sig. between group difference in affective fatigue (p=0.778).	3 months post INT	Lower total (t/Z=-3.311, p=0.002), behavioural (t/Z=-5.855, p < 0.001), sensory (t/Z=-4.033, p< 0.001), and cognitive fatigue (t/Z=-5.388, p< 0.001) in INT vs CONT. No significant between group difference in affective fatigue (p=0.915).

## Appendix 8: Qualitative Examples of Identified Themes (Study 2)

Themes	Theme frequency	Codes	Code frequency	Example quotes for theme	Response to theme
<b>Round 1</b>					
Tailor information	16	Ensure cancer survivors and their family/caregivers understand the information provided	6	<ul style="list-style-type: none"> <li>• Communication levels, jargon, making sure information is not just given but ensure understanding.</li> <li>• Important to check how information can be delivered since information can be tiring. Important also to address with how the patient and parents/network can use the information. “</li> <li>• Establish an open rapport with patient rather than just providing written documentation. i.e., a video</li> <li>• Coping with information overload and having a support person to collate information</li> <li>• Provide the patient with..." Whenever I see this, I am reminded of how most of this information has just been given to us in a handout with little explanation or exploration. I would like to see a discussion aspect to those practices. The same with "Inform" - while that is the practice there needs to be a check for understanding. I have been informed of many things during medical appointments but never fully understood the implications.</li> <li>• It is important that they know their patients and tailor their messages to how the patient process this. Not everyone wants detailed information, so know your client!</li> <li>• Avoid jargon as most 'civilians' won't recognize or understand. People generally are embarrassed to ask the meaning.</li> <li>• Patients need information on their treatment &amp; how to combat the side effects of both the disease &amp; treatment, but only enough for their needs at that time. There is more than enough going on inside their head.</li> <li>• Medical professionals need to show empathy with the patient and family and not see the patient as a statistic and talk over them as if they are just a job.</li> <li>• Personalisation of provided information in partnership with the healthcare professional should also be mentioned.</li> </ul>	An additional document was developed, emphasising the importance of underpinning the delivery of practices by the presence of effective, person-centred, health professional communication which involves the ability to establish and develop mutual understanding, rapport, trust, respect, and cooperation with people affected by cancer using clear and plain language.  Wording of practices in Domain 3 - (Improve Patient Knowledge) have been modified to reflect the need to provide information in a diversity of formats to accommodate different learning styles.
		Find out patient's/ cancer survivors information style (e.g., how would they prefer information to be delivered).	7		
		Place emphasis on delivering information with care no to overload patient.	3		
Consider patient preferences about involving support network	14	Consider patient preferences when involving support network in self-management support	10	<ul style="list-style-type: none"> <li>• Consultation with a support network should be contingent on an individual's preference</li> <li>• Incorporation of support networks, if the patient so chooses / wishes. not every patient aims to exchange experiences with other patients (wording should reflect this).</li> <li>• Must incorporate consent from patient into using the wider support network in action planning, not all patients want their families or friends involved. This should be worded as 'consider incorporating ... with patient's consent'.</li> <li>• Some patients are very shy of having their families/friends involved - they find it difficult to share how they feel.</li> <li>• Again, this can depend on the patient and how they feel about sharing</li> <li>• "Not all patients have the desire to include their support network into action planning so I think there should be more emphasis on the patient's needs" (Round 2)</li> <li>• Integration of evidence-based management strategies for managing fatigue, alongside consideration of patient priorities, cultural context, etc.</li> <li>• Patient consent to involvement of support network should be spelled out.</li> </ul>	Wording changed to Key Practice 3 to acknowledge the need to ensure coping strategies are aligned with patient preferences.  Practices that involve the inclusion of support networks (peer, family/caregiver) have been adjusted to reflect the need to consider individual preference.
		Consider patient preferences when involving other cancer survivors in self-management support	2		
		Consider patient preferences when collaboratively deciding the coping strategies to be incorporated in the patient's fatigue action plan	2		
Consider the patient's support network	4	Consider what the patient's support network needs to assist the patient to self-manage.	2	<ul style="list-style-type: none"> <li>• Identify caregivers/parents need of support from healthcare team for being able to support the patient</li> <li>• To what extent is fatigue degrading the patient's lifestyle and that of his partner/family?</li> <li>• Need to consider family.</li> </ul>	A new practice component was added to Domain 1 (Establishing Context and Defining the Problem), Key Practice 1.
		Consider how the patient's cancer-related fatigue affects support network.	2		
Focus on identifiable risk factors for fatigue	10	Focus on identifiable risk factors for fatigue	10	<ul style="list-style-type: none"> <li>• Health professionals, specially doctors should also carry the efforts needed to exclude and treat aggravating causes to cancer fatigue, like anemia, hormonal disturbances, insomnia, pain,...</li> <li>• Conduct testings that identify and eliminate other possibilities related to fatigue such as hormones, thyroid, fibromyalgia etc</li> <li>• Identify actionable risk factors for the fatigue itself. I practice in the malignant hematology setting, where we can often adjust or consider breaks of medications like lenalidomide or ibrutinib (being used for long-term disease control for MM or CLL, respectively) that can cause fatigue.”</li> <li>• Factors could be other disease factors or medical conditions and this should be assessed; and this should be addressed specifically.</li> </ul>	Changes made to wording of practice component 1c) to explicitly specify that the purpose of information collection is to identify risk factors for cancer-related fatigue that can inform coping strategies.
Identify who should deliver practices and how	10	Specify constraints to executing practices	4	<ul style="list-style-type: none"> <li>• This may need to be split up by [health professional] domain. Physicians like myself aren't equipped to do some of the tasks above, versus a social worker who might be able to provide direct coaching / counselling.</li> <li>• This comment pertains to all domains. All of this is great, but who, when and how will this care be delivered...</li> <li>• all the items are relevant. However, it is very much to do it all</li> <li>• very broad and should be focused on key precipitating or predisposing factors specific to fatigue; if we add all these expectations for managing fear of recurrence then fatigue support will not occur. perhaps engage other professional support for managing co-occurring depression, etc. but really focus on the key practice for fatigue.</li> </ul>	Referral and involvement of multidisciplinary healthcare team is already incorporated in Practice Component 8b. A new practice component specifically highlighting referral for managing psychological effects (Practice Component 9b) has been created and put forward for rating and feedback in Round 2. An additional document providing detail on the execution of the key practices and practice components (i.e., who and how) has been created and added to the second-round survey for participants to peruse. Acknowledges that cancer-related fatigue
		Specify the multidisciplinary nature of self-management support and the need to engage with other professional support	3		
		Specify what health profession does what.	3		

				<ul style="list-style-type: none"> <li>At some point in the recommendations, there should be a reference on how different health care professionals, community services and everybody communicate and work as a care team. This concerns also the acquisition of competencies to work with this population as in the exercise field, psychology, nutrition, social,....</li> <li>assume ahead of time that the health professional (clinician or nurse?) will have the capacity to deliver these practice components. Is there not a need to specify such constraints - or an absence of them?</li> <li>It should be an MDT (multidisciplinary team) model of working involving the team's expertise (with referrals if/as necessary)</li> </ul>	is multi-factorial and thus will require a multidisciplinary health team to manage. This study presents best practices, implementation of the framework (including how tasks and responsibilities can be shared amongst the healthcare team will be investigated in next research phase.
Positive attitudes to framework	10	Framework is a useful and comprehensive tool.	3	<ul style="list-style-type: none"> <li>Just a comment that this is a very comprehensive set of practices that should, in fact, be in place for every survivor not just those with fatigue. It is so relevant to the many issues we face once treatment has ended and there is no path for us to follow. Most of our family doctors are not aware of the complications we face, and the cancer centres are focussed on active treatment, so we tend to feel abandoned. Thank you for the opportunity to be part of a solution. I would like to think that these practices would become part of our normal follow-up. I look forward to the next stage.</li> <li>[About facilitating exchange between cancer survivors] To me this is by far the most important. Everything I have learnt in cancer management is from other cancer survivors belonging to the same demographics as me, worldwide in 6 different languages, all on social media. And NO it is NOT Facebook nor Dr Google, we are organised in subreddit or twitter discussion groups, all have PhDs, access to research publications, used to do scoping, subscribe to up to date, follow short specialist courses on line all over the world etc ... we are just ill and do not put Dr in front our name . We then disseminate the knowledge through the closed Facebook groups so patients can drive their care more effectively and co-design, co-create instead of being ""managed "" . The idea is to learn how to address our own needs with the support of professionals rather than professionals trying to support our needs, total shift in approach.</li> <li>[About facilitating exchange between cancer survivors] It helps to speak to someone who understands</li> <li>The specific strategies and examples provided are useful</li> <li>These all seem like good ideas!</li> <li>Employers should also be aware of the plan to the extent of documented support. Often an employer feels that because an employee 'looks' ok that he/she can do the same job as always. They do not see the fatigue after work, the length of preparation it takes to get ready for work, or the fatigue during the day. As a patient, we tend to hide our illness from employers from fear of being let go or transferred to a less appealing job.</li> <li>This is a very important symptom of cancer treatment and should be given more importance in follow up (Round 2)</li> <li>The patient should be given a plan as its difficult to self-motivate when you are feeling so low and tired (Round 2)</li> </ul>	We thank the panel for their feedback.
		Incorporation of exchange between cancer survivors and support network is important. Glad this component is included in the framework	2		
		Examples and strategies provided are useful for framework application.	4		
		Glad support with communicating fatigue to employers has been included in the framework	1		
Focus on referrals	6	Engage community services in provision of support.	6	<ul style="list-style-type: none"> <li>Holistic practical approach to managing fatigue not just limited to health environment but other pathways to access assistance where financially strapped to access medications gym yoga physio therapies etc</li> <li>Connect patient with community services so people with no one in the world are not left to die alone and receive some help.</li> <li>Helpful to inform individuals about available community-based resources for fatigue management</li> <li>Include appropriate referrals to other agencies and professionals with patient engagement and consent.</li> </ul>	It is agreed that community engagement is essential. The involvement of community services has already been incorporated (particularly Domain 2 – developing an action plan - in practice component 6b.) Referral and involvement of multidisciplinary healthcare team already incorporated in Practice 8b. A new practice component specifically highlighting the need for providing referrals when managing psychological effects (9b) was created.
		Engage and refer to other health professions.	2		
Assist implementation of framework	6	Include more examples to aid implementation of framework practices	4	<ul style="list-style-type: none"> <li>Recommend clearer linkage to cancer-related fatigue, as currently it is quite broad. Adding examples of strategies can also aid in implementation.</li> <li>Could automate [the collection of clinical, behavioural, and symptom information] with questionnaires the way that InA (from Savor Health - a text-based oncology nutrition artificial intelligence does): <a href="https://www.savorhealth.com/">https://www.savorhealth.com/</a></li> <li>[About provision of fatigue information] A patient brochure would be extremely helpful!</li> <li>Are the action plans co-created with patients in words or all in infographics? multiple choice?</li> <li>Strategies provided are very useful, recommend including for all practices.</li> </ul>	An accompanying document providing further information on the framework and context was created. All strategies and further examples of items in practice framework were moved to this document. Document will be distributed to panel participants in Round 2 for their perusal.
		Consider using tools to assist with creating action plans and collecting information	2		
Identify the applicability of framework	2	Consider the relevance of framework to underserved populations	2	<ul style="list-style-type: none"> <li>[Self-management support is] something for the privileged: people who have time to be concerned about their individual wellness rather than the collective, middle class affluent people. Obviously not directed to refugees. We too have cancer.</li> <li>other pathways to access assistance where financially strapped to access medications gym yoga physio therapies etc</li> </ul>	We agree that further targeted consultation with specific stakeholders is needed to understand relevance and applicability for different groups. Cultural influences on health and disease, and attitudes towards care will need to be considered when adapting the framework to different contexts in the next step.
Round 2					
Provide fatigue specific strategies and examples	7	Contextual elements missing	7	<ul style="list-style-type: none"> <li>Contextual element missing? (Home, work, clubs, community organisations)"</li> <li>Incorporate fatigue specific self-management strategies and strategies for coping with fatigue.</li> <li>Coping strategies for management of fatigue is relevant but this should also include fatigue-specific self-management strategies (i.e., adaptive pacing, physical activity, etc). So word as incorporates fatigue specific self-management strategies and strategies for coping with fatigue.</li> <li>While tailoring is ideal, what is missing is clarity regarding the characteristics on which the provision of information should be tailored (i.e., symptom severity? resources available? intervention preferences?)."</li> <li>Greater specificity would be helpful if these practice components would be used for teaching or evaluating practice. Perhaps "attend to requests for further symptom review, treatment modification, or counselling..."</li> </ul>	Strategies and examples of practice scenarios were included in a separate document attached to the survey. Further analysis shows not all panel participants opened document. Panel feedback shows inclusion of these strategies and examples are essential. They have now been presented clearly.

- |  |  |  |  |  |  |
|--|--|--|--|--|--|
|  |  |  |  | <ul style="list-style-type: none"><li>• I have a problem with adjective "" general "" i would like it to be targeted and " contextually relevant" otherwise, waste of time. We are already bombarded by these messages constantly so totally disregard it.</li></ul> |  |
|--|--|--|--|--|--|

## Appendix 9: Changes from Round 1 of Modified Delphi Study (Study 2)

Original Practice Statement	Modified Statement based on Panel Feedback
<b>DOMAIN 1: ESTABLISHING CONTEXT AND DEFINING THE PROBLEM</b>	
<b>Key Practice 1</b>	
1. Collect and use clinical and behavioural information to inform decision making about the patient's self-management of cancer-related fatigue	Reached consensus for inclusion in Round 1 and included in final framework
1a) Conduct a consultation and assessment with the patient, and if available, other key people in the patient's support network (e.g., carer's; family members) to collaboratively define key concerns, problem areas and priorities.	Reached consensus for inclusion in Round 1 and included in final framework
<b>NEW</b>	1b) Identify family members/informal caregivers need to have guidance from healthcare providers to facilitate their ability to support the patient with self-management strategies.
1c) Collect, record, and store key clinical, symptom and behavioural information.	1c) Collect and record key clinical, symptom, behavioural, <b>and psychological information and highlight risk factors that may contribute to the patient's cancer-related fatigue.</b>
<b>NEW</b>	1e) Conduct a fatigue (e.g., Brief Fatigue Inventory Questionnaire, informal questioning) to determine fatigue severity, onset, duration, pattern, associated patient distress, and interference with daily living.
<b>Key Practice 2</b>	
2. Assess the patient's capacity for self-management.	Reached consensus for inclusion in Round 1 and included in final framework
2a) Identify factors within the patient, and the patient's physical and social environment, that they perceive may improve or worsen their cancer-related fatigue (e.g. more severe fatigue in the afternoon).	Reached consensus for inclusion in Round 1 and included in final framework
2b) Identify the patient's beliefs, attitudes, and knowledge about cancer-related fatigue, and identify their current coping strategies.	2b) Identify the patient's <b>and the informal caregivers/ support network</b> beliefs, attitudes, and knowledge about cancer-related fatigue, and identify their current coping strategies.
2c) Identify factors (i.e., cultural consideration, language literacy levels, availability of peer support network, pre-existing conditions) that may affect the patient's ability to participate in self-management activities.	Reached consensus for inclusion in Round 1 and included in final framework
<b>DOMAIN 2: DEVELOPING AN ACTION PLAN</b>	
<b>Key Practice 3</b>	
3. Create a cancer-related fatigue management action plan in collaboration with the patient	Create a cancer-related fatigue management action plan in collaboration with the patient <b>that incorporates evidence-based coping strategies that are aligned with patient preferences.</b>
3a) Reflect on the patient's capacity for self-management (including barriers), and the clinical and behavioural information gathered during pre-assessments, to refine the patient's priorities, needs, and goals concerning their cancer-related fatigue and general lifestyle.	Reached consensus for inclusion in Round 1 and included in final framework
3b) Plan a culturally and contextually relevant fatigue self-management care plan drawing on clinical and psychosocial information gathered during pre-assessments, the patient's capacity for self-management support and the health professional's applied knowledge of cancer-related fatigue management strategies.	3b) Plan a culturally and contextually relevant fatigue self-management care plan drawing on clinical and psychosocial information gathered during pre-assessments, the patient's capacity for self-management support ( <b>including addressing identified barriers to self-management or leveraging specific strengths/ capabilities</b> ), and the health professional's



	applied knowledge of cancer-related fatigue management strategies.
3c) Incorporate the patient's support networks (family, friends, carers) into action planning.	3c) <b>Consider incorporating</b> the patient's support networks (family, friends, carers) into action planning <b>with the patient's consent.</b>
<b>DOMAIN 3: IMPROVE PATIENT KNOWLEDGE</b>	
<b>Key Practice 4</b>	
4. Provide information (visual, written, verbal) on cancer-related fatigue and common management strategies	Provide <b>tailored evidence-based</b> information on cancer-related fatigue and common management strategies <b>in a diversity of formats to accommodate different learning styles.</b>
4a) Inform the patient and their support network of the differences between cancer-related fatigue and 'normal' fatigue.	Reached consensus for inclusion in Round 1 and included in final framework
4b) Inform the patient and their support network of the causes, key risk factors, presenting characteristics, and the possible effects and interferences of cancer-related fatigue on daily living.	Reached consensus for inclusion in Round 1 and included in final framework
4c) Communicate tailored evidence-based information to the patient and their support network regarding the benefits of exercise and physical activity for managing cancer-related fatigue and have an awareness of the strength of such evidence.	Reached consensus for inclusion in Round 1 and included in final framework
4d) Communicate tailored evidence-based information to the patient and their support network on other management strategies for cancer-related fatigue (along with their risk and benefits) and have an awareness of the strength of such evidence.	4d) Communicate tailored evidence-based information to the patient and their support network on <b>psychological and complementary medicine</b> management strategies for cancer-related fatigue (along with their risk and benefits) and have an awareness of the strength of such evidence.
<b>Key Practice 5</b>	
5. Provide tailored evidence-based information on managing common psychosocial consequences of cancer and cancer-related fatigue	Provide tailored evidence-based information on managing common psychosocial consequences of cancer and cancer-related fatigue <b>in a variety of formats to accommodate different learning styles.</b>
5a) Provide the patient and their support network with evidence-based information on how psychological and psychosocial factors (e.g., fear of cancer recurrence or progression, anxiety, depression, and stress) contribute to, and are exacerbated by cancer-related fatigue.	Reached consensus for inclusion in Round 1 and included in final framework
5b) Provide the patient with coping strategies for managing psychological and psychosocial factors	<b>This was deleted as panel feedback indicated it was already covered in Domain 4 (Key Practice 9).</b>
5c) Provide the patient with coping strategies for processing and communicating with others about cancer-related fatigue and cancer experiences.	<b>This was deleted as panel feedback indicated it was already covered in Domain 4 (Key Practice 7).</b>
<b>Key Practice 6</b>	
6. Provide information about available social support	<b>Provide tailored evidence-based information</b> about available social support <b>in a variety of formats to accommodate different learning styles and check patient understanding</b>
6a) Facilitate the involvement of the patient's support network (family members, friends, carers, significant others) in cancer-related fatigue self-management activities	6a) <b>Consider</b> facilitating the involvement of the patient's support network (family members, friends, carers, significant others) in cancer-related fatigue self-management activities <b>with the patient's consent.</b>
6b) Provide the patient and their support network with education and information about how to seek further social support and inform the patient of relevant support services in their community.	Reached consensus for inclusion in Round 1 and included in final framework
6c) Facilitate the exchange of cancer and cancer-related fatigue experiences and/or discussions between the patient and other cancer survivors.	6c) <b>Consider</b> facilitating the exchange of cancer and cancer-related fatigue experiences and/or discussions between the patient and other cancer survivors, <b>if the patient agrees.</b>

**DOMAIN 4: TRAINING REHEARSAL (STRATEGY BUILDING)**

**Key Practice 7**

7. Provide the patient with problem solving and evidence-based solution-focused strategies to communicate with their systems of support (includes health professionals, non-health professionals, personal communities; and voluntary and community groups) about cancer-related fatigue.	Reached consensus for inclusion in Round 1 and included in final framework
7a) Provide the patient with the skills to self-advocate and communicate with health professionals, non-health professionals, personal networks, employees, and others about cancer-related fatigue.	Reached consensus for inclusion in Round 1 and included in final framework
7b) Provide coaching and counselling about navigating relationships and social support	Reached consensus for inclusion in Round 1 and included in final framework

**Key Practice 8**

8. Provide evidence-based coaching for lifestyle modifications that support living with cancer-related fatigue.	Reached consensus for inclusion in Round 1 and included in final framework
8a) Provide the patient and their support network with evidence-based tailored coaching and practical strategies for exercise (e.g., aerobic, resistance, yoga, balance) and physical activity (e.g., daily walking, morning stretches).	Reached consensus for inclusion in Round 1 and included in final framework
8b) Provide tailored coaching and practical strategies to the patient and their support network that supports the patient's everyday activities	Reached consensus for inclusion in Round 1 and included in final framework
8c) Refer the patient to relevant services and professionals for support when indicated (e.g., if you are unable to provide tailored coaching).	8c) <b>Involve</b> and refer the patient to relevant services and professionals for support when indicated (e.g., if you are unable to provide tailored coaching). <b>and in the planning and decision making of the patient's care.</b>
8d) Involve relevant services and professionals in the planning and decision making of the patient's care	<b>This was combined with practice component 8c) as per panel feedback (due to overlap).</b>

**Key Practice 9**

9. Provide the patient with evidence-based problem-solving strategies for coping with the psychological effects or risk factors of cancer-related fatigue.	Reached consensus for inclusion in Round 1 and included in final framework
9a) Provide patients with strategies for coping with anxiety, fear of recurrence or progression, stress, depression, and managing interpersonal relationships.	Reached consensus for inclusion in Round 1 and included in final framework
<b>NEW</b>	9b) Refer the patient to relevant services (e.g., psycho-social oncology) and professionals for support when they are unable to provide tailored coaching. (new)

**Key Practice 10**

10. Provide evidence-based general health promotion and education on lifestyle adaptation strategies.	Reached consensus for inclusion in Round 1 and included in final framework
10a) Provide relevant general lifestyle advice and counselling support to the patient and their support network.	Reached consensus for inclusion in Round 1 and included in final framework

**DOMAIN 5: CARE CO-ORDINATION AND MAINTENANCE**

**Key Practice 11**

11. Provide regular review of self-management goals and action plans in collaboration with the patient (and their social network).	Provide regular review of <b>self-management activities</b> , and self-management goals and action plans in collaboration with the patient, <b>their support network (with the patient's consent), and their health care team.</b>
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11a) Reformulate previously established goals based off the patient's confidence, needs, and progress (i.e., goal attainment).	Reached consensus for inclusion in Round 1 and included in final framework
11b) Establish long term goals prior to the conclusion of support to facilitate continual patient self-care beyond the self-management support program.	Reached consensus for inclusion in Round 1 and included in final framework
11c) Provide scheduled reviews to monitor cancer-related fatigue (e.g., severity and lifestyle interference), associated symptoms (e.g., stress, depression), and review of progress with self-management behaviours (e.g., confidence, physical activity, activity management).	Reached consensus for inclusion in Round 1 and included in final framework
<b>Key Practice 12</b>	
12. Provide practical support that facilitates ongoing self-management.	Reached consensus for inclusion in Round 1 and included in final framework
12a) Provide practical support to assist the self-monitoring of cancer-related fatigue symptom reporting (e.g., fatigue severity, energy levels, and other factors that impacted fatigue), and behaviour change (e.g., exercise, meditation habits, physical activity, and dietary habits).	Reached consensus for inclusion in Round 1 and included in final framework
<b>Key Practice 13</b>	
13. Be able available on request to review the symptoms of cancer-related fatigue.	Reached consensus for inclusion in Round 1 and included in final framework
13a) Be available for symptom review, treatment modification or counselling if symptom thresholds are exceeded.	13a) Be available for symptom review, treatment modification or counselling if symptom thresholds are exceeded <b>or if requested by the patient due to a change in support requirements.</b>
<b>Key Practice 14</b>	
Be able available on request to review the symptoms of cancer-related fatigue	<b>This was moved to a practice component of Key practice 13 (due to overlap) as per panel feedback</b>
14a) Be available for symptom review, treatment modification and/ or counselling if symptom thresholds are exceeded	<b>This was merged with practice component 13a as per panel feedback.</b>

# **Cancer-Related Fatigue Self-Management Support Practice Framework**

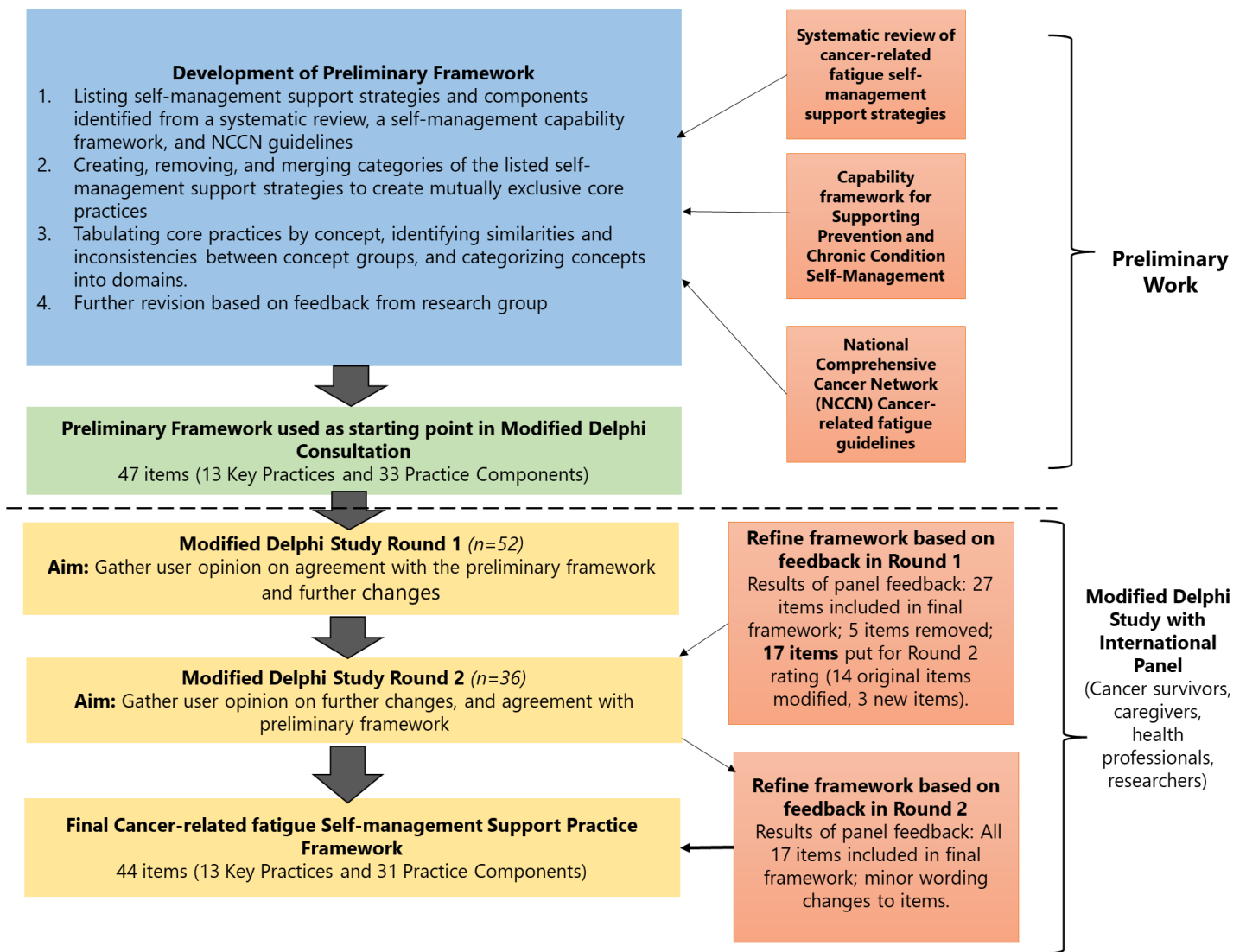
# CONTEXT

Cancer-related fatigue is one of the most common and distressing symptoms reported by people affected by cancer [1]. There is need for specific guidance [2, 3] to assist health professionals in facilitating the management of cancer-related fatigue [4, 5].

This Practice Framework presents the core practices required by health professionals to deliver effective self-management support to cancer survivors (pre- and post-cancer treatment) experiencing cancer-related fatigue, and presents an outline that is pragmatic, contextually adaptable, and clinically relevant.

The practices included in this framework revolve around an individual's perceived level of fatigue severity and interference, regardless of cancer diagnosis, treatment type, or phase in the cancer care continuum. This framework presents the core tasks that should be undertaken when providing support for cancer-related fatigue management, rather than explore changes within or between any subgroups.

# FRAMEWORK DEVELOPMENT



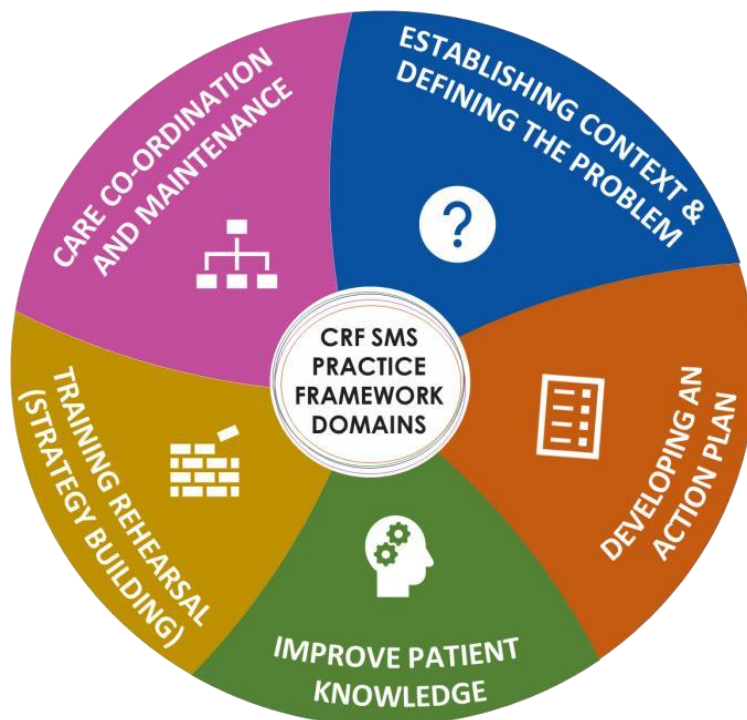
# COMPONENTS OF THE CANCER-RELATED FATIGUE SELF-MANAGEMENT SUPPORT PRACTICE FRAMEWORK

## DOMAINS

The practices included in this framework have been categorised into five domains. The domains of the practice framework provide a broad thematic organization for the self-management support practices and strategies. Each domain addresses a different set of essential processes that should be undertaken to sufficiently support cancer survivors to manage their cancer-related fatigue.

Each domain consists of corresponding Key Practices and Practice Components. The content of these Key Practices and Practice Components have been informed by:

- i. a systematic review of self-management support programs for cancer-related fatigue
- ii. The Capabilities for Supporting Prevention and Chronic Condition Self-Management Framework



## KEY PRACTICES

Key practices describe the proposed activities health professionals are required to undertake to provide best practice self-management support for cancer-related fatigue.

## PRACTICE COMPONENTS

Practice components describe the steps needed to complete a key practice. Health professionals are expected to demonstrate all practice components for all the key practices when providing self-management support for cancer-related fatigue. These practice components may require health professionals to apply, adapt, and integrate new and existing evidence-based knowledge.

## HOW CAN THIS FRAMEWORK BE USED?

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**Cancer-related fatigue is multifactorial – meaning that there are a diverse range of factors that can contribute to, or cause it (e.g., cancer type, cancer treatment type, anaemia, nutrition factors, psychological factors, etc.); therefore, it is expected that the provision of management support will require a multi-disciplinary approach.**

It is not expected that all health professionals be proficient in all practice components, whereby certain practices may fall outside of one's professional expertise or scope (e.g., radiation therapist providing psychological coping strategies). The provision of support for cancer-related fatigue management requires professional collaboration between differing specialities within a multidisciplinary care approach which includes an informed and supportive health care team.

The execution of the key practices and practice components specified in this document may require health professionals to apply, adapt, and integrate new and existing evidence-based knowledge. This practice framework does not

provide, present, or describe the capabilities or competencies required by health professionals. There are already clinical practice guidelines outlining evidence-based management strategies for cancer-related fatigue (e.g., NCCN, CAPO, Macmillan, other (Level I) empirical evidence). Instead, this practice framework outlines the tasks that health professionals and or health care teams should undertake when supporting people affected by cancer to manage their fatigue.

Finally, the execution of practices outlined in the framework should be underpinned by the presence of effective, person-centred, health professional communication which involves the ability to establish and develop mutual understanding, rapport, trust, respect, and cooperation with people affected by cancer using clear and plain language. This includes making appropriate adjustments (e.g., use of appropriate language and detail, use of appropriate verbal and non-verbal cues, confirming that the other person has understood) to meet the communication and information needs of patients and their support network (e.g., caregivers, family, friends) and providing opportunities for the patient and their support network to demonstrate their understanding.

**For the individual health professional**



**Use the Practice Framework as a tool:**

- to guide the provision of self-management support for CRF
- for determining your professional development needs
- for evaluating current practice when providing support to those managing CRF

**Use the Practice Framework to develop an understanding about:**

- the extent of CRF impact on those affected by cancer and the importance of its management
- the various roles of different health professionals in the delivery of self-management support for CRF

Use the Practice Framework and associated learning resources to undertake self-directed learning.

Refer colleagues new to working with people affected by cancer and/or CRF to the framework.

**For the clinical leader/ educator**



**Use the Practice Framework as a tool:**

- to develop clinician awareness and knowledge of evidence-based cancer-related management and assessment strategies
- to provide training/in-service programs to improve ability to undertake practices (how to use certain questionnaires, practice developing an action plan, etc.)
- to advocate for system-level changes to provide resources (time, space, and human) to deliver optimal support for CRF management

**For the CRF self-management intervention developer**



Use the Practice Framework to aid development of a CRF self-management intervention/program (determining the specific components that are needed).

**For the researcher**



**Use the Practice Framework as a tool:**

- to describe self-management support interventions for CRF
- to synthesize evidence on CRF self-management

**For the consumer experiencing CRF**



**Use the Practice Framework as a tool:**

- to develop understanding of the various roles of different health professionals in the delivery of self management support for CRF
- to advocate for improved delivery of cancer-related fatigue management support. to improve your care
- to advise your health care team(s) about the existence of the practice framework and teaching and learning resources in efforts



# CANCER-RELATED FATIGUE SELF-MANAGEMENT SUPPORT PRACTICE FRAMEWORK

**\*Note 1:** The examples ‘tools, strategies, and prompts’ section provides a guide to help health professionals consider the support expected. These descriptions provide examples but are not intended to be exhaustive. Information for the ‘tools, strategies, and prompts’ section was derived from the NCCN Cancer-related Fatigue Guidelines [6] and a systematic review of self-management support programs for cancer-related fatigue [7].

**\*\*Note 2:** The ‘patient’ refers to the individual experiencing cancer-related fatigue (encompasses those who are on active cancer treatment and those who have completed active cancer treatment).

## Domain 1: Establishing Context and Defining the Problem

Key Practice 1	Practice Components	*Examples of Tools, Strategies, Prompts, etc.
1. Collect and use clinical and behavioural information to inform decision-making about the patient's self-management of cancer-related fatigue.	1a) Conduct a consultation and assessment with the **patient, and if available, other key people in the patient's support network (with the patient's consent), to collaboratively define key concerns, problem areas, and priorities.	<p><b>Things for clinicians to consider</b></p> <ul style="list-style-type: none"> <li>How is fatigue impacting the patient's daily activities (social life, work life, personal feelings)? Examples of cancer-related fatigue presentation in patients can include lack of energy; lack of concentration; inability to complete daily tasks such as housework; poor concentration [6].</li> <li>Consider involving the patient's support network in information collection [6, 7]. Oftentimes the patient may not be aware that fatigue has impacted their life: however, their support network may be more cognizant of changes and the effect of fatigue [6].</li> </ul>
	1b) Identify family members/informal caregivers need for guidance from healthcare providers to facilitate their ability to support the patient with self-management strategies.	
	1c) Collect and record key clinical, behavioral, and psychological information and highlight clinical, behavioral or psychological risk factors that may contribute to the patient's cancer-related fatigue.	<p><b>Clinical information can include:</b> cancer treatment type, cancer treatment length, cancer recurrence or progression, referral history, age, medication history, pain levels [6] <b>Clinical risk factors of cancer-related fatigue can include:</b> anaemia, chemoradiation or other systemic treatments, hypothyroidism, hormonal cancer treatment depression, anxiety, stress, fluid/ electrolyte imbalance, pain</p> <p><b>Behavioural information can include:</b> sleep habits, current level of physical activity, diet, confidence in engaging in self-management behaviours</p> <p><b>Behavioural risk factors of cancer-related fatigue can include:</b> sleep disturbances, inactivity, poor diet</p> <p><b>Psychological information can include:</b> psychiatric history, history of depression and anxiety</p> <p><b>Psychological risk factors of cancer-related fatigue can include:</b> depression, anxiety, stress</p>

	<p>1d) Conduct a fatigue assessment to determine fatigue severity, onset, duration, pattern, associated patient distress, and interference with daily living.</p>	<p><b>Things for clinicians to consider [6]</b></p> <ul style="list-style-type: none"> <li>• Brief, self-reported, quantitative, and single-item assessments with empirically established cut-off scores are effective.</li> <li>• E.g., 0 to 10 numerical rating scale (0 = no fatigue and 10 = worst fatigue), mild fatigue indicated as a score of 1 to 3, moderate fatigue as 4 to 6, and severe fatigue as 7 to 10.</li> <li>• Evaluation of fatigue in children can be modified to a scale of 1 to 5 or asked if they are 'tired' or 'not tired'.</li> </ul>
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Key Practice 2	Practice Component	Example of Tools, Strategies, Prompts, etc.
<p>2. Assess the patient's capacity for self-management.</p>	<p>2a) Identify factors within the patient, and the patient's physical and social environment, that they perceive may improve or worsen their cancer-related fatigue.</p>	<p><b>Things for clinicians to consider [7].</b> Are there things the patient and/or the patient's support network have noticed that makes their fatigue worse or better? (for example, patients can describe worse fatigue on treatment days; more severe fatigue in different parts of the day; changes during certain weather)</p>
	<p>2b) Identify the patient's (and their informal caregiver's/ support network's) beliefs, attitudes, and knowledge about cancer-related fatigue, including differences between patients and informal caregivers and identify their current coping strategies.</p>	<p><b>Things for clinicians to consider [7]</b></p> <ul style="list-style-type: none"> <li>• What does the patient and their support network know about cancer-related fatigue?</li> <li>• How has the patient managed (or been managing) their fatigue? (e.g., What strategies have they tried, and not found success with? What do they feel has worked?)</li> </ul>
	<p>2c) Identify factors (i.e., cultural consideration, language literacy levels, availability of peer support network, pre-existing conditions) that may affect the patient's ability to participate in self-management activities.</p>	<p><b>Things for clinicians to consider [6, 7]</b></p> <ul style="list-style-type: none"> <li>• What factors might affect the patient's ability to undertake exercise and other fatigue management activities (e.g., lymphoedema, neuropathy in fingers, lack of transport, financial status, physical status, lack of support to assist with daily tasks.)</li> <li>• How does the patient's informal caregivers/ support network feel about providing assistance with support?</li> </ul>

## Domain 2: Developing an Action Plan

Key Practice 3	Practice Component	Example of Tools, Strategies, Prompts, etc.
<p>3. Create a cancer-related fatigue management action plan* in collaboration with the patient that incorporates evidence-based coping strategies that are aligned with patient preferences.</p>	<p>3a) Reflect on the patient’s capacity for self-management (including barriers), and the clinical and behavioral information gathered during pre-assessments, to refine the patient’s priorities, needs, and goals concerning their cancer-related fatigue and general lifestyle.</p>	<p><b>Things for clinicians to consider [6, 7]</b></p> <ul style="list-style-type: none"> <li>• What does the patient wish to get out of the support provided?</li> <li>• How motivated is the patient to address their cancer-related fatigue?</li> <li>• A particular patient may need more support network engagement (health professionals, friends, family, carer) and structural involvement versus another who may be highly self-motivated.</li> <li>• Consider using a readiness ruler to guide conversations around priorities, importance, confidence, and personal change.</li> </ul>
	<p>3b) Plan a <u>culturally and contextually relevant</u> fatigue self-management care plan. The plan should be informed by clinical and psychosocial information gathered during pre-assessments, the patient’s capacity for self-management (including addressing identified barriers to self-management or leveraging specific strengths/capabilities), and the health professional’s applied knowledge of cancer-related fatigue management strategies.</p>	<p><b>Culturally and contextually relevant</b> takes into consideration sociocultural factors (e.g., cultural and linguistic diversity, age, gender, disability, religion, socioeconomics, geographical locations) and acknowledges and incorporates the importance of culture, the assessment of cross-cultural relations, and the adaptation of services to meet culturally unique needs.</p> <p><b>Things for clinicians to consider [7]</b></p> <ul style="list-style-type: none"> <li>• Ensure goals are SMART (specific, measurable, actionable, realistic, time-bound), patient-centred, and include specific actions for moderately challenging behaviors.</li> <li>• Goal development process may need to include motivational interviewing techniques to address patient priorities and concerns; rolling with resistance when required, and facilitating the patient’s self-agency</li> </ul>
	<p>3c) Consider incorporating the patient’s support network (family, friends, carers) into action planning with the patient’s consent.</p>	<p><b>Things for clinicians to consider</b></p> <ul style="list-style-type: none"> <li>• The inclusion of a support network in action planning can increase uptake of fatigue self-management strategies [7].</li> <li>• How can the patient’s support network assist the patient to achieve goals in action plan?</li> <li>• For example, in a situation of escalating fatigue at the end of life, family members may wish to designate individuals to assume activities relinquished by the individual with cancer [6].</li> </ul>

**\*Definition/ components of a Cancer-related fatigue Action Plan:** The fatigue self-management action plan should be developed in collaboration with the patient and (if available) their other supports (including carers). The care plan should facilitate the patient’s engagement in their own care (leveraging the patient’s strengths and capabilities) and contain patient defined problems and goals, community education programs and resources, community support networks, allocated time for review and follow-up.

### Domain 3: Improving Patient Knowledge

Key Practice 4	Practice Component	Example of Tools, Strategies, Prompts, etc.
<p>4. Provide tailored evidence-based information on cancer-related fatigue and common management strategies in a diversity of formats to accommodate different learning styles</p>	<p>4a) Inform the patient and their support network of the differences between cancer-related fatigue and 'normal' fatigue.</p>	<p><b>Cancer-related fatigue vs. normal fatigue:</b> Cancer-related fatigue is a physical, emotional and/or cognitive tiredness that is more persistent and severe than normal fatigue and cannot be relieved by adequate sleep and rest [6].</p> <p><b>Things for clinicians to consider [6]</b></p> <ul style="list-style-type: none"> <li>• There is a need to relay to the patient that if fatigue does occur often, it is not necessarily an indication that the treatment is not working or that the disease is progressing/recurring.</li> <li>• Reassurance is important as fear of progression is a main reason for the under-reporting of fatigue.</li> </ul>
	<p>4b) Inform the patient and their support network of the causes, key risk factors, presenting characteristics, and the possible effects and interferences of cancer-related fatigue on daily living.</p>	<p><b>Examples of risk factors for cancer-related fatigue [6]</b> Insomnia; depression, anxiety and stress, pain; being overweight, anaemia; sudden weight loss, poor diet, other medical conditions (e.g., heart problems, diabetes). <b>Examples of presenting characteristics and interference on daily living [6]</b> Difficulty making decisions, sleeping, maintaining attention and concentration; poor memory, feeling drained with no energy or strength, inactivity, low mood.</p>
	<p>4c) Communicate tailored evidence-based information to the patient and their support network regarding the benefits of exercise and physical activity for managing cancer-related fatigue and have an awareness of the strength of such evidence.</p>	<ul style="list-style-type: none"> <li>• Several meta-analyses have been conducted to provide a comprehensive evaluation of the impact of increased activity upon cancer-related fatigue. Studies suggest that exercise and physical activity has a beneficial effect on fatigue in patients during and after cancer treatment [6].</li> <li>• It is reasonable to encourage patients to engage in a moderate level of physical activity (3 to 5 hours per week) during and after cancer treatment [6].</li> </ul>
	<p>4d) Communicate tailored evidence-based information to the patient and their support network on psychological and complementary medicine management strategies for cancer-related fatigue (along with their risk and benefits) and have an awareness of the strength of such evidence.</p>	<p><b>Examples of management strategies (excluding physical activity and exercise) [6]</b> Energy conservation, sleep therapy, activity management, counselling, cognitive behavioural therapy.</p>

Key Practice 5	Practice Component	Example of Tools, Strategies, Prompts, etc.
5. Provide tailored evidence-based information on managing common psychological consequences of cancer and cancer-related fatigue in a variety of formats to accommodate different learning styles	5a) Provide the patient and their support network with evidence-based information on how psychological and psychosocial factors (e.g., fear of cancer recurrence or progression, anxiety, depression, and stress) contribute to, and may be exacerbated by cancer-related fatigue.	<p><b>Things for clinicians to consider [6]</b></p> <ul style="list-style-type: none"> <li>• There is a strong correlation between emotional distress (depression, anxiety), stress, and cancer-related fatigue.</li> <li>• Psychological and symptom distress also have a negative effect on the patient's confidence to undertake fatigue self-management behaviours.</li> </ul>

Key Practice 6	Practice Component	Example of Tools, Strategies, Prompts, etc.
6. Provide tailored evidence-based information about available social support in a variety of formats to accommodate different learning styles and check patient understanding	6a) Consider facilitating the involvement of the patient's support network (family members, friends, carers, significant others) in cancer-related fatigue self-management activities with the patient's consent.	<p><b>Things for clinicians to consider</b></p> <ul style="list-style-type: none"> <li>• The availability of dependable caregivers can significantly impact the functional, emotional, and financial capacity of a patient and impact their pursuit of fatigue management [6].</li> <li>• Involving the personal support network in self-management solutions (i.e., family members exercising with the patient) may increase compliance/adherence to cancer-related fatigue self-management strategies [7].</li> <li>• A personal support network can be particularly key when a patient lacks the economic and supportive resources to obtain tangible support [6].</li> </ul>
	6b) Provide the patient and their support network with education and information about how to seek further social support and inform the patient of relevant support services in their community.	<p><b>Things for clinicians to consider</b></p> <ul style="list-style-type: none"> <li>• What are the available community-based resources for fatigue management?</li> <li>• Are there community options for physical activity programs?</li> <li>• What are the offerings of local advocacy groups?</li> </ul>
	6c) Consider facilitating the exchange of cancer and cancer-related fatigue experiences and/or discussions between the patient and other cancer survivors (peer support), if the patient wishes to do so.	<p><b>Practical support strategies [7]</b></p> <p>Exchange can occur through in-person discussion groups, patient stories (written), patient videos, online forums.</p> <p><b>Things for clinicians to consider [6]</b></p> <p>Use a guided group setting for peer exchange to avoid well-meaning but non-evidence-based suggestions and to allow for consideration of whether someone's experience is truly relevant to another person. Also take into consideration groups being limited to the right stage (in-treatment for primary cancer, living with secondary cancer, etc.).</p>

### Domain 4: Training Rehearsal (Strategy Building)

Key Practice 7	Practice Component	Example of Tools, Strategies, Prompts, etc.
7. Provide the patient with problem solving and evidence-based solution focused strategies to communicate with their systems of support (includes health professionals, non-health professionals, personal communities; and voluntary and community groups) about cancer-related fatigue.	7a) Provide the patient with the skills to self-advocate and communicate with health professionals, non-health professionals, personal networks, employees, and others about cancer-related fatigue.	<p><b>Strategies can include [7]</b></p> <ul style="list-style-type: none"> <li>• Providing examples of questions to ask healthcare professionals and examples of goals to prepare for discussions (e.g., “Tomorrow morning I will write a list of questions about fatigue to take with me to my appointment with the nurse next week.”)</li> <li>• Advising patients to show their fatigue diary to their healthcare teams, and invite their significant others to accompany them to consults and explain fatigue interference in terms of everyday life (e.g., feeling drained, having difficulty climbing stairs, cooking etc.)</li> <li>• Providing guidance on how to ask clarifying questions.</li> </ul>
	7b) Provide coaching and counselling about navigating relationships and social support.	

Key Practice 8	Practice Component	Example of Tools, Strategies, Prompts, etc.
8. Provide evidence-based coaching for lifestyle modifications that support living with cancer-related fatigue.	8a) Provide the patient and their support network with evidence-based tailored coaching and practical strategies for exercise (e.g., aerobic, resistance, yoga, balance) and physical activity (e.g., daily walking, morning stretches).	<p><b>Things for clinicians to consider [6]</b></p> <p>Improved satisfaction with physical activity is often reported when family involvement in a program increases. Encourage patients to engage in a moderate level of physical activity (at least 30 minutes a day <u>OR</u> at least 3 to 5 hours per week) during and after cancer treatment. It is critical that:</p> <ul style="list-style-type: none"> <li>• Patients choose a type of exercise they enjoy (as this increases the likelihood that they engage in physical activity)</li> <li>• Providers discuss specific implementation strategies (type of exercise, time of day, days of the week, location of activity) to enable patients to make frequent activity a reality.</li> <li>• Activity prescribed is individualized based on age, gender, cancer type, and fitness level.</li> <li>• Activity begins with a low level of intensity and duration and is modified as the patient’s condition changes.</li> </ul>
	8b) Provide tailored coaching and practical strategies to the patient and their support network that supports the patient’s everyday activities.	<p><b>Strategies can include</b> coaching on meditation, relaxation, and breathing exercises; providing nutritional consultation; coaching on changing sleep habits; providing advice on re-structuring daily activities and energy conservation; cognitive behavioural therapy [7].</p> <p><b>Examples of energy conservation strategies [6]</b></p> <ul style="list-style-type: none"> <li>• Maintaining a fatigue diary which will allow the patient to ascertain peak energy periods, and then plan their activities accordingly within a structured routine.</li> <li>• Labor-saving techniques (wearing bathrobe instead of drying off, assistive devices such as walker, etc.)</li> </ul>

Key Practice 8	Practice Component	Example of Tools, Strategies, Prompts, etc.
		<p><b>Examples of sleep hygiene strategies [6]</b></p> <ul style="list-style-type: none"> <li>• Going to bed and waking up at the same time each night, getting out of bed after 20 minutes if unable to fall asleep, avoiding long or late afternoon naps, avoiding caffeine in the afternoon.</li> </ul>
	8c) Refer the patient to relevant services and professionals for support when indicated, and involve these services in the planning and decision making of the patient's care.	<p><b>Examples of relevant services or health professions</b></p> <ul style="list-style-type: none"> <li>• Referral to exercise specialists (e.g., physical therapist, physical medicine, exercise physiologist, rehabilitation specialist) for an assessment and provision of exercise prescription.</li> <li>• Referral to cancer specific exercise programs</li> <li>• Community outreach programs</li> </ul>

Key Practice 9	Practice Component	Example of Tools, Strategies, Prompts, etc.
9. Provide the patient with evidence-based problem-solving strategies for coping with the psychological effects or risk factors of cancer-related fatigue.	9a) Provide patients with strategies for coping with anxiety, fear of recurrence or progression, stress, depression, and managing interpersonal relationships.	<p><b>Can occur through [7]:</b> Coaching on interpersonal relationships, distress management, sharing experiences with family and other cancer survivors, and assignments for building mental and social activity.</p> <p><b>Specific strategies can include [7]:</b></p> <ul style="list-style-type: none"> <li>• Cognitive restructuring and reframing; relaxation exercises; stress-management, breathing exercises, counselling, mindfulness therapy.</li> <li>• Activating positive emotions, overcoming depressive periods, breathing exercises, mindfulness therapy.</li> </ul>
	9b) Refer the patient to relevant services (e.g., psycho-social oncology) and professionals for support when you are unable to provide tailored coaching.	<p><b>Examples of relevant services or health professions</b></p> <p>Psychologist, behavioural therapist, counsellor, social worker, support network, community organisations.</p>

Key Practice 10	Practice Component	Example of Tools, Strategies, Prompts, etc.
10. Provide evidence-based health promotion and education on lifestyle adaptation strategies.	10a) Provide relevant lifestyle advice and counselling support to the patient and their support network.	<p><b>Examples of relevant lifestyle advice</b></p> <p>Promotion and support for physical activity, exercise, sleep hygiene, diet, activity management and regulation, stress management, and general health and wellbeing (e.g., preventing weight gain, health nutrition, increasing fluid intake, anger management).</p>

## Domain 5: Care Co-ordination and Maintenance

Key Practice 11	Practice Component	Example of Tools, Strategies, Prompts, etc.
11. Provide regular review of self-management activities, and self-management goals and action plans in collaboration with the patient, their support network (with the patient's consent), and their health care team	11a) Reformulate previously established goals based off the patient's confidence, needs, and progress (i.e., goal attainment).	<p><b>Things for clinicians to consider [7]</b></p> <ul style="list-style-type: none"> <li>Review should incorporate constant encouragement to improve fatigue self-management engagement and confidence.</li> </ul>
	11b) Establish long-term goals prior to the conclusion of support to facilitate continual patient self-care beyond the self-management support program.	
	11c) Provide scheduled reviews to monitor cancer-related fatigue (e.g., severity and lifestyle interference), associated symptoms (e.g., stress, depression), and review of progress with self-management behaviours (e.g., confidence, physical activity, activity management).	<p><b>Things for clinicians to consider [7]</b></p> <ul style="list-style-type: none"> <li>Scheduled reviews can occur during consultations or logbook/diary review.</li> </ul>

Key Practice 12	Practice Component	Example of Tools, Strategies, Prompts, etc.
12. Provide practical support that facilitates ongoing self-management.	12a) Provide practical support to assist the self-monitoring of cancer-related fatigue symptom reporting (e.g., fatigue severity, energy levels, and other factors that impacted fatigue), and behaviour change (e.g., exercise, meditation habits, physical activity, and dietary habits).	<p><b>Support Strategies can include [7]</b> Providing diaries, logs, activity trackers, pedometers, heart rate monitors, frequent telephone calls, automated email/text message reminders, home visits.</p> <p><b>Things for clinicians to consider [7]</b></p> <ul style="list-style-type: none"> <li>Consider providing equipment that enables the patient to engage in physical activity or exercise in their homes.</li> <li>Consider recording self-management support coaching/consult sessions to facilitate home practice.</li> </ul>

Key Practice 13	Practice Component	Example of Tools, Strategies, Prompts, etc.
13. Attend to requests to review the symptoms of cancer-related fatigue.	13a) Attend to requests (from the patient) for further symptom review, treatment modification or counselling if symptom thresholds are exceeded or if requested by the patient due to a change in support requirements.	<p><b>Examples include</b> facilitating additional counselling on request; ensuring patient accessibility to care coordinators, nurse practitioners, and psychologists for additional support.</p>



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