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Internet-delivered interventions for sexual and reproductive health following cancer

The Fex-Can Young Adult project

REBECCA SKOG

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Abstract

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This thesis is embedded within the Fex-Can Young Adult research project and consists of five papers. The overall aim was to develop and evaluate internet-delivered interventions targeting sexual problems and fertility-related distress following a cancer diagnosis, with the ultimate goal of improving the quality of survivorship among individuals diagnosed with cancer during young adulthood (18-39 years).

Paper I reported findings from a randomized controlled trial evaluating the efficacy of the Fex-Can Sex program in alleviating sexual dysfunction 1.5 years following a cancer diagnosis during young adulthood. No significant effects of the program were demonstrated, and participant activity in the intervention was limited.

Paper II explored interactive activity and the content of discussions forum posts within the Fex-Can Sex and Fex-Can fertility programs. A limited proportion of participants met criteria for high level activity. Four themes were constructed through thematic analysis of the discussion forum posts: *Fertility fears*, *Perceptions of the changed body*, *Missing out on life*, and *Importance of support and information*.

Paper III presented the internal pilot trial and randomized controlled trial of the Fex-Can 2.0 intervention, which was designed to alleviate sexual problems and fertility-related distress among individuals diagnosed with cancer during young adulthood.

Paper IV presented the collaboration between patient research partners and researchers in the refinement and further development of the Fex-Can intervention. Using qualitative content analysis for analysis of multimodal data (impact log information, field notes, individual interviews), three main categories were constructed: *Collaborative working process*, *Group atmosphere* and *Concrete impact*.

Paper V investigated changes in perceptions of the body during the first five years following a cancer diagnosis in young adulthood. Over half of female and one-fourth of male participants reported body image disturbance at 1.5 years post-diagnosis, with significant improvements in body image observed over time among males and among females diagnosed with breast cancer or lymphoma.

The work presented in this thesis contributes to existing research by providing insight into the sexual and reproductive health of young adults diagnosed with cancer, and by informing future research aimed at refining and evaluating internet-delivered interventions.

Keywords: Cancer survivorship, Sexual and reproductive health, Body image, Young adults, Internet-delivered interventions, Patient and public involvement, Complex interventions

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List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

I. Bergström, C., Skog, R., Eriksson, LE., Lampic, C., Wettergren, L. (2024). Efficacy of a web-based psychoeducational program targeting young adults with sexual problems 1.5 years after cancer diagnosis – Results from a randomized controlled trial. *Digital Health,* 10, 20552076241310037.

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III. Skog, R., Olsson, E. M. G, Gorman, J. R., Bober, S. L., Lampic, C., Wettergren, L. (2025). An internet-delivered psychoeducational intervention (Fex-Can 2.0) targeting fertility-related distress and sexual dysfunction in young adults diagnosed with cancer: Study protocol of a randomized controlled trial with an internal pilot phase. *PLOS ONE*, 20(4), e0322368.

IV. Marklund, S*., Skog, R*., Sjödin, L., Rose, J., Silén, M., Wettergren, L., Lampic, C. (2026). Navigating long-term co-creative research with young adults diagnosed with cancer. *Manuscript in preparation*. *Shared first authorship.

V. Skog, R., Marklund, S., Lampic, C., Wettergren, L. (2026). Body image during the first 5 years following a cancer diagnosis in young adulthood – a population-based cohort study. *Manuscript submitted to Psycho-Oncology*.

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Disclosure

During the preparation of this thesis, Microsoft Co-pilot and ChatGPT was used to check for grammar and spelling. All content provided by AI tools were reviewed, edited and refined by the author, who takes full responsibility for the content of this thesis.

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Abbreviations

BIS	Body Image Scale
BPNT	Basic Psychological Needs Theory
BSP	Brief Sexual Profile
CBT	Cognitive Behavioral Therapy
CG	Control Group
CONSORT	Consolidated Standards of Reporting Trials
EMM	Estimated Marginal Means
EORTC QLQ-C30	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30
GRIPP2-SF	Guidance for Reporting Involvement of Patients and the Public Short Form
HADS	Hospital Anxiety and Depression Scale
IG	Intervention Group
LMM	Linear Mixed Models
MBCT	Motivation and Behavior Change Techniques
MRC	Medical Research Council
NIHR	National Institute for Health and Care Research
NSFS	Need Satisfaction and Frustration Scale
PPI	Patient and Public Involvement
PROMIS SexFS	Patient Reported Outcome Measures Information Systems Sexual Function and Satisfaction
PRP	Patient Research Partner
RCAC	Reproductive Concerns After Cancer scale
RCC	Regional Cancer Centres
RCT	Randomized Controlled Trial
SD	Standard Deviation
SDT	Self-Determination Theory
SPIRIT	Standard Protocol Items: Recommendations for Interventional Trials
SRHR	Sexual and Reproductive Health and Rights
SRQR	Standards for Reporting Qualitative Research
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
TIDIER	Template for Intervention Description and Replication
YA	Young Adult

Introduction

Cancer during young adulthood

Cancer is a disease of the aging population, with a majority of new cancer cases occurring in individuals aged ≥60 years (Socialstyrelsen, 2025a). In Sweden, roughly 2,000 young adults (18-39 years) are diagnosed with cancer every year, making up approximately 3% of new cases (Socialstyrelsen, 2025a). In high income countries, cancer incidence among young adults has risen, and mortality has declined (Hughes et al., 2024a; Miller et al., 2020). With a 5-year survival rate exceeding 80%, a growing population of are living with and beyond cancer (Miller et al., 2020).

Throughout this thesis, young adulthood is defined as the age range 18-39 years. Young adults are considered a unique group in oncology, in part due to factors such as distributions of types of cancer, tumor biology and risks of long-term complications (Barr et al., 2016; Ferrari et al., 2021; Miller et al., 2020). Common cancers in the age group includes breast cancer, melanoma of the skin, testicular cancer, thyroid cancer, cervical cancer, lymphoma and brain tumors (Barr et al, 2016; Miller et al., 2020; Socialstyrelsen, 2025a). Tumor biology and clinical characteristics may differ from those observed among children or older adults (Ferrari et al., 2021). Generally, the literature suggests that young adults are often diagnosed with more aggressive tumors, are at risk for delayed treatment, and requires more intensive treatments (Barr et al., 2016; Cathcart-Rake et al., 2021; Murphy et al., 2019). The increased risk of long-term and late complications of disease and treatment, including occurrence of secondary cancers, cognitive impairment, fatigue and psychological distress, are further frequent and pose a threat to well-being and quality of life (Adams et al., 2020; Janssen et al., 2021; Rosgen, 2022; Zhang et al., 2025). Previous studies indicate that young adults experience high levels of anxiety and depression following cancer, and are at greater risk of psychological distress than both older cancer survivors (>40 years) and peers without a history of cancer (Osmani et al., 2023; Sjödin et al., 2025).

Navigating the cancer experience

Understanding the challenges experienced in cancer survivorship requires acknowledging the interplay between physical, emotional and social dimensions of health (Engel, 1977; Zebrack et al., 2016). According to the biopsychosocial model (Engel, 1977), health and illness are dynamic processes shaped by biological (e.g., genetics, physiology), psychological (e.g., emotions, mental health) and social factors (e.g., relationships, norms). These dimensions may not only shape disease onset and progression, but also shape individual responses to treatment and recovery. For example, chemotherapy-induced hair loss may evoke body image concerns, which in turn can lead to social withdrawal and emotional distress. Consequently, addressing cancer survivorship requires an integrated approach that considers the full complexity of these interconnections (Engels, 1977; Zebrack et al., 2016).

Young adulthood represents a critical developmental stage characterized by transitions towards independence, and pursuit of long-term goals. Regardless of disease or health status, this period involves heightened vulnerability to disruptions of trajectories across physical, psychological and social domains (Zebrack et al., 2016). A cancer diagnosis during this stage can profoundly disrupt these trajectories. Rowland (1990) proposed that all individuals diagnosed with cancer experience a universal set of disruptions related to cancer including disruptions of personal relationships; issues of independence; achievement of life goals; concerns about body-sexual image and integrity; and existential issues. The nature of these disruptions is further hypothesized to vary based on age-related roles and responsibilities (Rowland, 1990; Zebrack et al., 2011). For the young adult, who is in the process of establishing autonomy, pursuing education and careers, and forming intimate relationships, these disruptions may be particularly distressing (Zebrack et al., 2011).

Previous research has underscored the complex psychosocial challenges faced by young adults following cancer, including difficulties in educational attainment, employment, and in the development and maintenance of intimate relationships (Bellizzi et al., 2012; Warner et al., 2016). Bellizzi et al. (2012) found that negative impact of cancer and treatment was mainly reported on financial- and work-related circumstances, body image, romantic relationships, and plans for having children in the future, while positive impact were noted in relationships with family and friends, health competence, and future goals. Mental health concerns are also prevalent following a cancer diagnosis during young adulthood; a period when the incidence of anxiety and depression is already high (Gustavson et al., 2018). Cancer may further exacerbate

these vulnerabilities, reducing quality of life and creating barriers to treatment adherence and self-management (Zebrack et al., 2016). In addition, sexual and reproductive health concerns are especially common and salient, with potential long-term implications for sexual function, body image, identity, and opportunities for parenthood (Cherven et al., 2024; Choi et al., 2022; Guzik et al., 2021; Lidington et al., 2021). Despite the prevalence of these issues, expert consensus highlights that such concerns are frequently underreported and under-addressed, with limited availability of tailored resources and interventions (Vaz-Luis et al, 2022). Given that most young adults are expected to live for several decades post-diagnosis (Miller et al., 2020), addressing the psychosocial needs is essential for promoting long term quality of life and well-being.

Sexual and reproductive health and rights

Sexual and reproductive health is not merely the absence of disease, dysfunction or infirmity, but rather a state of physical, emotional, mental, and social well-being in matters relating to sexuality and reproduction (Starrs et al., 2018). To promote sexual and reproductive health, sexual and reproductive rights must be realized. Sexual and reproductive rights refer to individual's right to make free and informed decisions about sexuality, relationships, marriage and childbearing, to have safe and pleasurable sexual experiences, and lifelong access to information, resources and services needed to achieve and maintain sexual and reproductive health (Starrs et al., 2018). Sexual and reproductive health and rights (SRHR) thus involves matters relating to having a safe and satisfying sex life, and to be given the prerequisites to make informed decisions about reproduction (Starrs et al., 2018).

Sexual and reproductive health and rights in the cancer context

Sexual and reproductive health and rights are essential for health and well-being across the life span (Flynn et al., 2016; Mishra et al., 2010; Wellings & Johnson, 2013). In the context of cancer, these needs and rights may be compromised, as cancer and its treatment can result in sexual dysfunction, sub- or infertility, and negative physical, emotional, and social well-being in matters relating to sex life and reproduction (Bober & Varela, 2012; Logan et al., 2019). For individuals diagnosed with cancer during young adulthood, disease and treatment further coincides with a developmentally- and reproductively important period of life (Cherven et al., 2024; Zebrack et al., 2011). Young adults thus simultaneously face common age-related sexual and reproductive concerns (e.g., issues of contraception use, sexually transmitted infections,

sexual self-efficacy), as well as specific concerns that arise due to cancer and cancer treatment (Frederick et al., 2019). The immediate, long-term and late effects of disease and treatment on sexual and reproductive health can further negatively affect romantic relationships, intimacy and quality of life (Cherven et al., 2024; Hawkey et al., 2021). Additionally, insufficient access to timely, high-quality information, resources, and supportive care may further inhibit the sexual and reproductive health rights of individuals during and after cancer (Albers et al., 2020; Benedict et al., 2016a).

Sexuality and sexual dysfunction

Sexuality is a multidimensional construct, encompassing biological (e.g., anatomy, hormones), psychological (e.g., emotions, thoughts, desires) and social and cultural (e.g., relationships, norms, values) components (Ekdahl, 2017; World Health Organization, 2006). Sexual function typically refers to biological and physiological aspects of sexuality, including sexual responses such as desire, arousal and orgasm (Ekdahl, 2017).

Historically, linear, sequential models of human sexual response have dominated the field (Levin, 2017). More recent approaches however, conceptualize sexual response as non-linear and circular, incorporating contextual and psychosocial influences (Levin, 2017). The circular model by Basson (2000) was developed as a way of better conceptualizing the sexual response cycle of females. In this model, sexual desire, arousal and satisfaction are shaped by previous sexual experiences, and, in turn, influence future sexual experiences. Importantly, the model proposes that motivation for sexual activity may arise not only from spontaneous desire, but from a wish for intimacy, emotional closeness, or affirmation, emerging from a state of sexual neutrality (i.e., response desire) (Basson, 2000; Parish et al., 2021). Compared with earlier linear models, which largely excluded subjective experiences, contemporary non-linear models more fully account for the psychological and social factors that shape sexual responses (Levin, 2017).

Sexual dysfunction commonly refers to difficulties that occur during the sexual response cycle and is classified within two primary diagnostic systems: the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Diseases (ICD). Although these systems differ in terminology and number of dysfunctions specified, sexual dysfunction is generally categorized into disorders of sexual desire and arousal, erectile dysfunction, genito-pelvic pain, and orgasmic or ejaculation dysfunction (Levin,

2017). Both systems further specify that problems should be persistent, occur frequently, and be associated with significant distress. Sexual dysfunction may arise form physiological or psychological factors, or a combination of both (Elmerstig, 2012). Importantly, the experience of sexual dysfunction is subjective and context-dependent, influenced by factors such as the perceived importance of sex at different life stages, relational context, and social and cultural norms (Elmerstig, 2012). Consequently, sexual functioning that deviate from normative definitions is not necessarily experienced as a problem.

Sexuality following cancer

Sexual problems following cancer may arise as a result of both the disease itself and many common cancer treatments (Sadovsky et al., 2010; Schover et al., 2014). Treatments may result in damage to nerves and blood vessels, altered hormone production, pain, and internal and external bodily changes (Sadovsky et al., 2010). Consequently, cancer survivors may experience erectile and ejaculatory problems (Bober & Varela, 2012; Stanton et al., 2018), problems with pain and vaginal lubrication (Ljungman et al., 2018; 2019), and low interest in sexual activity and satisfaction with sex life (Ljungman et al., 2018; 2019; Wettergren et al., 2022). Bober and Varela (2012) proposed a comprehensive integrative biopsychosocial approach for understanding and addressing sexual problems in cancer survivors. This model emphasizes that sexual problems are multifactorial, arising from interactions of four domains: biologic, psychological, interpersonal and social/cultural.

> *Biological factors* include problems related to hormonal alterations (e.g., treatment induced menopause), changes in body integrity and loss of body part(s), as well as pain and fatigue from treatment.
>
> *Psychological factors* include emotional reactions (e.g., symptoms of depression and anxiety), cognitive impact (e.g., negative thinking, negative thoughts about the body) and motivation (e.g., self-efficacy, reduced confidence).
>
> *Interpersonal factors* refer to difficulties communicating, experiencing discomfort with or fearing intimacy, and relationship discord.
>
> *Social/cultural factors* includes social norms, social perceptions and cultural/religious beliefs and values.

Among individuals diagnosed with cancer in young adulthood, many will experience some degree of sexual problems. Previous studies indicate that

between 50% and 60% of young adult cancer survivors report sexual problems within the first two years following diagnosis (Acquati et al., 2018; Wettergren et al., 2017; 2022). In a study by Wettergren et al. (2017), 49% of young cancer survivors reported negative impact of cancer and its treatment on sexual function at one-year post-diagnosis, with 70% reporting persistent problems at the two-year follow-up. Similarly, Acquati et al. (2018) found that 52% of young adult cancer patients reported sexual problems at approximately two years post-diagnosis. Among female young adult cancer survivors, more than 60% report sexual dysfunction in at least one domain of the PROMIS Sexual Function and Satisfaction measure at 1.5 years following diagnosis (Wettergren et al., 2022).

Several demographic, psychological and clinical factors have been associated with sexual problems in young cancer survivors. Such factors include female sex, older age (within the young adult age range, 18-39 years), and higher levels of emotional distress (Acquati et al., 2018; Wettergren et al., 2022). Body image disturbance has also been consistently linked to higher levels of sexual dysfunction (Ljungman et al., 2018, 2019; Rosenberg et al., 2013; Wettergren et al., 2022). Clinical factors associated with increased sexual problems include higher treatment intensity and a diagnosis of breast- and gynecological cancer (Vrancken Peeters et al., 2024; Wettergren et al., 2022). Among females diagnosed with breast cancer, current endocrine treatment has been linked sexual dysfunction (Ljungman et al., 2018), while receipt of radiotherapy and being more recently diagnosed have been linked to greater sexual problems among young survivors of cervical cancer (Donovan et al., 2007). Changes in sexual function and body image often disrupt sexual self-image (Gilbert et al., 2013), and many survivors describe missing out on sexual and romantic milestones, concerns about forming intimate relationships, and relationship strain due to sexual problems or changes (de Souza et al., 2021; Wirtz et al., 2023).

Body image following cancer

Body image plays a fundamental role in individuals' self-esteem and identity, and is closely connected to emotional well-being and social functioning (Kling et al., 2018; Moore et al., 2021). It also plays a central role in sexual and reproductive health, influencing sexuality, intimacy, and confidence in relationships (Horvath et al., 2020; Paterson et al., 2016). Body image is generally considered a complex and multidimensional construct, involving affective (e.g., feelings towards the body), cognitive (e.g., thoughts about the body) and

behavioral (e.g., compensatory behaviors in response to one's body) dimensions (Cash, 2004). In the cancer context, Fingeret (2016) conceptualized body image along a continuum, ranging from minimal concerns to severe body image disturbance. Many will experience a normative level of body image concerns, meaning that while they may struggle to adjust to changes, they have realistic expectations on body image outcomes (Fingeret, 2016).

Cancer and its treatment commonly result in significant changes to the body, affecting appearance, sensation, cognition and function (Fingeret et al., 2014). Surgical treatments may involve loss of body part(s), scarring and lymphedema, whereas chemotherapy and radiotherapy may cause hair-loss, skin changes, and weight fluctuations. Although these changes may vary in visibility and duration, changes or perceived changes may be a significant source of distress and discomfort, negatively affecting body image (Annunziata et al., 2012; Fingeret et al., 2014; Lehmann & Tuinman, 2018). Rhoten (2016) identified three attributes of body image disturbance among adults treated for cancer: self-perceived changes in appearance accompanied by dissatisfaction, decline in an area of function, and psychological distress regarding these changes (Rhoten, 2016).

Given the profound impact of cancer and its treatment on the body, there is a growing body of knowledge on body image among cancer populations. Although body image disturbance has been documented among a variety of cancer types (e.g., head and neck-, colorectal-, gynecological-, and testicular cancer), much of the literature has focused on breast cancer (Lehmann et al., 2015). Among young adults, reported prevalence of body image disturbance varies widely, ranging from 17% to 63%, with females generally reporting more negative impact compared to males (Saris et al., 2022; Vani et al, 2021). While body image concerns may improve as time since diagnosis increases (Dempsey et al., 2022; Rosenberg et al., 2020), long-term impact have also been observed. For instance, in a cohort of 3,735 individuals diagnosed with cancer during young adulthood, approximately 15% reported a negative body image an average 12 years post-diagnosis (Saris et al., 2022).

Fertility following cancer

Fertility may be compromised by cancer itself, as well as by several of the most common cancer treatments (Di Tucci et al., 2022; Himpe et al., 2023). Among females, treatments may negatively affect ovarian function and reproductive organs, resulting in premature ovarian insufficiency and sub-or

infertility (Himpe et al., 2023; Levine et al., 2015). Among males, treatments may lead to oligo- or azoospermia, hormonal changes, or ejaculatory difficulties (Himpe et al., 2023). Previous studies have shown that females diagnosed with cancer during adolescence and young adulthood have lower pregnancy rates than age-matched peers (Magelssen et al., 2008), and experience lower birth rates than expected compared with the general population (Sunguc et al., 2024).

Several fertility preservation methods can improve chances of future biological and genetic parenthood (Purandare et al., 2025). For males, sperm banking is an effective method, however, the process can be experienced as stressful and emotionally charged (Bentsen et al., 2024a). In contrast, fertility preservation for females, such as embryo and oocyte cryopreservation, is rather invasive and time consuming, and restricted by various treatment considerations (Purandare et al., 2025; Rodriguez-Wallberg & Oktay, 2014). Reflecting these differences, fertility preservation is used to a greater extent among young adult male cancer patients than among females in Sweden (71% vs. 15%, respectively) (Wide et al., 2021). Fertility preservation may alleviate some of the negative psychosocial consequences by providing hope or reassurance regarding the possibility of future biologic or genetic parenthood (Lehmann et al., 2025a). However, regardless of whether fertility preservation is pursued, many young adults experience significant feelings of uncertainty related to fertility and future family building (Bentsen et al., 2024a; Lehmann et al., 2025a).

Fertility-related distress

Regardless of knowledge about whether cancer and its treatment has affected fertility, fertility-related distress is common following cancer and can persist long into survivorship (Drizin et al., 2021; Gorman et al., 2012, 2015; Logan et al., 2019). Fertility-related distress refers to psychological distress experienced in relation to fertility and parenthood (Gorman et al., 2014). Fertility-related distress further encompasses worries about personal health and the ability to care for (future) children, concerns related to dating and disclosure of fertility status, and fears of transmitting a genetic cancer risk to future offspring (Gorman et al., 2019). According to a biopsychosocial model proposed by Canzona et al. (2021), fertility-related distress among adolescents and young adults with cancer can arise from multiple interacting factors, including pre-cancer parenthood preferences, demographic factors, and developmental and biological differences that shape how individuals perceive and respond to fertility risk. This model delineates four interrelated domains for fertility

concerns; affective, informational, coping and logistical (Canzona et al., 2021). Individuals may thus experience emotional uncertainty (affective), receive insufficient or unclear fertility-related information (informational), engage in coping strategies such as avoidance or consideration of alternative paths to parenthood (coping), and encounter practical barriers such as financial or geographical constrains (logistical). Interactions among these domains influence fertility-preservation decision-making and may contribute to additional emotional burden, such as decisional regret (Canzona et al., 2021).

Problems and concerns related to fertility has been identified as among the most distressing long-term consequences of cancer (Logan et al., 2019; Ussher & Perz, 2019). In a cross-sectional study of 1010 individuals diagnosed with cancer in young adulthood, 54% of females and 27% of males reported high levels of fertility-related distress at 1.5 years post-diagnosis (Rodriguez-Wallberg et al., 2023). Survivors without children prior to diagnosis, and those desiring (additional) children appear to be at particular risk for high levels of fertility-related distress (Ljungman et al., 2018; Rodriguez-Wallberg et al., 2023; Ruddy et al., 2014; Ussher & Perz, 2019). Additional factors associated with fertility-related distress include receipt of chemotherapy (Ljungman et al., 2018; Ruddy et al., 2014), being single (Rodriguez-Wallberg et al., 2023), relationship dissatisfaction (Ussher & Perz, 2019), and negative body image (Ljungman et al., 2019).

Fertility-related distress may represent a substantial psychosocial burden in young adulthood, with implications for intimate relationships, sexual and relationship satisfaction, and overall quality of life (Canada & Schover, 2012; Hawkey et al, 2021). In a study of young adult female cancer survivors, higher levels of current reproductive concerns were associated with moderate to severe depressive symptoms (Gorman et al., 2015). Qualitative accounts further highlight the variety of uncertainties associated with fertility following cancer, including perceived loss of control over one’s body and reproductive capacity (Armuand et al., 2015; Bentsen et al., 2023), reduced sense of agency (Parton et al., 2019), and challenges to femininity or masculinity (Ussher et al., 2018).

Unmet sexual and reproductive health and right needs

Several studies have documented substantial unmet needs among young adults diagnosed with cancer in matters relating to sexual and reproductive health and rights, highlighting limited, inconsistent, or suboptimal communication and care provided (Berkman et al., 2023; Ferrari et al., 2021; Lehmann et al.,

2022; Reese et al., 2017a). Such needs often concern practical and emotional support (e.g., coping strategies, help with adjustment to changes), information (e.g., education, resources, realistic expectations) and needs related to communication, including proactive, provider-initiated discussions and normalization of SRHR concerns (Black et al., 2020; Lehmann et al., 2022, 2025b).

In Sweden, the national care program for cancer rehabilitation developed by the Regional Cancer Centres (RCC) outlines guidelines for addressing patients' sexual and reproductive rehabilitation needs (Regionala cancercentrum i samverkan, 2023). These guidelines stipulate that physicians and navigating nurses are responsible for informing patients about the potential impact of cancer and cancer treatment on sexual and reproductive health, and relevant SRHR competence should be available to patients. In a study by Bergström et al. (2023), 68% of males and 54% of females reported receipt of information about the potential impact of cancer on sexual function. With regard to fertility, most young adult cancer patients reported having received information about the potential impact on fertility, and 84% of males compared with 40% of females reported having received information about fertility preservation (Wide et al., 2021). However, many young adults in Sweden continue to report unmet sexual and reproductive needs following cancer (Ung Cancer, 2023). According to a report from the Swedish non-profit organization Ung Cancer, SRHR-information, rehabilitation, and support currently provided is insufficient. The report further underscores the importance of systematically integrating SRHR into follow-up care and ensuring access to age-appropriate support and interventions after treatment completion (Ung Cancer, 2023).

Complex interventions in health

Complex interventions are typically defined as interventions with multiple interacting components which, when applied to an intended target population, may produce variable outcomes depending on implementation and context (Richards, 2015). In line with the Medical Research Council (MRC) framework for developing and evaluating complex interventions, complexity may arise from factors such as the number of behaviors targeted and their interactions, the number and variability of outcomes, and the degree of flexibility in intervention delivery (Richards, 2015). As interventions do not operate in isolation, complexity can also arise as a result of interactions between interventions and the context in which they are implemented or interacted with (Richards, 2015; Skivington et al., 2021).

The MRC framework for complex interventions provides structured guidance for designing, testing and implementing complex interventions in health, and emphasizes the importance of ensuring that interventions are theory-driven and evidence-based, practical and implementable, and transparently and rigorously reported. According to this framework, development and evaluation of complex interventions can be divided into four interconnected and often nonsequential phases: (i) development or identification of the intervention, (ii) feasibility, (iii) evaluation, and (iv) implementation. These phases further share a common set of core elements (Figure 1), which should be considered and addressed throughout the research process (Skivington et al, 2021).

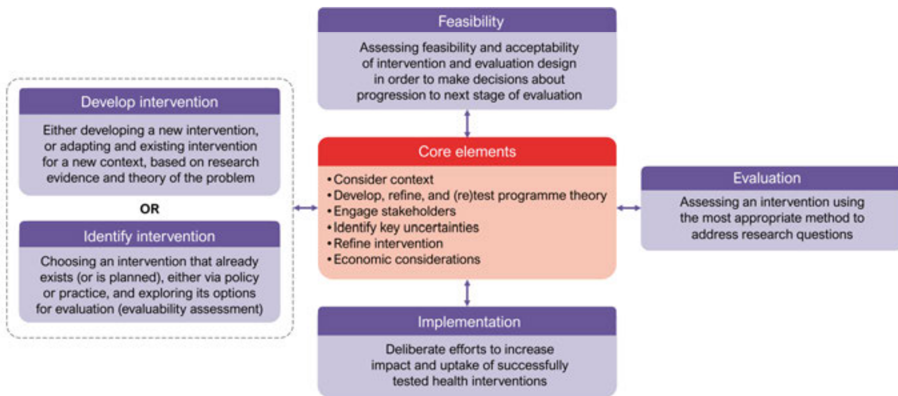

Figure 1. Phases and core elements of the MRC Framework for developing and evaluating complex interventions. Retrieved from Skivington et al. (2021). Licensed under CC BY 4.0.

Intervention development

In connection to the MRC framework, O'Cathain and colleagues (2019) presented a framework of 11 key actions for development of interventions aiming to improve health and healthcare (Table 1). Although these actions may not always be necessary or feasible to perform, authors encourage developers to consider the relevance of such actions during the development process (O'Cathain et al., 2019). While actions are presented in a sequential way in Table 1, actions should be undertaken dynamically and continuously revisited.

Table 1. Summary of the framework of actions for intervention development presented by O'Cathain and colleagues (2019)

Action	Description
Plan the development process	Identify the problem and consider the feasibility and necessity of developing an intervention
Involvement of interestholders	Considered and plan for integration of patient and public involvement in the process of intervention development
Bring together a team and establish a decision-making process	Include a team representing the relevant expertise and agree on a decision-making process with in the team
Review published evidence	Identify existing inventions and understand the evidence base
Draw on existing theories	Identify one or several theoretical frameworks to inform the intervention
Articulate program theory	Develop a program theory to be tested and refined during the development process
Undertake primary data collection	Utilize a variety of methods, including qualitative and quantitative approaches
Understand context	Consider the context in which the intervention will be implemented
Pay attention to future implementation of the intervention	Explore and understand facilitators and barriers to future use of the intervention
Design and refine the intervention	Generate the intervention in collaboration with interestholders and work iteratively with prototypes of the intervention
End of development phase	Describe the development process for transferability and future evaluation.

Patient and public involvement in research

Patient and public involvement (PPI) in research refers to research being done with or by patients and the public, rather than to, for, or about them (National Institute for Health and Research [NIHR], 2024). Arguments for PPI in research can be summarized into (i) normative or emancipatory, meaning that patients have a right to impact research on their condition, (ii) consequentialist or efficacy-oriented, suggesting that the lived-experience perspective brought forward through PPI can improve the efficiency and value of research, and (iii) political and practical arguments, suggesting that alliances between researchers and patients and the public increases accountability and

transparency of research (Greenhalgh et al., 2019). Patient and public involvement in research may thus offer an opportunity for empowerment for those who are affected by the topic targeted by the research, can contribute to studies that are more relevant and acceptable to future study participants, and increase the transparency and accountability of research (Kaisler & Missbach, 2020; Nissen et al., 2018).

Patient research partners (PRPs) can be involved throughout the research cycle, and may be involved at different levels of involvement (NIHR, 2024). Commonly, levels of involvement include consultation, collaboration and co-production or partnership (Colomer-Lahiguera et al., 2023; Robinson, 2014). Consultation involves inviting interestholders to provide feedback on materials such as research proposals and study documents to inform decision-making by the research team. It offers valuable input, is typically less resource-intensive and often occurs as a one-off interaction (Colomer-Lahiguera et al., 2023; Robinson, 2014). Collaboration entails a more active and ongoing relationship, with interestholders being more involved in decision-making process (Robinson, 2014). Compared to consultation, collaboration requires greater time, resources and commitment from both researchers and PRPs. Finally, partnership represents shared leadership, where researchers and PRPs jointly make decisions throughout the research process (Colomer-Lahiguera et al., 2023).

Over the past decades, increased attention has been given to involvement of PRPs in cancer research, with a particularly sharp increase in studies published over the past 10 years (Colomer-Lahiguera et al., 2023; Pii et al., 2019). Systematic reviews of PPI in cancer research show that PPI is often applied in early stages of research (e.g., prioritization of research topics) and often occur at a consultation level (Colomer-Lahiguera et al., 2023; Pii et al., 2019). Importantly, while descriptions and reporting on PPI efforts in research may support researchers in conducting PPI and understanding its impact, systematic reviews indicate that PPI activities are often insufficiently reported (Colomer-Lahiguera et al., 2023; Pii et al., 2019).

Use of theory in interventions

In intervention development, researchers may consider use of one or several theoretic frameworks (O'Cathain et al., 2019). Use of theory may aid researchers in identifying what is important and relevant, and further guide the development process and design of the intervention. Bartholomew and Mullen (2011) describe several different roles that theory may have in the design and

evaluation of behavior change interventions, including in the selection of program components, and for strategies for delivery to change determinants relevant to the target behavior (Bartholomew & Mullen, 2011). Notably, a systematic review found that extensive use of theory and incorporation of several behavior change techniques were associated with larger effects in internet-delivered behavior change interventions (Webb et al., 2010).

Self-determination theory

Self-determination theory (SDT) is a macro theory of human motivation, development and behaviour (Ryan & Deci, 2018). SDT posits that basic psychological needs and autonomous versus controlled forms of motivation are central to understanding motivated behaviour (Hagger et al., 2020; Ryan & Deci, 2018). A core assumption of SDT is that individuals have an inherent tendency towards growth and integration of the self, which is supported or hindered by social and contextual factors (Ryan & Deci, 2018). SDT consists of six interrelated mini-theories: (I) Cognitive evaluation theory; (II) Organismic integration theory; (III) Causality orientations theory; (IV) Basic psychological needs theory; (V) Goal contents theory and (VI) Relationships motivation theory. Together, these mini-theories address:

I. The social and contextual factors that support or thwart intrinsic motivation.
II. Internalization and integration of extrinsically motivated behaviors.
III. Motivational styles that are relevant across context and domains.
IV. The impact of satisfaction and frustration with basic psychological needs on well-being.
V. Intrinsic and extrinsic content of goals.
VI. The quality and consequences of close relationships.

Collectively, the mini-theories offers a comprehensive framework for understanding how social contexts and individual differences interact to support autonomy, competence and relatedness, thereby fostering motivation and psychological well-being. For purposes of the present thesis, basic psychological needs theory (BPNT) is described in greater detail below.

Basic psychological needs theory

BPNT focuses on how the satisfaction and frustration of basic psychological needs influence both well- and ill-being (Ryan & Deci, 2018). BPNT identifies three universal needs: autonomy, competence and relatedness. Autonomy

reflects the need to experience a sense of volition and self-endorsement in one´s actions; competence refers to the need to feel effective and capable in carrying out behaviors; and relatedness encompasses the need to feel connected to others and experience belonging (Hagger et al., 2020; Ryan & Deci, 2018). Satisfaction of these needs is essential for optimal development, integrity and psychological health, whereas need frustration is associated with reduced motivation, diminished well-being and non-optimal functioning (Hagger et al., 2020; Ryan & Deci, 2018). The basic psychological needs are considered universal, representing innate psychological conditions necessary for optimal development across individuals and contexts (Ryan & Deci, 2018). Although the relative salience of each need may vary across individuals and domains, SDT posits that all three needs are essential and interdependent. Optimal functioning therefore occurs when autonomy, competence and relatedness are simultaneously supported (Hagger et al., 2020; Ryan & Deci, 2018)

Self-determination theory in interventions

SDT has been used to inform intervention aimed at enhancing motivation and behavior change across multiple domains (Hagger et al., 2020; Ntoumanis et al., 2021). These interventions typically employ a range of need-supportive strategies designed to promote satisfaction of the basic psychological needs. Examples of such need-supportive strategies include providing choice and meaningful rationale (autonomy), facilitating experiences of mastery and skill development (competence), and promoting supportive interpersonal relationships and help-seeking behaviors (Table 2) (Teixeira et al., 2020).

Table 2. Examples of motivation and behavior change techniques (MBCT) to support participants autonomy and basic psychological needs (Teixeira et al., 2020)

Autonomy-supportive techniques	
MBCT	**Definition and description**
Elicit perspectives on behaviors	Encouraging exploration and sharing of perspectives on behaviors allows for increased self-knowledge which can inform choices.
Provide meaningful rationale	Encourage participants to identify personally meaningful rationales for behavior change and maintenance to foster autonomous motivation.
Provide choice	Give participants opportunity to make own choices about their behavior and goals, to allow for sense of ownership and responsibility of their behavior.
Competence-supportive techniques	
Address obstacles for change	Encourage identification of barriers to behavior change and ways of overcoming them to increase confidence.
Offer constructive and relevant feedback	Provide relevant and tailored feedback on goals and behaviors which can encourage and guide future behavior.
Promote self-monitoring	Prompt monitoring of progress or performance which can increase participants self-awareness and progress.
Relatedness-supportive techniques	
Acknowledge and respect perspectives	Acknowledge participants perspective in communication and provide statements of empathy to elicit attention to participants experiences.
Show unconditional regard	Provide positive and encouraging support regardless of success or failure to demonstrate unconditional care and support.
Prompt identification and seek support	Encourage identification of support sources and promote effective ways in seeking support to increase confidence in ability to overcome challenges.

Pingree and colleagues (2010) proposed a conceptual model explaining how engagement with internet-delivered interventions may influence quality-o-life-related outcomes among cancer survivors. Grounded in SDT, the model identifies psychological need satisfaction as a central mechanism linking eHealth engagement to well-being, consistent with evidence that fulfillment of the basic psychological needs supports quality of life (Ryan et al., 2007).

Engagement with an intervention is further proposed to yield proximal outcomes such as increased knowledge, enhanced competence, and greater perceived social support, particularly when active engagement is fostered, for example through strategies like personalized content and tailored feedback (Beatty & Binnion, 2016; Schubart et al., 2011). The proximal outcomes are hypothesized to promote basic psychological need satisfaction, thereby facilitating health-related behavior change, including improved self-care and monitoring (Pingree et al., 2010). In turn, need satisfaction and subsequent behavioral change, such as improved adherence to medication or treatment and effective use of health care resources, may contribute to enhanced quality of life (Ryan et al., 2007).

Internet-delivered interventions

Internet-delivered interventions have the potential to improve access to support and information by addressing common barriers such as competing priorities, time-constraints and geographical constraints (Carlbring et al., 2018; Moshe et al., 2021). Internet-delivered interventions refer to:

> "A primarily self-guided intervention program that is executed by means of a prescriptive online program operated through a website and used by consumers seeking health- and mental-health related assistance. The intervention program itself attempts to create positive change and or improve/enhance knowledge, awareness, and understanding via the provision of sound health-related material and use of interactive web-based components". (Barak et al., 2009).

Barak and colleagues (2009) categorized such interventions into three primary subtypes: web-based education interventions; self-guided web-based therapeutic interventions; and human-supported web-based therapeutic interventions. These subtypes can be characterized by four key components: program content, multimedia use, interactive activities, and guidance and feedback. *Program content* refers to the nature and purpose of the intervention, with educational programs primarily aiming to provide information, whereas therapeutic interventions are designed to promote behavior change (Barak et al., 2009). Therapeutic interventions may incorporate components such as psychoeducation, mindfulness, and cognitive behavioral therapy (CBT) to enhance coping, distress regulation, and increased understanding of the problem and maintaining mechanisms (Creswell et al., 2017; Ekdahl, 2017; Fan et al., 2023; Wang et al., 2020). *Multimedia use* reflects type and variability of media formats employed to convey content, with greater variability often associated with increased engagement (Barak et al., 2009). *Interactive activities* capture

level of opportunity to participate in an interactive way, including through self-assessments and monitoring tasks. Finally, *guidance and feedback* relate to the extent of support and guidance provided, which vary from fully unguided formats to automated, provider-supported, or peer-supported interventions (Barak et al., 2009). Peer support may increase participants sense of social connection and improve feelings of hope and empowerment (Fortuna et al., 2020; Yeo et al., 2025; Ziegler et al., 2022).

While *web-based educational interventions* primarily consist of therapeutically inactive content, self-guided and human-supported interventions are structured to promote cognitive, affective and behavioral change through active engagement (Barak et al., 2009). These interventions are typically delivered in modules and includes varying degrees of multimedia, interactive online activities, and feedback. The key distinction between self-guided and human-supported therapeutic approaches lies in level of guidance provided, ranging from automated feedback to personalized support of varying intensity (Barak et al., 2009). While greater level of guidance has generally been associated with improved outcomes and retention (Richards & Richardson, 2012), some studies suggest that guided and self-guided intervention may yield similar outcomes for anxiety disorders, with amount of guidance moderating effect sizes between groups (Oey et al., 2023).

Adherence and attrition in internet-delivered interventions

While internet-delivered interventions have been found to be effective for several conditions, including depression and anxiety disorders (Griffiths et al., 2010; Pauley et al., 2023), it is also well-known that such interventions are susceptible to low adherence and high attrition rates (Beatty & Binnion, 2016; Prior et al., 2024). Treatment adherence, commonly defined as the amount of an intervention that a participant engages with or completes, represents a persistent challenge in internet-delivered interventions (Beatty & Binnion, 2016). Adherence may refer both to engagement with intervention materials (e.g., reading texts, watching videos) and to adherence to prescribed behavioral activities in daily life, such as completing homework assignments (Alfonsson et al., 2016). Attrition can take different forms, and Eysenbach (2005) distinguishes between dropout attrition, referring to failure to complete follow-up assessments, and non-usage attrition, which occurs when participants discontinue use of the intervention despite remaining in the study.

Low adherence and high attrition may reduce the sample size, introduce systematic bias, and threaten internal validity and generalizability in randomized

controlled trials (RCTs) (Beatty & Binnion, 2016; Karekla et al., 2019; Prior et al., 2024). Insufficient engagement may also compromise intervention efficacy by limiting participants exposure to intervention content, thereby reducing the likelihood of receiving an adequate therapeutic dose (Kelders et al., 2012). Several individual and intervention-related factors have been associated with adherence to internet-delivered interventions. Such factors include being female (Beatty & Binnion, 2016), older age (Fuhr et al., 2018), inclusion of guidance or therapist support (Beatty & Binnion, 2016; Hilvert-Bruce et al., 2012; Kelders et al., 2012), tailored content and communication (Wangberg et al., 2008), and higher perceived treatment credibility or expectancy (Beatty & Binnion, 2016). In a study examining adherence, dropout, and clinical outcomes, Alfonsson et al. (2016) found that treatment credibility significantly predicted dropout and that attrition was associated with lower levels of intrinsic motivation for engaging in the treatment.

Internet-delivered interventions in cancer care

Over the past decades, an increasing number of interventions targeting individuals diagnosed with cancer have been delivered over the internet. Internet-delivered interventions have been suggested as a way of increasing access to psychosocial care and support for an increasingly large population living with and beyond cancer (Leykin et al., 2012). For young adults diagnosed with cancer, who constitute a relatively small and geographically dispersed group, internet-delivered interventions may be especially advantageous, as it reduces barriers related to location, time constraints and competing life demands (Devine et al., 2018). Moreover, internet-delivered interventions are generally well aligned with young adults' preferences for intervention delivery and their use of technology in everyday life and in health contexts (Devine et al., 2018; McCann et al., 2019; Mostafa et al., 2025; Rabin et al., 2013). Six main elements have been identified in previous literature to develop effective internet-delivered interventions in the context of chronic disease, cancer survivorship and psycho-oncology (Kuijpers et al., 2013; Leykin et al., 2012). Such elements include (i) education and information based on evidence; (ii) self-monitoring; (iii) personalized feedback and tailored information; (iv) training of skills and self-management; and (v) communication with health-care professionals and (vi) peers (Kuijpers et al., 2013; Leykin et al., 2012).

Existing internet-delivered interventions have targeted a variety of physical- and psychological symptoms in the immediate and long-term sequelae of cancer and cancer treatment. Systematic reviews have shown that such interventions may be effective in alleviating depression and fatigue (Wang et al.,

2020), appear feasible for symptom management and psychological distress (Fridriksdottir et al., 2018; Willems et al., 2020) and may be a suitable complement to standard care (Wang et al., 2020). However, the considerable heterogeneity of interventions, in terms of, for example, study design and outcome measures, limits the results and more rigorous studies evaluating efficacy and effectiveness are warranted (Fridriksdottir et al., 2018; Viola et al., 2020; Wang et al., 2020; Willems et al., 2020).

Internet-delivered interventions for sexual problems

Systematic reviews have examined the use of digital interventions in sexual health, including reviews focusing specifically on sexual health following cancer (Kang et al., 2018; Matthew & Yang, 2020; Zarski et al., 2022). Across studies, internet-delivered interventions are generally perceived as an accessible and acceptable way to receive sexual health care and support, in part due to increased privacy, flexibility, and convenience (Albers et al., 2020; Benedict et al., 2022; Reese et al., 2017b).

Internet-delivered sexual health interventions typically combine psychoeducational content with therapeutic components such as CBT, mindfulness, tailored information, and interactive components addressing physical, psychological, and relational aspects of sexual health (Benedict et al., 2022; Kang et al., 2018, Zimmaro et al., 2025). To date, most interventions have targeted adult survivors of prostate-, breast-, and gynecological cancer (Classen et al., 2013; Gorman et al., 2022; Hummel et al., 2015; Schover et al., 2012, 2013; Wittman et al., 2017; Wootten et al., 2014). Evidence from such studies have demonstrated some promising results. For example, in an RCT evaluating a sexologist-guided CBT intervention following breast cancer, Hummel et al. (2017) found significant improvements in sexual functioning and body image compared to the control group. Similarly, Wootten et al. (2017) examined an online intervention for prostate cancer survivors and reported improvements in sexual satisfaction among participants who received access to the intervention and to a peer discussion forum. Such improvements were further found to be driven by gains in sexual function, masculine self-esteem, and sexual confidence (Wootten et al., 2017). Despite promising results, studies have also been limited by low adherence and high attrition rates. In a pragmatic trial of an online self-help intervention, Schover et al. (2020) observed significant post-treatment improvements in sexual function and increased use of sexual aids, however high attrition resulted in outcome data being available for only 30% of female participants (Schover et al., 2020).

Internet-delivered interventions for fertility-related aspects

Among existing internet-delivered interventions addressing fertility-related aspects, the majority have focused on young female survivors, with particular emphasis on reducing decisional conflict related to fertility preservation through decisional aids (Wang et al., 2019). Such decisional tools have generally been found to be well-accepted, improve fertility knowledge, and support informed decision-making (Allingham et al., 2018; Ehrbar et al., 2019; Tseng et al., 2021; Woodard et al. 2018). Other internet-delivered fertility interventions have primarily focused on providing educational content aimed at increasing fertility-related knowledge among female cancer patients. Meneses et al. (2010a) developed an internet-delivered intervention covering reproductive health and fertility, and available fertility-preservation options. When evaluated using a pre-post study design, the intervention demonstrated significant improvements in physical and social functioning, as well as increased fertility-related knowledge (Meneses et al., 2010b). Similarly, Stark et al. (2019) presented an online survivorship care plan addressing a range of women's health issues following breast cancer, including hot flashes, fertility-related concerns, contraception, and vaginal symptoms. Although the intervention did not result in greater improvements in primary outcomes compared to the control group, participants in the intervention group reported reduced fertility-related concerns (Su et al., 2019). Few interventions have addressed fertility-related distress following cancer among males. One exception is a study by Gelgoot et al. (2022), who evaluated the usability of a mobile application providing fertility information to young men diagnosed with cancer. Participants found the information relevant and accessible, and perceived it to increase their fertility-related knowledge.

The Fertility and Sexuality following Cancer research program

Overview

The Fertility and Sexuality following Cancer (Fex-Can) research program focuses on fertility-related distress and sexual dysfunction among individuals diagnosed with cancer during childhood (0-17 years) and young adulthood (18-39 years). Fex-Can involves four different sub-projects: (i) Fex-Can Young Adult, (ii) Fex-Can Childhood, (iii) Fex-Talk, and (iv) Co-creation. The work presented in this thesis has been conducted as part of the Fex-Can Young Adult (Fex-Can YA) project and the co-creative project. Fex-Can YA consists of a longitudinal cohort study (Wettergren et al., 2020), with an embedded randomized controlled trial (Figure 2) (Lampic et al., 2019).

Figure 2. Overview of the Fex-Can YA project

The Fex-Can cohort

The Fex-Can cohort study aims to explore the prevalence and predictors of sexual dysfunction and fertility-related distress following a cancer diagnosis in young adulthood, and to investigate trajectories of these issues over time (Wettergren et al., 2020). For the Fex-Can cohort, all individuals aged 18-39 years when diagnosed with selected cancers (breast-, cervical-, ovarian-, testicular cancer, brain tumor and lymphoma) during a period of 18 months (January 2016 - August 2017) were identified via Swedish national quality registries. Exclusion criteria included (i) lack of valid postal address, (ii) non-

ability to read and/or understand Swedish language and (iii) reporting poor health and/or significant cognitive impairment hindering completion of surveys. Of 1535 eligible individuals, 36 were excluded (invalid postal address: n=18, death: n=12, cognitive impairment: n=3, administrative failure: n=3), and thus 1499 were approached for participation at approximately 1.5 years post-diagnosis. To accurately time data assessments to participants' time of diagnosis, data collection was performed in three different waves (Figure 3).

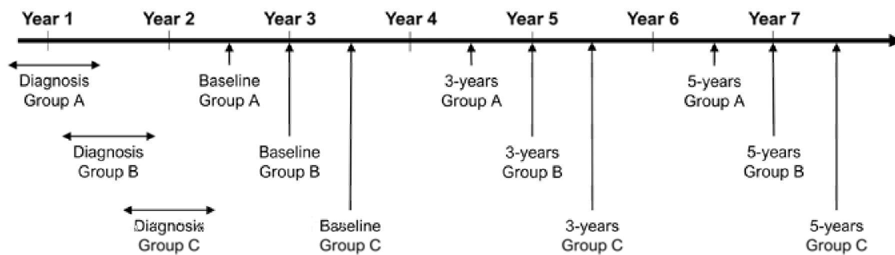

Figure 3. Timing of assessment of Fex-Can cohort waves. Retrieved from Lampic et al. (2019). Licensed under CC BY 4.0

Upon providing written informed consent, participants were asked to respond to surveys at 1.5, 3 and 5 years post-diagnosis. Surveys could be completed on paper or online, and on request, via phone. The cohort study also included a cross-sectional assessment of a comparison group of similar age from the general population. Both groups responded to comprehensive surveys covering instruments to assess sexual function and satisfaction, fertility-related distress, and secondary outcome measures (Table 3). Participants received two cinema tickets at completion of each assessment.

Table 3. Outcome measures included in the Fex-Can YA project

Outcome	Measure
Primary outcomes	
Sexual function and satisfaction	Patient-Reported Outcome Measure Information System Sexual Function and Satisfaction measure v2.0 (PROMIS SexFS v2.0) (Weinfurt et al., 2015).
Fertility-related distress	Reproductive Concerns After Cancer (RCAC) scale (Gorman et al., 2014; 2020).
Secondary outcomes	
Body image	Body Image Scale (BIS) (Hopwood et al., 2001).
Health-related quality of life	European Organization for Research and Treatment of Cancer Quality of Life Core Questionnaire (EORTC QLQ-C30) (Aaronson et al., 1993)

Emotional distress	Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)
Self-efficacy related to fertility	Study-specific Example: *I feel confident that I can handle negative thoughts and feelings about my ability to have children*
Self-efficacy related to sex	Study-specific Example: *I feel confident that I can handle negative thoughts and feelings about my sex life*
Fertility-related knowledge	Study-specific Example: *I have good knowledge about how ability to have children may be affected by cancer and different types of cancer treatment*

The surveys further included questions about receipt of information about the potential impact of cancer treatment on sex life and fertility, about pre-cancer wish for (more) children, and pre-cancer satisfaction with sex life. Background variables were collected in the survey, and several clinical variables was extracted from registry data, and updated at each data collection. Treatment intensity was classified into four levels (least, moderately, very, or most intensive/extensive) according to diagnosis, stage and treatment modalities, using the adapted Intensity of Treatment Rating Scale (ITR 3.0): the ITR-YA (Hedman et al., 2022). This allowed for comparisons of treatment across diagnoses.

The Fex-Can RCT

Based on the 1.5-year assessment of the Fex-Can cohort study, participants whose responses met the criteria for sexual dysfunction or fertility-related distress were invited to participate in an RCT evaluating the efficacy of the Fex-Can Sex and Fex-Can Fertility programs (Lampic et al., 2019). For inclusion in the Fex-Can Sex program, sexual dysfunction was defined as 0.5 standard deviation (SD) from the population mean in at least one selected domain of the PROMIS SexFS v2.0 (Weinfurt et al., 2015). For the Fex-Can Fertility program, fertility-related distress was defined as a mean score of ≥4 in at least one dimension of the RCAC scale (Gorman et al., 2014, 2020). Participants who met criteria for both programs were allocated to Fex-Can Sex or Fex-Can Fertility program based on severity of reported problems, evaluated by a registered psychologist and a registered nurse specialized in psychosocial oncology. Participants consenting to participation in each program were randomly assigned to either the intervention- or control group with an allocation ratio of 1:1, allocated in blocks stratified by sex and diagnosis. The control condition

consisted of standard care, which may or may not have included information on sexuality and fertility following cancer and support from health care professionals.

The RCT is a two-parallel-group superiority trial, evaluating the efficacy of the Fex-Can intervention in alleviating sexual dysfunction (Fex-Can Sex) and fertility-related distress (Fex-Can Fertility) as compared to standard care. Primary outcome for Fex-Can Sex was the PROMIS SexFS v2.0 domain *Satisfaction with sex life*. For the Fex-Can Fertility program, primary outcomes were the mean of the total RCAC score and the mean scores for each of the six dimensions included in the RCAC. The 1.5-year assessment of the Fex-Can cohort study served as the baseline for the RCT. Participants further completed surveys directly at end of the intervention (post-intervention assessment), and 12-weeks after the intervention was completed. As part of the post-intervention assessment, intervention group (IG) participants were also asked to respond to questions about use and experiences of the intervention. Finally, a subset of IG participants was invited to participate in semi-structured interviews about experiences of their participation (Obol et al., 2020).

The Fex-Can (1.0) intervention

The Fex-Can (1.0) intervention is an internet-delivered psychoeducational self-help intervention, developed in collaboration with PRPs (Hovén et al., 2020; Winterling et al., 2016). It consists of two separate programs; Fex-Can Sex and Fex-Can Fertility, aiming to alleviate sexual dysfunction and fertility-related distress, respectively (Lampic et al., 2019).

Both programs were organized in six consecutive modules, delivered over a period of 12 weeks, with participants receiving access to a new module every two weeks (Figure 4). In total, the Fex-Can Sex program included eight different modules, with two being geared specifically towards females (Discomfort and pain, Orgasm), and two towards males (Erection, Orgasm and ejaculation), respectively. All participants in the Fex-Can Fertility program received the same modules. Modules included educational- and behavior change content, videos and texts by young adult cancer survivors, quizzes and reflective questions, exercises based on, for example, mindfulness and CBT, and a moderated peer discussion forum. The discussion forum could be accessed by participants from both programs throughout the intervention period, and was moderated by research team members, as well as by one of the PRPs.

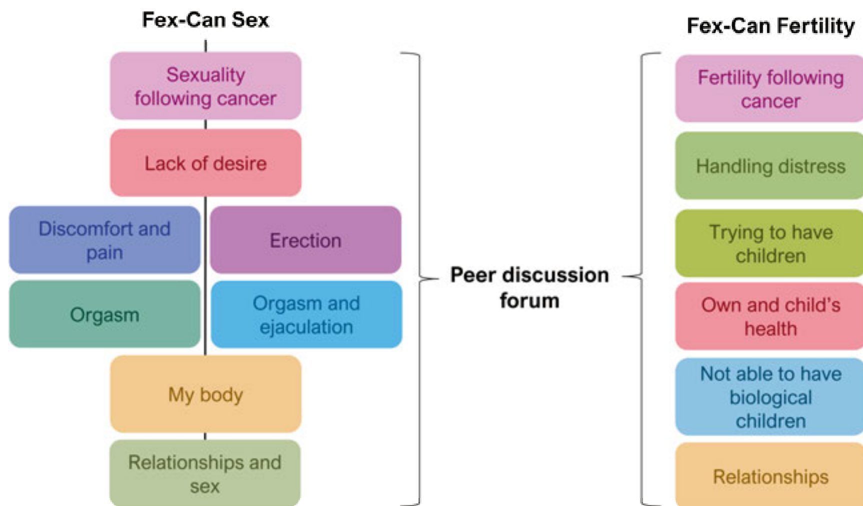

Figure 4. Overview of modules included in the Fex-Can Sex and the Fex-Can Fertility

The intervention was designed to support the basic psychological needs in accordance with self-determination theory (Ryan & Deci, 2018; Winterling et al., 2016). Intervention components were thus structured to support autonomy by providing relevant information and choices available to guide decision-making and encourage engagement in health-related behaviors. Competence was targeted through psychoeducational materials aimed at increasing knowledge and understanding, complemented by techniques such as self-monitoring and partial feedback. To foster relatedness, the intervention offered opportunities for interaction with peers and moderators, as well as stories from young adult cancer survivors to normalize experiences (Winterling et al., 2016).

Patient and public involvement in the Fex-Can Young Adult project

Patient and public involvement is a core part of the Fex-Can research program. In 2014, a collaboration with PRPs was set up, which lasted for over five years (Hovén et al., 2020; Winterling et al., 2016). A total of 10 young adults diagnosed with cancer and two mothers of children treated for cancer as teenagers were involved (Hovén et al., 2020). PRPs and the research group met during 1-day meetings to develop key components of the Fex-Can (1.0) intervention (Hovén et al., 2020; Winterling et al., 2016). Evaluation of this collaboration was conducted by assessing impact on content, system and service quality (Winterling et al., 2016), as well as on the experiences of researchers and PRPs involved in the collaboration (Hovén et al., 2020). Results highlighted the feasibility of involving PRPs in development process, and emphasized the

importance of accommodating meeting structures and feedback for involvement of PRPs (Hovén et al., 2020; Winterling et al., 2016). In 2024, a new collaboration with PRPs was initiated, which aims to refine and further develop version 2.0 of the Fex-Can intervention. This collaboration is presented in Paper IV of the present thesis.

Summary of research gaps

In summary, individuals diagnosed with cancer during young adulthood often experience profound and potentially long-lasting impact on sexual and reproductive health, including challenges related to body image. Such difficulties may substantially impair well-being and quality of life, yet they remain insufficiently addressed in routine cancer care for young adults. Internet-delivered interventions offer an accessible and flexible complement to traditional healthcare services, and are well aligned with young adults' preferences for digitally supported care. To ensure relevance and acceptability, interventions should be developed in close collaboration with the target population. However, the processes and impact of patient and public involvement in research are rarely described in sufficient detail, limiting the understanding of how to meaningfully engage interestholders and integrate their perspectives throughout intervention development. Addressing gaps in sexual and reproductive health care is essential for alleviating sexual problems and fertility-related distress in the young adult cancer population. Through the development and evaluation of internet-delivered interventions, this thesis seeks to improve access to sexual and reproductive health support and ultimately improve quality of survivorship.

Aims

Overall aim of thesis

The overall aim of this thesis was to develop and evaluate internet-delivered interventions targeting sexual problems and fertility-related distress following a cancer diagnosis, with the ultimate goal of improving the quality of survivorship for individuals diagnosed with cancer during young adulthood.

Specific aims

I. To test the efficacy of the internet-delivered intervention Fex-Can Sex in reducing sexual dysfunction in young adults following a cancer diagnosis compared to standard care.

II. To investigate interactive participation and content of a moderated discussion forum within an internet-delivered intervention aimed at alleviating sexual dysfunction and fertility distress in young adults diagnosed with cancer.

III. To describe the design of the internal pilot trial and randomized controlled trial of the Fex-Can 2.0 intervention.

IV. To describe and evaluate a long-term, co-creation process of refining and improving an internet-delivered psychoeducational intervention focusing on fertility-related distress and sexual problems following cancer.

V. To investigate prevalence of body image disturbance, and change in body image over the first five years following a cancer diagnosis. Further, to identify factors associated with body image disturbance over time.

Ethical considerations

All included studies were conducted in accordance with the Declaration of Helsinki (World Medical Association, 2025). Data was handled according to the EU General Data Protection Regulation (GDPR) and the Patient Data Act. All studies included in the Fex-Can YA project have been ethically approved by the Regional Ethical Review Board in Stockholm (2013/1746-31/4; 2014/2244-32;2015/2042- 32/4;2017/916-32; 2017/1416-32) and the Swedish Ethical Review Authority (2023-02745-01; 2024-01576-02; 2025-02691-02).

Apart from Paper III, which includes no collection of primary data, written informed consent was collected from all participants. Participants included in the Fex-Can cohort study (Paper V) received a unique code number, as indicated on the survey. As participants for the Fex-Can RCT (Papers I & II) were drawn from the Fex-Can cohort study sample, no new code numbers were assigned at inclusion in the RCT. The code key was stored separate from research data, and only accessible by members of the research team. All data was handled and stored according to the GDPR. As such, storage of paper records was locked in spaces on department premises, and storage of electronic records on secure, password-protected servers. All research team members have formal training in research ethics. For all included studies, great care has been taken to phrase written information, interview- and survey questions in a manner that does not evoke unnecessary worry. However, for many, intimate questions about fertility and sexual function and satisfaction may be of particularly sensitive nature.

Participation in the Fex-Can (1.0) and Fex-Can 2.0 interventions

The Fex-Can (1.0) intervention was generally well received, and no adverse effects were recorded. However, qualitative feedback in open-ended survey questions and the discussion forum indicated that for some participants, this was their first exposure to information about the potential impact of cancer treatment on sexuality and fertility. While several participants reported that this information facilitated understanding and acceptance of experienced problems, others expressed feeling stressed about receiving this new information, particularly regarding fertility. Given the inherent uncertainty in

predicting individual fertility outcomes after cancer, and the limited eligibility for assisted reproductive technologies, provision of fertility-related information may have contributed to increased worry among some participants.

In contrast to the original Fex-Can intervention, in which all young adult cancer survivors meeting the cut-off for sexual dysfunction or fertility-related distress were approached for participation, participants in the revised intervention (Fex-Can 2.0) are self-selected. Participants are thus recruited through social media, patient organizations and through their health care providers at oncology- and hematology clinics, meaning that they contact the research team if interested in the study and are subsequently assessed for eligibility through screening interviews. Participants will further be closely monitored throughout the intervention via structured start-up and exit sessions, personalized feedback, and when posting in the discussion forum. This allows for identification of participants with elevated distress or worry that merits concern. Furthermore, an internal pilot trial will be conducted prior to the full-scale RCT, during which potential adverse effects from the intervention can be detected.

Study design and methodology

Ontology and epistemology

> But research questions are not inherently "important," and methods are not automatically "appropriate." Instead, it is we ourselves who make the choices about what is important and what is appropriate, and those choices inevitably involve aspects of our personal history, social background, and cultural assumptions. (Morgan, 2007).

The work presented in the present thesis involves the utilization of both quantitative and qualitative research methods. While the quantitative parts included focus on evaluating efficacy and understanding change over time and thus allows for generalizability and assessing outcomes, the qualitative components explore processes and experiences, providing deeper insight and understanding. These different approaches offer different views on reality and knowledge, reflecting their distinct ontological and epistemological foundations (Kaushik & Walsh, 2019).

In this dissertation, I take a pragmatic approach to reality and science (Morgan, 2007). As such, reality is viewed as something that is continuously renegotiated, and knowledge as socially constructed and fallible (Kaushik & Walsh, 2019). Choice of method is dependent on the question asked, and selected based on what will solve the problem, and different methods are applied based on their capacity to answer the research question (Allemang et al., 2022). Importantly, we as researchers are not separate from the phenomenon under study, rather our experiences influence what we investigate and how. The pragmatic stance adopted further aligns with principles of patient and public involvement (Allemang et al., 2022). Both pragmatism and PPI share a focus on reducing power imbalances through engagement and dialogue to ensure research reflects priorities of those with a lived experience. Both further emphasize partnerships and co-creation, moving beyond paternalism to foster equitable research. By combining pragmatism and perspectives of those with a lived experience, we can conduct research that is relevant, works in practice, and matters to those who are affected (Allemang et al., 2022).

Overview of study design and methods

The present thesis consists of two primarily qualitative and two primarily quantitative studies, as well as a study protocol without formal data collection (Table 4). The two first studies in this thesis are based on data from the Fex-Can RCT and evaluates the efficacy of the Fex-Can Sex program (Paper I) and investigates activity in and content of a discussion forum included in the Fex-Can Sex and Fex-Can Fertility programs (Paper II). Paper III describes the future pilot testing and evaluation of the next generation of the Fex-Can intervention, Fex-Can 2.0. Paper IV presents the involvement of patient research partners in the refinement of the intervention, and is based on multimodal qualitative data such as impact log information, field notes and individual interviews. Finally, the last paper included in this thesis (Paper V) utilizes data from all assessments of the Fex-Can cohort study, in which participants were assessed at 1.5, 3 and 5 years following a cancer diagnosis in young adulthood.

Table 4. Study design, participants, data and analyses of included papers

Paper	Design	Participants	Data	Analyses	Part of
I	RCT	n=138	Self-reported, & registry data	Descriptive, t-tests, LMM, TA	Fex-Can RCT
II	Qualitative	n=135	Self-reported, registry & log data	Descriptive, TA	Fex-Can RCT
III	Study protocol	N/A	N/A	N/A	Fex-Can 2.0
IV	Qualitative	n=4	Individual interviews, impact logs & field notes	Qualitative content analysis	Fex-Can 2.0
V	Longitudinal	n=1010	Self-reported & registry data	Descriptive, LMM, post-hoc analyses	Fex-Can cohort

RCT: Randomized Controlled Trial, LMM: Linear Mixed Models, TA: Thematic Analysis, N/A: Not Applicable

Measures

Within the Fex-Can YA project, participants were asked to respond to comprehensive surveys covering standardized measures (Table 5), sociodemographic- and clinical variables, as well as several study specific questionnaires and items.

Table 5. Summary of standardized measures utilized in the Fex-Can YA project and in papers included in the present thesis

	RCAC[a]	PROMIS SexFS[b]	BIS[c]	HADS[d]	EORTC QLQ-C30[e]	NSFS[f]
Fex-Can RCT	x	x	x	x	x	
Paper I		x	x	x	x	
Fex-Can cohort	x	x	x	x	x	
Paper V			x	x		
Fex-Can 2.0	x	x	x	x	x	x
Paper IV	x	x	x	x	x	x

[a] Reproductive Concerns After Cancer Scale
[b] Patient Reported Outcome Measures Information Systems Sexual Function and Satisfaction
[c] Body Image Scale
[d] Hospital Anxiety and Depression Scale
[e] European Organization for Research and Treatment of Cancer Quality of Life Core-30
[f] Need Satisfaction and Frustration Scale

PROMIS SexFS v2.0

Sexual function and satisfaction is assessed using the Patient-Reported Outcome Measurement Information System Sexual Function and Satisfaction measure (PROMIS SexFS v2.0) and the Brief Sexual Profile (BSP). PROMIS SexFS is a validated, customizable instrument applicable across cancer and non-cancer populations (Flynn et al., 2013; Weinfurt et al., 2015).

PROMIS SexFS v2.0 covers eleven scored domains and six non-scored item pools. In the Fex-Can project, selected generic domains include: Interest in sexual activity, Orgasm (Ability and Pleasure), Anal discomfort with sexual activity, Sexual activities, Therapeutic aids for sexual activity, Bother regarding sexual function, and Satisfaction with sex life. An example item is "How interested have you been in sexual activity?" (domain Interest in sexual activity). Body-part specific domains include: Vaginal lubrication for sexual activity, Vaginal discomfort with sexual activity, Vulvar discomfort with sexual activity (Labial and Clitoral), and Erectile function, including items such as "How difficult was it to become lubricated ("wet") during sexual activity or intercourse?" (domain Vaginal lubrication for sexual activity). The BSP comprises a subset of PROMIS SexFS v2.0 items (thirteen items across eight domains for females, nine items across five domains for males). Items refer to experiences during the past month and are rated on a five-point scale (1 = Not

at all/None to 5 = Very/A lot), with an additional response option for no sexual activity in the previous 30 days.

Item response theory is used to calculate domain scores, where 50 represents the mean for the American general population (standard deviation = 10). A SexFS v2.0 BPS summary score is created by averaging T-scores with equivalent weights across domains included, as proposed in a study by Schover et al. (2020). BSP change scores are then calculated as the difference between baseline and follow-up scores. PROMIS SexFS v2.0 has demonstrated acceptable content-, construct-, known-groups validity (Weinfurt et al., 2015). The instrument has been culturally adapted and translated into Swedish in line with the FACITrans and PROMIS procedure (Hovén et al., 2023). The Swedish version has been found to be valid and reliable in both clinical and non-clinical young adult populations (Hovén et al., 2023).

Reproductive concerns after cancer scale

The Reproductive Concerns After Cancer (RCAC) scale was developed by Gorman and colleagues (2014) to comprehensively assess fertility concerns among young adult female cancer survivors. It is multidimensional and consists of 18 items making up six domains: *Fertility potential* (e.g., "I am afraid I won't be able to have any (more) children"), *Partner disclosure* (e.g., "I worry about telling my (potential) spouse/partner that I may be unable to have children"), *Child's health* (e.g., "I am worried about passing on a genetic risk for cancer to my children"), *Personal health* (e.g., "Having (more) children will make me more nervous about getting cancer again"), *Acceptance* (e.g., "I can accept it if I'm unable to have (more) children") and *Becoming pregnant* (e.g., "I am overwhelmed by thoughts of trying to get pregnant (again)"). The scale has been adapted and evaluated in the young adult male cancer population (RCAC-M) (Gorman et al., 2020).

Responses are reported on a 5-point Likert-scale, ranging from 1 (strongly disagree) to 5 (strongly agree). For each subscale, mean scores range from 1-5 and higher scores represent more concerns in each domain. Items on the *Acceptance* subscale are reversed scored, and thus higher scores represent less acceptance. The scale has demonstrated good internal consistency, construct, convergent and known-groups validity across multiple cultural adaptions (Gorman et al., 2014; 2019; 2020). It has been culturally adapted and translated into Swedish (Anandavadivelan et al., 2020). In the Swedish context, the scale demonstrated construct and known-groups validity, as well as satisfactory reliability for five out of the six domains (Anandavadivelan et al., 2020).

The Body Image Scale

The Body Image Scale (BIS) was developed as a brief scale for assessing body image following cancer, primarily for use in clinical trials (Hopwood et al., 2001). The scale consists of 10 items covering affective (e.g., "Have you been feeling self-conscious about your appearance?"), cognitive (e.g., "Have you felt dissatisfied with your body?") and behavioral (e.g., "Did you avoid people because the way you feel about your body?") dimensions of body image. Responses are reported on a 4-point Likert scale (0 = *Not at all* to 3 = *Very much*), and scores are calculated by the sum of responses (range: 0-30). Higher scores indicate higher levels of body image disturbance. Previous research has proposed a total score of ≥10 as a cut-off for body image disturbance reaching a clinically relevant level (Chopra et al., 2021). The scale has been translated into Swedish (Olsson et al., 2016) and has demonstrated convergent validity, internal consistency and test-retest reliability (Hopwood et al., 2001; Melissant et al., 2018).

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) was developed to screen for anxiety and depression in non-psychiatric hospital settings, and thus excludes somatic symptoms that could be caused by the illness itself (Bjelland et al., 2002; Zigmond & Snaith, 1983). HADS consists of two 7-item subscales focusing on symptoms of anxiety (HADS-A) and depression (HADS-D). The subscales can be analyzed separately, or a total score can be used as an overall measure of psychological distress. Responses are recorded on a 4-point Likert scale, and items refer back to how participants have felt over the past week. Item scores for the total HADS scale are combined into an overall score ranging from 0-42, with higher scores indicating greater emotional distress. For the subscales, scores range from 0-21, where higher scores reflecting greater symptom severity. The scale has demonstrated convergent and discriminant validity, internal consistency, and test-retest reliability in cancer populations (Annunziata et al., 2020; Bjelland et al., 2002).

EORTC Quality of Life Core questionnaire

The European Organization for Research and Treatment of Cancer Quality of Life Core-30 (EORTC QLQ-C30) (v3.0) questionnaire was developed for use in clinical trials (Aaronson et al., 1993) and designed to be multidimensional, appropriate for self-administration, and applicable across cultural settings (Fayers & Bottomley, 2002). The questionnaire covers nine multi-item scales

including five functional scales, three symptom scales, a global health status scale, and six single items. Scores are linearly transformed to a score ranging between 0-100. For symptom scales, higher scores indicate more symptom burden, and for functional and global quality of life scales, higher scores indicate better health. The scale is widely used in oncology research, demonstrating strong psychometric properties and robust validity for assessing health-related quality of life in cancer patients (Aaronson et al., 1993; Shih et al., 2013).

Need Satisfaction and Frustration Scale

The Need Satisfaction and Frustration Scale (NSFS) was developed to assess satisfaction and frustration with the basic psychological needs in line with SDT (Longo et al., 2016; Ryan & Deci, 2018). The NSFS includes a total of 18 items focusing on autonomy (e.g., "I feel completely free to make my own decisions"), competence (e.g., "I feel highly effective at what I do"), and relatedness (e.g., "I feel very close and connected with other people"). For each basic psychological need, three items assess need satisfaction and three assess need frustration. Responses are reported on a 5-point Likert scale (1 = Very seldom to 5 = Very often) (Aurell et al., 2016). The NSFS has been translated into Swedish and is validated in the Swedish general population (Aurell et al., 2015).

Paper I

Study design

In Paper I, data from the Fex-Can RCT were used to evaluate the efficacy of the Fex-Can (1.0) Sex program in alleviating sexual dysfunction among young adults diagnosed with cancer. The intervention was assessed in a two-armed RCT in which participants were randomized either to the intervention group, which received the Fex-Can Sex program, or to a control group receiving standard care. The trial was preregistered in the ISRCTN registry, and reported in accordance with the Consolidated Standards of Reporting Trials (CONSORT) Statements (Hopewell et al., 2025) and the Template for Intervention Description and Replication (TIDieR) checklist (Hoffman et al., 2014).

Study participants

Participants were drawn from the 1.5-year assessment of the Fex-Can cohort study (Wettergren et al., 2020). Those who met the cut-off for sexual dysfunction (defined as 0.5 SD from the population mean in any of the selected PROMIS SexFS v2.0 domains) were eligible and approached for participation. Out of 356 cohort study participants approached, 138 (39%) individuals consented to participation and were subsequently randomized to either the IG (n=72) or the CG (n=66).

Data collection

Primary outcome was the PROMIS SexFS v2.0 domain *Satisfaction with sex life*. Secondary outcomes included additional PROMIS SexFS v2.0 domains, emotional distress (HADS), body image (BIS), health-related quality of life (EORTC QLQ-C30), and self-efficacy related to sex (see Table 3 for the full list). The 1.5-year assessment of the Fex-Can cohort study constituted the baseline assessment for the RCT, and participants were further assessed at end of the 12-week intervention (post-intervention survey), and again three months later (follow-up). Further, the post-intervention survey covered self-perceived evaluation questions, including items on use of the intervention and perceived improvement or deterioration in sexual problems. Two open-ended questions were further included in the self-perceived evaluation, covering experiences of potential changes in sexual problems, and opportunity to provide additional comments. Finally, log data from the intervention platform was used to assess participants level of activity in the program.

Data analysis

Sociodemographic and clinical characteristics of participants were presented using descriptive statistics. For evaluation of the efficacy of the Fex-Can Sex program, data were analyzed in an intention-to-treat manner. To assess potential differences in primary and secondary outcomes between the IG and CG, independent t-tests were utilized at post-intervention and the three-month follow-up. Linear mixed models (LMM) with a participant-specific random intercept, performed by an external statistician, were used for two types of subgroup analyses. First, LMMs were used to analyze interaction effects of time and level of sexual dysfunction at baseline (high versus low level). High level of sexual dysfunction was defined as >1 SD from the American population mean. Second, LMMs were used to analyze the effects of level of activity in the intervention (high level of activity, low level of activity, and control group)

on the outcome. High level of activity was defined as having opened at least three out of the six modules, and having spent a minimum of 20 minutes on the intervention website. Additionally, one of the following criteria should be fulfilled: (i) having spent a minimum of three minutes in the discussion forum, (ii) posted at least once in the discussion forum, or (iii) responded to at least 50% of reflective questions and quizzes. Participants who did not fulfill these criteria were classified as low activity participants, including those who never logged into the program. Responses to open-ended questions included in the post-intervention survey were analyzed using qualitative thematic analysis (Braun & Clarke, 2022).

Paper II

Study design

Paper II is part of the Fex-Can RCT, and utilizes both quantitative and qualitative methods in investigating interactive participation and discussion forum posts made by participants in the Fex-Can (1.0) intervention.

Study participants

Participants for the study included all individuals allocated to the intervention group of both the Fex-Can Sex and Fex-Can Fertility programs. Out of 792 Fex-Can cohort study participants who met the criteria for either of the two programs, 262 (33%) accepted participation and were subsequently randomized to either the IG (n=135) or the CG (n=126). In total, 72 participants were allocated to the Fex-Can Sex IG, and 64 to the Fex-Can Fertility IG. Due to a technical error, one Fex-Can Fertility participant did not receive the intervention, resulting in a final sample of 63 IG participants in the Fex-Can Fertility program.

Data collection

Participants sociodemographic- and clinical variables were collected through self-administered surveys, as well as through Swedish National Quality registries for the included diagnoses. Discussion forum posts and activity log data were retrieved from the intervention portal. Participants could opt to be anonymous when posting in the forum, and could provide "likes" to post made by others.

Data analysis

Sociodemographic- and clinical characteristics of participants were analyzed using descriptive statistics and compared between subgroups of high- and low-activity participants, as defined by criteria outlined under Paper I. Comparisons were performed using Student's t-test, chi-square test, and Fisher's exact test. All tests were two-tailed, with $p < .05$ considered statistically significant.

Discussion forum posts were analyzed using qualitative thematic analysis following Braun & Clarke's six-phase approach (2022): (i) familiarization with data, (ii) generating initial codes, (iii) searching for themes, (iv) reviewing themes, (v) defining and naming themes, and (vi) writing the report. Following repeated readings of the text and note-making, the entire text material was coded. Next, possible themes and subthemes where constructed, followed by working to define and name themes. Themes and subthemes were discussed and revised in an iterative approach in the full co-author group. Finally, discussion forum posts were categorized based on type of post (description of own experiences, relating/responding to another post, asking for experiences of others).

Paper III

Study design

Paper III describes the planned internal pilot trial and RCT of the Fex-Can 2.0 intervention. The trial will be performed in a two-armed superiority RCT, with participants equally randomized to an intervention- or a control group. Participants allocated to the IG will receive the Fex-Can 2.0 intervention, while the CG will receive standard care, which may or may not include information and support related to for sexual- and reproductive health. The study protocol adheres to the Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) statement for clinical trial protocols (Chan et al., 2013) and the TIDieR checklist (Hoffman et al., 2014).

Study participants

Participants are recruited via social media, patient organizations, and oncology- and hematology clinics. Potential participants are eligible if (i) diagnosed with cancer in the past five years, (ii) aged 18-39 years at study entry, (iii) experience significant fertility-related distress and/or sexual problems, and (iv) prepared to spend a minimum of 30 minutes per week working with the

intervention. Further, exclusion criteria include inability to communicate in Swedish, and suicidality or a significant psychiatric condition. Participants are self-selected, i.e., those who are interested in participating in the study report interest via the intervention platform, phone or e-mail. After receiving information about the study and being assessed for eligibility through screening interviews, eligible participants are invited to the RCT. Upon providing informed consent and responding to the baseline survey, participants are randomized to either the IG or CG with a 1:1 allocation ratio, stratified by sex.

Data collection

Participants will be requested to respond to surveys at baseline, 6 weeks into the intervention (mid-intervention assessment), directly at end of the intervention, and 12 weeks later. Primary outcomes will be fertility-related distress (RCAC) and the PROMIS SexFS v2.0 Brief Sexual Profile (BSP). Secondary outcomes include body image (BIS), emotional distress (HADS), health-quality of life (EORTC-QLQ C30), self-efficacy in managing thoughts and feeling related to fertility and sex life, and fertility- and sexuality-related knowledge. Satisfaction and frustration with basic psychological needs will be assessed using the Need Satisfaction and Frustration Scale (NSFS) (Longo et al., 2016). The NSFS will be examined as a potential mediator of the relationship between the intervention and its outcomes.

Internal pilot study

The first 70 participants enrolled in the Fex-Can 2.0 will be included in an internal pilot trial. Internal pilot trials refer to pilot studies that are built into the main trial (Giangrogorio & Thabane, 2015). This allows for trialing of key uncertainties of an intervention, and if successful, an internal pilot can seamlessly progress into a full-scale RCT and results from the pilot can be included in the full-scale evaluation (Avery et al., 2017; Giangrogorio & Thabane, 2015). During the internal pilot, study procedures will be trialed to determine the feasibility of moving on to a full-scale trial, evaluated according to prespecified progression criteria on recruitment, data collection, attrition, adherence, and delivery of the intervention (Table 6). A stop-amend-go system is used to assess these criteria, where *go* indicates that criteria are met and the trial can progress immediately, *amend* indicates that progression is possible following necessary modifications, and *stop* indicates that criteria are not met and progression should not occur unless substantial changes can be made (Avery et al., 2017).

Table 6. Progression criteria of the Fex-Can 2.0 internal pilot trial

Criterion	Threshold
Recruitment and enrolment	
1. Time needed to recruit 70 participants	≤6 months
	7-8 months
	≥8 months
2. Proportion of participants meeting the cut-off for sexual dysfunction and/or high fertility-related distress [a]	≥75%
	50-74%
	<50%
Drop out	
3. Rate of participants dropping out of the study	≤10%
	21-30%
	>40%
Adherence	
4. Proportion of intervention group participants reaching the level of intended usage [b]	≥60%
	40-59%
	<40%

[a] Sexual dysfunction is defined as 1 SD (10 points on the T-scale) from the population mean of 50 in the PROMIS SexFS v2.0, and high levels of fertility-related distress is defined as ≥4 in at least two domains of the RCAC
[b] Intended usage is defined as participants completing a minimum of 75% of allocated modules, including its exercises, quiz, and reflective questions

Additionally, some progression criteria will be assessed qualitatively. Firstly, time needed for intervention delivery (e.g., to conduct screening interviews, start-up and exit session, provide feedback) will be documented to assess the feasibility of delivery. Further, participants experience of the intervention will be assessed through individual interviews.

The refinement of the Fex-Can (1.0) intervention

The Fex-Can 2.0 intervention builds on the Fex-Can (1.0) intervention (Fex-Can Sex and Fex-Can Fertility), and was refined and further developed to overcome identified shortcomings. Following the Framework of actions for intervention development by O'Cathain et al. (2019), the revision and adaption were carried out through an iterative process focusing on relevant actions.

- Firstly, in action *planning of the development process*, the foundation for the intervention refinement process was established, including actions such as identification of problems, identifying resources and applying for funding.

- *Involvement* of *interestholders* was ensured through the establishment of a patient and public involvement group that collaborated with the Fex-Can project team to generate and refine the intervention.

- Action *drawing on existing theories* included revisiting self-determination theory and confirming its relevance for the Fex-Can 2.0. Further, to refine its application in the content and delivery.

- A *program theory* was further articulated using the eHealth effects model by Pingree et al. (2010), to explain how the intervention is expected to achieve its intended outcomes.

- Finally, in action *designing and refining the intervention*, ideas about the intervention was generated in collaboration with patient research partners and prototypes were subsequently reviewed by the group and reworked in an iterative process.

The Fex-Can 2.0 intervention

Fex-Can 2.0 is an internet-delivered psychoeducational intervention, aiming to alleviate sexual dysfunction and fertility-related distress following cancer. The program is delivered over 12 weeks, with a new module being introduced every other week. There are a total of 13 modules in the intervention; two being mandatory and thus accessed by all intervention group participants (*Fertility and sexuality following cancer* and *Closing module*) (Figure 5).

Figure 5. Modules included in the Fex-Can 2.0 intervention

The remaining modules are selected for each participant based on problems experienced, as assessed during a start-up session with a research team member. The intervention concludes with an individual exit session to discuss potential remaining problems and experiences of the program (Figure 6).

Figure 6. Flow chart of participants journey through the Fex-Can 2.0

Overall, the intervention reflects key features of internet-delivered interventions as defined by Barak et al. (2009), including structured content, interactive activities, multimedia, and feedback support. Modules include psychoeducational content providing participants with general- and cancer-specific information on sexual and reproductive health, as well as strategies to manage problems and concerns experienced. Further, the program incorporates several exercises informed by CBT and mindfulness-inspired approaches, and participants receive human-supported feedback at completion of such exercises. Participants are encouraged to engage with all relevant exercises, and to identify strategies that are most helpful for their individual needs. The program also includes self-monitoring components, such as brief quizzes and reflective questions, designed to promote reflection on information provided in the modules and on participants' experiences related to sexuality and/or fertility. Multimedia content, including videos, audio

recordings, and written quotes from young adult cancer survivors is integrated to provide peer perspectives. Throughout the program, participants have access to a moderated asynchronous discussion forum, enabling sharing of experiences and peer support. As participants follow their own set of modules through the program, modules were designed with consistent core components and structure to facilitate comparability in subsequent analyses.

Theoretical underpinnings

The Fex-Can 2.0 intervention is theoretically underpinned by SDT and its mini-theory basic psychological needs theory (Ryan & Deci, 2018). Thus, the content and delivery of the Fex-Can 2.0 program aim to support participants (i) sense of being in control of their lives and actions (autonomy), (ii) capacity to take actions to improve their situation (competence), and (iii) sense of belonging (relatedness). Several need-supportive strategies are incorporated into the program (Teixeira et al., 2020). Autonomy-supportive techniques include providing clear rationales for intervention components and offering participants meaningful choices among multiple strategies, exercises, and options for managing experienced problems. Competence-supportive techniques include the use of psychoeducational content aimed at increasing knowledge and understanding, combined with techniques such as self-monitoring, and constructive feedback on completed exercises. Such techniques may help participants reflect on their experiences, identify effective and preferred coping strategies, and foster a sense of mastery. Finally, relatedness-supportive techniques include opportunities for interaction with intervention providers and peers, as well as the inclusion of videos and quotes from young adults describing sexual or fertility-related challenges following cancer, which may help normalize participants' experiences.

Paper IV

Study design

In Paper IV, the process of involving PRPs in the revision and refinement of the Fex-Can intervention is presented. PRPs and researchers collaborated through shared working group meetings conducted over an 18-month period. The study is reported in accordance with the Guidance for Reporting Involvement of Patients and the Public-Short Form (GRIPP2-SF) checklist (Staniszewska et al., 2017) and the Standard for Reporting Qualitative Research (SRQR) checklist (O'Brien et al., 2014).

Patient research partners and researchers

PRPs were recruited for the collaboration via patient organizations, personal contacts and outreach on social media. The aim was to involve approximately ten young adults (18-39 years) diagnosed with cancer and who had experiences of sexual problems and/or fertility-related distress. Individuals expressing interest were invited to a screening interview, during which they received further information about the collaboration and described their experiences. This information was used in an effort to ensure diversity in the group, in terms of aspects such as type of cancer, age, sexual orientation, family constellation, education, and type of problems experienced. The final PRP group consisted of ten individuals (eight women and two men), aged 26-39 years, diagnosed with breast cancer, cervical cancer, sarcoma, and oral cavity cancer. Over time, two PRPs withdrew due to time constraints and changes in personal circumstances. All PRPs were paid for time spent on their involvement.

All Fex-Can research project group members were involved in setting goals for the collaboration, discussing and establishing strategies and the structure of the collaboration, and working with the outputs from the shared working group meetings. Four Fex-Can project group members were further directly involved in the collaboration, taking responsibility for the planning, conduct and communication with the involved PRPs throughout the process.

Data generation

Data for this study included field notes, information from impact logs and individual interviews with PRPs. Field notes included detailed descriptions of the shared working group meetings, as well as reflections from researchers during and in-between meetings. Impact logs developed by the NIHR Applied Research Collaboration West (NIHR ARC West) (n.d.) were adapted for the present study and included practical information about meetings, ideas and suggestions generated during the meetings, and impact of such suggestions on the research project. Finally, individual interviews with PRPs were conducted, focusing on PRPs motivation, expectations and emotional aspects of their involvement, as well as several aspects related to the conduct of the collaboration, such as the recruitment process, communication and organization. Interviews were conducted by an independent researcher not involved in the larger Fex-Can project.

Data analysis

The multimodal data was analyzed using qualitative content analysis, as described by Graneheim and Lundman (2004). The analysis started off with initial familiarization with the materials, followed by identification and condensations of meaning units. Subsequently, meaning units were coded and finally grouped into categories and subcategories which were discussed among the larger co-author group. Analyses of raw interview data was conducted by an independent researcher, and later reviewed by one the Fex-Can research project members. Analyses of different forms of data were integrated, and final categories and subcategories presented are based on all three data sources. To ensure that no misinterpretations had occurred during the analyses, PRPs and researchers reviewed and discussed the results at a shared working group meeting.

Paper V

Study design

Paper V is part of the Fex-Can cohort study, and utilizes data from all assessments (1.5, 3 and 5 years post-diagnosis). The study was reported in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for cohort studies (von Elm et al., 2008).

Study participants

Participants included in the Fex-Can cohort were identified via Swedish national quality registries for the included diagnoses. All individuals diagnosed with selected cancers at ages 18-39 years between January 2016 and August 2017 were identified. Out of 1535 individuals identified, 1499 were approached for participation, and a total of 1010 participants completed the 1.5-year assessment. Individuals who declined participation or did not complete the first assessment were excluded from receiving subsequent surveys. Participants received two cinema tickets for completing each assessment.

Data collection

Primary outcome for Paper V was body image, as assessed using the Body Image Scale (BIS) (Hopwood et al., 2001). Additional variables included the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), as well as sociodemographic and clinical data retrieved either via the Swedish national quality registries or self-reported in the surveys.

Data analysis

Sociodemographic- and clinical characteristics were presented by sex using descriptive statistics. Differences between participants responding only at the 1.5-year assessment and those responding at 1.5 years plus one or two additional surveys were assessed using chi-squared tests, two-tailed independent *t*-test or Mann-Whitney U-tests. A *p*-value of $< .05$ was considered statistically significant. Linear Mixed Models were fitted separately for females and males using the R packages Ime4 and ImerTest (Bates et al., 2015). Models were built using a hierarchical approach, beginning with fixed effects for time and random intercepts to account for individual differences in body image at 1.5 years and with-subject correlation. Candidate fixed effects were added in a stepwise manner, and models were compared using likelihood ratio tests and Akaike's Information Criterion (AIC). Variables associated with missingness were included in all models to adjust for potential bias. Among females, those who responded only to the 1.5-year assessment reported high levels of emotional distress. Therefore, emotional distress scores (HADS) were decomposed into a 1.5-year variable to account for missingness, and a variable representing within-person deviation from the 1.5-year score. Model assumptions were assessed using residual diagnostics. Given minor deviations from normality, and that LMMs are robust to mild deviations from normality (West et al., 2022), model-based and robust standard errors were compared to account for potential heteroscedasticity and non-normality, yielding similar results. For post-hoc analyses, estimated marginal means were conducted, using the emmeans package in R (Lenth, 2025). To control for multiple comparisons, Tukey-adjusted *p*-values were used for pairwise comparisons. All statistical analyses were performed in R version 4.2.2 (R Core Team, 2021).

Results

Paper I

Participant characteristics

A total of 138 participants were included in the RCT evaluating the Fex-Can (1.0) Sex program; 72 were randomized to the IG and 66 to the CG. The majority of participants were female (83% in the IG, 85% in the CG), and mean age of participants was 34.4 years in the IG, and 34.7 years in the CG.

Effects of the Fex-Can Sex intervention

A total of 122 participants (88%) responded to the post-intervention survey, followed by 97 participants (70%) at the follow-up assessment. No significant differences in the primary outcome, sexual satisfaction, were observed between the IG and CG directly at end of the Fex-Can Sex intervention. Similarly, no differences were found for any of the secondary outcome measures. While participants with higher levels of sexual dysfunction (defined as ≥1 SD from the population mean) at baseline improved significantly over time, this pattern was observed in both the intervention and control groups. Overall, few participants met the criteria for high level of activity (22%), and participants spent a mean of 20.7 (SD 21.3) minutes on the intervention. Participants' level of activity in the intervention did not affect the results.

Self-perceived evaluation

A total of 56 IG participants (78%) responded to self-perceived evaluation questions. Seventy-three percent expressed appreciation for the program, and 63% reported that it had helped them manage problems experienced. The majority (91%) would recommend the program to others. The post-intervention survey further included open-ended questions addressing perceived changes in sexual problems following the intervention, as well as any additional thoughts about sexuality or the intervention. Four themes were constructed in the thematic analysis of responses to such questions. In theme *Perceived benefits* participants described increased acceptance of their situation and an enhanced sense of belonging following the program. Theme *Barriers to*

participation involved participants accounts of time constraints and competing responsibilities. In theme *Not for me,* some participants expressed that the program did not feel relevant to them, either because they did not perceive a current need or because their cancer type was not sufficiently represented. Finally, theme *Suggestions for the future* encompassed wishes for inclusion of materials for a partner, diagnosis-specific versions of the program, and for continued access to the program.

Paper II

Participant characteristics

Paper II included a total of 135 participants randomized to the intervention group of the Fex-Can Sex and Fex-Can Fertility programs. Mean age of participants was 33.6 years, and a majority were female (81%), had university level education (66%) and were working or studying at study entry (75%).

Level of activity in the intervention

Approximately 50% of participants opened at least three out of six modules, and 41% spent 20 minutes or more on the intervention website (Table 7). Regarding interactive activity, roughly a fourth of participants spent three or more minutes in the discussion forum, and responded to 50% or more of the quizzes and reflective questions included. Finally, 19 participants (14%) wrote own posts in the discussion forum.

Table 7. General and interactive activity in the Fex-Can intervention

Criteria	**Participants** (n=135)
General activity	No (%)
a. Opened at least 50% of modules (3/6)	65 (48)
b. Spent ≥20 minutes on the intervention website	55 (41)
Interactive activity	
c. Spent ≥3 minutes in the discussion forum	35 (26)
d. Written ≥1 post in the discussion forum	19 (14)
e. Responded to ≥50% of quizzes and reflective questions	31 (23)

In total, 33 participants (24%) met the criteria for high activity participation. No significant differences in sociodemographic or clinical characteristics were observed between high activity and low activity participants. Ninety-one participants (67%) accessed the discussion forum, and mean time spent in the forum was 7.9 minutes (SD 21.0). A total of 57 post were posted by 19 participants, with a majority of posts being descriptions of own experiences. Approximately a third of posts related to or was a direct response to posts made by others, and five posts specifically asked about experiences of other participants.

Discussion forum

In the thematic analysis of discussion forum posts, four main themes were constructed: *Fertility fears*, *Perceptions of the changed body*, *Missing out on life*, and *Importance of support and information* (Figure 7).

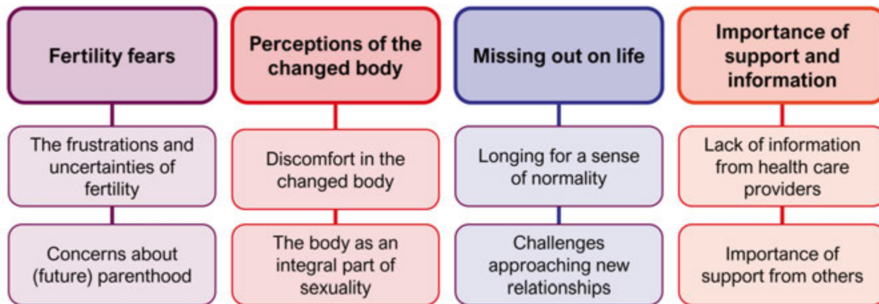

Figure 7. Themes and sub-themes from the thematic analysis

Fertility fears

Theme *Fertility fears* encompassed both the uncertainties surrounding the ability to achieve a pregnancy (subtheme *The frustrations and uncertainties of fertility*), as well as concerns about how current and/or future parenthood might unfold over time (subtheme *Concerns about (future) parenthood*). Further, experiencing loss of control over reproductive decision-making was experienced as distressing, even for participants who were content with their family size prior to cancer. Concerns about fertility were heightened in the context of the partnered relationship, with posters describing feelings of stress and guilt towards their partners for not knowing whether they would be able to conceive.

Perceptions of the changed body

Posters described experiences of discomfort and dissatisfaction related to changes in appearance and function following cancer (subtheme *Discomfort*

in the changed body). Appearance-related changes led to discomfort being naked and fears of negative reactions and comments from others, which in turn resulted in avoidance or use of different strategies to conceal the body. Posters also discussed the impact of bodily changes on sexuality and intimacy (subtheme *The body as an integral part of sexuality*). Changes were described in relation to both appearance and function, where some noted that their bodies no longer responded to sexual stimuli as before, and other described how dissatisfaction with their appearance led to discomfort with sexual activity.

Missing out on life

Theme *Missing out on life* reflected a longing for a sense of normality, and the frustration experienced over a reduced ability to live life as before cancer (subtheme *Longing for a sense of* normality). Concerns about dating and future relationships were described as particularly challenging, yet as something that many desired (subtheme *Challenges in approaching new relationships*). Posters noted that communicating about cancer-related sexual problems was difficult, and expressed a fear of being rejected in the dating context.

Importance of support and information

Theme *Importance of support and information* encompassed the lack of or limited information that participants reported receiving from their health care providers (subtheme *Lack of information from health care providers*) and the value of having someone to talk to (subtheme *Importance of support from others*). Posters described difficulties in findings someone to confide in, particularly regarding topics such as sexuality and fertility.

Paper IV

Three main categories were constructed in the qualitative content analysis: *Collaborative working process*, *Group atmosphere* and *Concrete impact*. Each main category further includes two to four subcategories. Categories are based on data from all three data sources, i.e., information from impact logs, field notes, and individual interviews with PRPs (n=4).

Collaborative working process

Category *Collaborative working process* describes the collaboration between PRPs and researchers involved in the shared working group. Shared working group meetings were conducted in person on weekends. Prior to each meeting, researchers engaged in preparatory work, and PRPs completed home

assignment by reviewing relevant materials. As outlined in subcategory *Forms of collaboration*, all meetings followed a structured format (Table 8).

Table 8. Overview of meeting agenda for shared working group meetings

Structure	Explanation
1. Welcome and brief overview	Going through the meeting agenda and planned activities
2. Sharing of life updates since last meeting	Sharing of important life updates, done in a structured turn-taking manner
3. Feedback from the research team	Reviewing how input from PRPs has been interpreted and incorporated into the intervention, opportunity for reflection
4. Lunch	Joint lunch, opportunity to recharge and socialize
5. Workshop sessions	Based on the preparatory home assignment. Different workshop formats, including full group and smaller group formats
6. Break	Time to recharge, coffee, snacks.
7. Group reflection	Reflections about the meeting, about whether something should be done differently at the next meeting

Furthermore, deliberate efforts were undertaken to ensure clarity and transparency in relation to the PPI process and intervention development (subcategory *Feedback and transparency*). PRPs were informed regarding which elements of the intervention that could and could not be altered, for instance due to technical constraints of the internet platform or pre-determined intervention components. In an iterative approach, researchers provided feedback and demonstrated how PRPs contributions were integrated into the intervention, thus ensuring that their input had not been misunderstood and enabling visualization of contributions. Finally, use of preparatory home assignments, combined with explicit communication regarding what PRPs could impact, contributed to a productive working environment (subcategory *Efficient ways of working*).

Group atmosphere

Screening interviews conducted during the recruitment of PRPs were essential in establishing a diverse group, for example with respect to cancer type and experiences of sexual problems and/or fertility-related distress (subcategory *Diverse working group*). Interviews further ensured that PRPs were clearly informed about what the involvement would entail, which was appreciated by

PRPs. The shared working group meetings were structured to foster a supportive environment and accommodate different preferences by alternating between individual tasks and group discussions (subcategory *Supportive meeting environment*). At the first meeting, shared ground rules were established to guide communication and participation, including equitable turn-taking and acceptance of differing perspectives. PRPs reported feeling safe and able to express different views, and relationships among PRPs and between PRPs and researchers were promoted through sharing of personal life updates at the start of each meeting.

Concrete impact

Main category *Concrete impact* presents the impact that PRPs had on the intervention and future internal pilot trial. A summary of discussions and changes applied in the Fex-Can 2.0 intervention is presented in Table 9.

Table 9. Examples of PRP impact on the Fex-Can 2.0 intervention

Summary of discussions	Summary of changes applied
Language and content	
Use of inaccessible, medical & technical language	Texts were reviewed and updated by researchers and PRPs at several time points to ensure clarity and accessibility
Lack of rationale for inclusion of content in the program	Rationales were added and reviewed by PRPs
Structure and layout	
Readability not optimal, material often experienced as a “wall of text”	Content was subsequently structured under clear headings to improve readability, and more space and images were added
Structure content to be relevant for persons with and without partners	Subheadings were added in relevant sections, for example in exercises where participants could invite a partner
Intervention design elements	
Teasers to introduce new modules	Teasers (2-4 minutes long) were recorded following input from PRPs on content.
Ability to get a visual representation of progression in the program	Incorporated in the new platform [a]
Future pilot trial	
Suggestions for the content and layout of recruitment materials, e.g., wish for more discrete materials	Language, content and layout updated following input from PRPs, and reviewed at subsequent shared working group meetings

Suggestions of channels for recruitment and provision of materials in relevant channels	All channels noted down and materials sent out to PRPs who offered to help with recruitment

[a] A new platform was employed in spring 2025 due to discontinuation of the old platform
PRP = Patient research partner

Considerable attention was given to language, visual presentation, and content structure following input from PRPs. PRPs emphasized the importance of avoiding language, imagery or terminology that were inaccessible or that could inadvertently place blame or reinforce social norms, and provided suggestions for more neutral and inclusive alternatives. Discussions also addressed the organization, length and level of detail of texts. While preferences differenced regarding the amount of information included, the group agreed on structuring content so that general information was presented first, with more detailed materials accessible through collapsible sections. PRPs further advocated for a more engaging intervention design, leading to the inclusion of components such as brief audio introductions (*teasers*), which were developed and refined collaboratively. In preparation for the pilot trial, PRPs also contributed to recruitment strategies by reviewing and revising recruitment materials and screening interview content, by suggesting recruitment channels, and by supporting dissemination of recruitment materials through patient organizations.

Paper V

Participant characteristics

A total of 1010 participants responded to the 1.5-year assessment, followed by 722 and 659 at 3 and 5 years, respectively. Seventy-eight percent of those who responded to the 1.5-year assessment also completed either or both follow-ups. At 1.5 years, 69% of respondents were female, 55% had university level education, and a majority were working or studying. Mean age at study entry was 33.2 years and 30.7 years among females and males, respectively.

Body image at 1.5, 3 and 5 years post-diagnosis

A total of 54% of female participants and 24% of male participants reported Body Image Scale (BIS) scores reaching the ≥10 cut-off at the first assessment, indicating clinically relevant body image disturbance. At follow-ups, approximately 40% of females and 15% of males met the cut-off for body image disturbance.

Change in body image over time

Among females, there was a significant main effect of time, showing that body image changed significantly across the three assessments. Body image scores were significantly lower at 3 ($\beta = -1.58$, $p<.001$) and 5 years ($\beta = -2.73$, $p<.001$) post-diagnosis, as compared to their score at 1.5-years. However, a significant interaction effect between time and diagnosis was found, indicating that the effect of time varied depending on type of cancer. Body image improved significantly across all assessments among participants diagnosed with breast cancer, while females with lymphoma improved between 1.5 and 3 years and over the entire study period, but not between the later assessments. For males, there was a significant main effect of time on body image. Compared to BIS scores at 1.5 years, participants had significantly lower scores at 3 ($\beta = -0.87$, $p = 0.001$) and 5-years post diagnosis ($\beta = -1.06$, $p<.001$).

Associated factors

Factors associated with higher levels of body image disturbance over time among both females and males included receipt of higher level of treatment intensity (females: $\beta = 1.57$, $p=0.001$, males: $\beta = 1.44$, $p=0.014$). Higher levels of emotional distress were further found to be associated with more body image disturbance (females: $\beta = 0.27$, $p<.001$, males: $\beta = 0.36$, $p<.001$). Among females, 1.5-year educational level and occupational status and birth country was found to be significantly associated with body image. Participants with university level education, those who were working or studying, and those born outside of Sweden reported lower BIS scores.

Discussion

The aim of the present thesis was to develop and evaluate internet-delivered interventions for sexual problems and fertility-related distress following cancer, with the ultimate goal to improve the quality of survivorship for individuals diagnosed with cancer during young adulthood. The work presented is embedded within the Fex-Can Young Adult research project, which aims to investigate and alleviate sexual problems and fertility-related distress among young adults following a cancer diagnosis. The present thesis thus includes results from the evaluation of the original Fex-Can (1.0) intervention (Papers I & II) and from the population-based Fex-Can cohort study (Paper V). Further, Papers III and IV are situated within the MRC phase *developing or identifying a complex intervention* and presents the planned pilot trial and future evaluation of Fex-Can 2.0, as well as the collaboration with patient research partners in the development of the Fex-Can 2.0 intervention.

Summary of main findings

Results from the evaluation of the Fex-Can (1.0) Sex intervention showed no statistically significant effects on primary or secondary outcomes (Paper I). Although participants with higher baseline level of sexual dysfunction improved over time in several PROMIS SexFS domains, these improvements were observed among participants in both the intervention- and control condition. Findings from both Papers I and II further revealed limited level of activity of participants in both the Fex-Can Sex and Fex-Can Fertility programs. Subgroup analyses comparing participants with high versus low levels of intervention activity showed that activity level did not influence outcomes (Paper I). Across both the Fex-Can Sex and Fex-Can Fertility programs, 24% of intervention group participants met criteria for high activity usage, with 67% of IG participants accessing the discussion forum (Paper II). Among those who accessed the forum, a minority contributed own posts, whereas the majority engaged by "lurking" (i.e., reading without posting). Forum posts addressed concerns about fertility status and parenthood, discomfort with appearance and sexual body image, concerns about missing out on life and important milestones, as

well as the value of receiving support and information. Despite limited engagement and the absence of demonstrated intervention effects, a majority of participants expressed appreciation for the intervention. Participants described perceived benefits such as increased acceptance and sense of belonging (Paper I), and valued the support received from peers and moderators in the discussion forum (Paper II). In response to shortcomings identified in the evaluation of the Fex-Can (1.0) intervention, development of a revised version (Fex-Can 2.0) was initiated (Paper III). Refinement of the original intervention was conducted in collaboration with PRPs (Paper IV). Efforts to foster effective collaboration and create a safe and inclusive working environment were appreciated by PRPs, and their extensive input had significant impact on the intervention and future pilot trial, illustrating the influence that patient and public involvement can have on the intervention development process. Finally, a substantial proportion of young adults diagnosed with cancer report body image disturbance at 1.5 years post-diagnosis (Paper V). Although body image concerns among males and females diagnosed with breast cancer and lymphoma improved over time, considerable proportions of participants continued to report high levels of body image disturbance and 3 and 5 years post-diagnosis.

Discussion of findings

Fertility, sexuality and psychosocial challenges

Young adulthood represents a time in life where several developmental milestones and tasks are navigated and approached (Zebrack et al., 2011; 2016). A cancer diagnosis during this period may disrupt such processes, posing a significant threat to the individuals well-being. The nature of disruptions experienced following a cancer diagnosis and treatment may vary across this young adulthood continuum, reflecting differences in priorities such as parenthood, dating, exploration of sexuality and body image (Canzona et al., 2021; Lehmann et al., 2025b; Moore et al., 2021). These experiences are further shaped by disease progression, treatment burden, social support and mental health challenges (Hughes et al., 2024b; Penn et al, 2017), and psychosocial impact of cancer and its treatment should thus be understood through the dynamic interplay of developmental, clinical and contextual factors.

Many young adults describe fertility in the cancer context as a major source of frustration and uncertainty, both in terms of fertility status and regarding future parenthood (Paper II). Fertility-related distress may further significantly affect romantic relationships, contributing to relational stress, challenges with intimacy, feelings of guilt, and concerns about dating, with young

adults reporting concerns about not being an adequate (future) partner (Benedict et al., 2016b; Hawkey et al., 2021; Logan et al., 2019; Perz et al., 2013; Yoshida et al., 2024). Further, loss of control over reproductive decisions was emphasized both among discussion forum posters and in previous research, where it has been described as a particularly distressing consequence of cancer treatment (Logan et al., 2019; Ussher et al., 2018). Although fertility-related distress tends to be higher among individuals without children prior to diagnosis, and among those wishing to have (more) children (Ljungman et al., 2018; Yoshida et al., 2024), fertility concerns are also reported among individuals who report being satisfied with their family size before their cancer diagnosis (Paper II) (Ussher et al., 2018; Yoshida et al., 2024). Findings from Paper II further highlight the impact of cancer and its treatment on sexuality, including altered physical sensations, discomfort in being naked in from of partners, and challenges in maintaining intimacy. These findings align with previous research, showing that sexual problems following cancer commonly intersect with body image concerns and contribute to insecurity in romantic and sexual contexts (Bentsen et al., 2024b; Sleeman et al., 2025; Wirtz et al., 2023). Given that young adulthood often involves dating, sexual identity development, and formation of long-term relationships, such disruptions may be particularly distressing. Beyond fertility and sexuality, young adults describe broader challenges in resuming life after cancer, including feelings of isolation, difficulty socializing, and frustration in relation to unmet expectations for life progress (Paper II) (Sleeman et al., 2025). Experiences of missing out on anticipated milestones, such as forming relationships, advancing careers, or starting families, may contribute to feelings of loss and disconnection, heightening vulnerability to emotional distress during survivorship (Hughes et al., 2024b; Zebrack & Butler, 2012).

Importantly, both previous research and discussion forum participants highlight that young adults often receive limited or insufficient information about sexual and reproductive health from health care providers (Bergström et al., 2023; Berkman et al., 2023; Lehmann et al., 2022). Posters in Paper II described having to actively seek information and expressed uncertainty about whom to approach with their concerns. Discussions about fertility and sexuality were often perceived as difficult to initiate with both partners and health care professionals. Consequently, participants valued the opportunity to connect with peers in the forum, and such spaces may provide accessible venues for support and information, and serve as a complement to traditional care (Sleeman et al., 2025).

Body image in the cancer context

Concerns about the body are common during young adulthood, reflecting normative developmental challenges related to appearance, sexuality and identity (Bucchianeri et al., 2013; Milton et al., 2021). In the context of cancer, disease and treatment may introduce abrupt changes to the body that may amplify existing vulnerabilities (Moore et al., 2021). Experiencing such changes during a stage of life in which body image is particularly important may intensify distress and negatively affect intimacy and mental well-being, with effects that can persist beyond treatment (Bellizzi et al., 2012; Moore et al., 2021; Vani et al., 2021).

Previous research indicate that a substantial proportion of young adult cancer survivors experience negative impact on their body image (Paterson et al., 2016; Vani et al., 2021), and findings from the present thesis further show that 54% of females and 24% of males experience body image disturbance at 1.5 years post-diagnosis (Paper V). Discussion forum posts (Paper II) add depth to these findings, illustrating how bodily changes following cancer contribute to experiences of discomfort and dissatisfaction. Posters described frustration related to altered bodily function, unease in sexual relationships, heightened concern about others' perceptions, and avoidance of social situations. These accounts underscore the multidimensional nature of body image (Cash, 2004; Hopwood et al., 2001), where participants express affective (e.g., feeling uncomfortable), cognitive (e.g., fearing perceptions of others) and behavioral (e.g., concealing their bodies and avoiding activities) components of body image.

Research on body image in young adult cancer survivors has largely focused on breast cancer (e.g., Miaja et al., 2017; Paterson et al., 2016), and results from Paper V confirm the high prevalence of body image disturbance in this group. Results also indicate substantial concerns among female lymphoma survivors, with 77% reporting body image disturbance 1.5 years post-diagnosis. Although few studies have previously focused on body image among survivors of lymphoma, existing studies have found that 39% report body dissatisfaction at a median of two years after hematopoietic stem cell transplantation (Kang et al., 2021), while older survivors (aged >45 years) indicate modest negative effects on body image at six months after chemo- or chemoimmunotherapy (Olsson et al., 2016). The high prevalence observed in the Fex-Can cohort may partly reflect level of treatment intensity, as approximately 60% of females with lymphoma received higher levels of treatment intensity, which is a factor known to negatively affect body image as demonstrated in Paper V

and previous research (Rosenberg et al., 2020; Saris et al., 2022; Yoo et al., 2024). Although body image disturbance decreased over time for males and for females diagnosed with breast cancer and lymphoma, a substantial proportion of participants reported body image disturbance at each assessment (Paper V). This aligns with previous research suggesting gradual improvement in body image over time, while also indicating that such difficulties may persist for some individuals long after diagnosis and treatment (Dempsey et al., 2022; Rosenberg et al., 2020; Saris et al., 2022). Similar long-term challenges have been documented across related quality-of-life domains, including sexuality, fertility-related distress, and emotional well-being (Acquati et al., 2018; Oveisi et al., 2023; Rosenberg et al., 2020; Sjödin et al., 2025; Stroeken et al., 2024). Collectively, these findings underscore the need for sustained, targeted interventions addressing body image and related psychosocial concerns in young adult cancer survivorship.

Moving on to the next step: the Fex-Can 2.0 intervention

Although results from the evaluation of the Fex-Can (1.0) Sex program showed that participants appreciated the program and felt that it had helped them manage their problems, no significant effects were demonstrated (Paper I). Previously reported results from the evaluation of the Fex-Can (1.0) Fertility program further showed limited effects on the primary outcome (RCAC), although improvements were observed for specific dimensions and for fertility-related knowledge (Micaux et al., 2022). Level of activity of participants in both programs was limited (Paper II), and subgroup analyses on level of intervention activity did not impact the results (Paper I) (Micaux et al., 2022).

Previous research has identified low level of activity, engagement and adherence as core concerns in the evaluation of internet-delivered interventions (Beatty & Binnion, 2016; Ryan et al., 2018). Research on dose-response relationships in internet-delivered interventions have demonstrated mixed results (Donkin et al., 2013). While some studies report associations between greater usage (e.g., higher completion rates, more frequent logins) and better outcomes (Cobb et al., 2005; Manwaring et al., 2008), other indicate that only the proportion of intervention content completed is consistently related to outcomes, with other usage metrics showing inconsistent associations (Donkin et al., 2011). The relationship between usage and outcome may also be curvilinear, meaning that it reaches a point of saturation beyond which additional use offers no further benefit (Donkin et al., 2013). While participants' usage of an intervention often can be readily assessed in internet-delivered interventions (e.g., by looking at log ins, completed tasks), an operationalization of intended

usage is necessary to assess adherence (Donkin et al., 2013; Sieverink et al., 2017). Such an operationalization allows for assessment of whether participants activity in the intervention matches what was intended by intervention developers.

The original Fex-Can (1.0) intervention included no formal definition of intended usage, and criteria for level of activity in the intervention was set posteriori, and it is unclear whether it actually captured participants level of activity or engagement with the program. Regardless, the overall activity level in the intervention was low, and the evaluation of the effects of the interventions are thus limited by the sparse utilization of the program (Eysenbach, 2005). In evaluating the shortcomings of the Fex-Can (1.0) intervention, several factors relating to adherence and activity can be identified. In Table 10, a summary of changes adopted in version 2.0 of the intervention is presented.

Table 10. Summary of and changes adopted in Fex-Can 2.0

	Fex-Can 1.0	**Fex-Can 2.0**
Level of guidance	Primarily self-guided	Higher level of guidance
Feedback support provision	Static, automated feedback	Human-supported feedback on reflective questions and exercises
Level of tailoring	No tailoring	Modules selected based on individuals' problems and concerns as assessed in an individual start-up session
Selection of participants	Drawn from large population-based cohort study based on pre-defined criteria	Self-selected, included based on their experiences as described in individual screening interviews
Intended usage and level of activity	No set definition of intended usage	Set definition of intended usage and instructions on minimum expected level of activity

Level of guidance and tailoring and provision of support

The Fex-Can (1.0) intervention was primarily self-guided, and participants received automatic feedback on quizzes completed within the program and could communicate with moderators and peers in an asynchronous discussion forum. Further, participants enrolled in the Fex-Can Sex program had opportunity to partake in an individual exit session to discuss potential remaining problems. Self-guided or self-help interventions are generally cost-effective

and relatively easy to implement (Kraepelien et al., 2023). Such interventions have further shown promise in reducing emotional distress (Oey et al., 2023) and improving sexual function and satisfaction among breast- and cervical cancer survivors (Schover et al., 2013). Additionally, a pragmatic trial by Schover et al. (2020) demonstrated significant improvements in sexual functioning and use of sexual aids following a digital self-help intervention. However, in both studies by Schover et al. (2013; 2020), limited participant engagement and activity was reported, and in the 2020 study, high attrition rates meant that results were ultimately reported for only 30% of female participants (Schover et al., 2020).

Previous research indicate that participants often value and benefit from some level of facilitation or human support in self-guided interventions, with such support being associated with increased activity and engagement (Beatty & Binnion, 2016; Hilvert-Bruce et al., 2012; Kelders et al., 2012; Ugalde et al., 2017; Xie et al., 2020). Beyond supporting engagement, the inclusion of guidance may also enable greater tailoring to individual needs, which is a feature preferred among participants in previous studies (Mayer et al., 2022; Smith et al., 2024). Such tailored support has been suggested to enhance both uptake and effectiveness of internet-delivered interventions (Hovingh et al., 2025; Schubart et al., 2011). In this next generation of the Fex-Can (2.0) intervention, level of guidance and human support has thus been increased. Firstly, two synchronous sessions delivered via telephone or video conference are introduced at the beginning and end of the program to build alliance and provide support. Furthermore, the session at the beginning of the program allows for greater tailoring to each participant's needs (e.g., deciding which modules should be provided for each participant). Additionally, participants will receive individualized feedback on exercises and reflective questions from an allocated intervention deliverer, ensuring tailored support throughout the program. However, inclusion of a higher level of guidance must be balanced against considerations such as privacy, accessibility and participant burden, as well as complexity in future potential implementation.

Participant selection

Participants in the evaluation of the original Fex-Can (1.0) intervention were recruited from the population-based Fex-Can cohort study, meaning that all individuals in Sweden diagnosed with cancer between ages 18-39 years during a specified time period who met the inclusion criteria were invited to participate (Wettergren et al., 2020). This approach ensured broad coverage of young adults diagnosed with cancer, which is a clear strength in terms of representativeness. However, the passive recruitment strategy utilized (i.e., being invited

based on predefined criteria rather than actively seeking support) may represent a weaker motivator for engagement and sustained intervention use (Eysenbach, 2005). Additionally, the cut-off used for sexual dysfunction was insufficient in identifying individuals in need for the Fex-Can Sex program (Paper I). Open-ended responses in the post-intervention survey revealed that several participants joined primarily to contribute to research or because they considered support for sexual health to be important, rather due to personal need, which in turn may reduce motivation to participate in the intervention. Previous studies have shown that higher levels of need are associated with greater use of internet-interventions (Montalescot et al., 2024).

For Fex-Can 2.0, recruitment will be based on self-selection, meaning that individuals will contact the research team to be assessed for inclusion. Rather than relying on predefined cut-offs for defining sexual problems and/or fertility-related distress, inclusion will consider participants' own experiences and self-perceived need. While this approach may potentially reduce reach and pose recruitment challenges, it is expected to improve engagement.

Usage and activity in the intervention

To assess participants' adherence to the Fex-Can 2.0 intervention, a definition of intended usage was established (Donkin et al., 2013; Sieverink et al., 2017). Intended usage was defined as completion of at least 75% of the six allocated modules, including the exercises, reflective questions and quiz components within each module. This threshold was chosen to reflect a minimum level of exposure considered necessary to reasonably expect beneficial effects. Previous research has shown that a higher proportion of completed intervention content is associated with improved outcomes in internet-delivered interventions (Donkin et al., 2011).

In addition, expectations regarding activity in the intervention is explicitly communicated to participants. As part of the inclusion criteria for Fex-Can 2.0, participants should be able to spend a minimum of 30 minutes per week engaging with the intervention. This requirement was introduced to set realistic expectations regarding the time and effort required, while acknowledging that participants may be undergoing ongoing or recent cancer treatment and may experience fluctuating energy levels. The intervention was therefore designed to allow flexibility in how and when participants engage with its content, with the 30-minute threshold representing a minimum recommended level of weekly engagement.

Considerations in intervention development

According to the MRC framework, *development* refers to the "whole process of designing and planning an intervention, from initial conception through feasibility, pilot or evaluation study" (Skivington et al., 2021). The development phase of the MRC framework thereby bridges the gap between generating an intervention idea and conducting formal testing in later phases (O'Cathain et al., 2019, Skivington et al., 2021). O'Cathain and colleagues (2019) further elaborate on this phase by introducing guidance for the development of complex interventions, outlining a set of actions to be considered. In the refinement of the Fex-Can (1.0) intervention, several actions are considered, with three key actions being particularly relevant to the present thesis: *involving interestholders*, *draw on existing theories*, and *designing and refining*. These actions are discussed in detail below.

Involving interestholders

Involvement of interestholders in the intervention development process can increase the understanding of the problem at hand, inform research priorities, and identify barriers and facilitators to recruitment and engagement (O'Cathain et al., 2019). Although PPI is increasingly considered an integral part of research, descriptions of how PPI is conducted and experienced are often limited. As such, there has been calls to strengthen the reporting of PPI processes in order to better understand what works, for whom it works, and under which circumstances it works (Shakhnenko et al., 2024; Staniszewska et al., 2017).

In the refinement and further development of Fex-Can (1.0), several key strategies used in the collaboration between PRPs and researchers were identified (Paper IV). These included the importance of structured meeting formats, an iterative and cyclical approach for feedback, and transparency through clear communication regarding roles and scope of involvement. This is in line with previous studies, which have described provision of feedback and opportunity for reflection on the impact of contributions from PRPs as crucial for promoting sense of agency and ownership, and for enhancing motivation for involvement (Birch et al., 2020; Crocker et al., 2017; Mathie et al., 2018). Similarly, the evaluation of the PRP involvement in the development of the original Fex-Can (1.0) intervention highlighted that an iterative approach, where PRPs input was actively acknowledged, were essential for fostering motivation and confidence (Hovén et al., 2020). Furthermore, clarifying expectations about the purpose and scope of involvement is recognized as important in effective PPI (Nissen et al., 2018). Such efforts help establish realistic expectations and

enable PRPs to focus on aspects that can be meaningfully influenced. Taken together, these findings underscore that meaningful involvement of PRPs requires structured processes that prioritize communication, feedback and transparency.

Draw on existing theories

The guidance by O'Cathain et al. (2019) further emphasize the importance of drawing on existing theories when developing complex interventions. Utilizing relevant theory can inform both content and delivery of interventions, and may facilitate the identification of mechanisms of change, enabling researchers to assess whether the intervention operate as intended (Michie & Prestwich, 2010).

The original Fex-Can (1.0) intervention was grounded in self-determination theory, which posits that satisfaction of autonomy, competence and relatedness is essential for optimal functioning and well-being. In the evaluation of Fex-Can (1.0), no formal assessment of whether these needs were supported by the intervention was conducted. While measures of self-efficacy, often considered a proxy measure for *competence*, were included, no instruments captured autonomy or relatedness. This is particularly important since all three needs are mutually dependent (Ryan & Deci, 2000). Obol and colleagues (2022) conducted a qualitative study to explore experiences of participation in the Fex-Can (1.0) intervention within the theoretical frame of basic psychological needs theory. Results showed that the intervention appeared to support participants need for competence and relatedness, while participants descriptions of autonomy were vague. Authors further found that components that are supportive of relatedness appears to be of special importance to this young adult population (Obol et al., 2022).

SDT further serves as the theoretical foundation for Fex-Can 2.0 (Paper III), given its relevance for promoting motivation and quality-of-life outcomes in internet-delivered interventions (Pingree et al., 2010). To operationalize SDT in Fex-Can 2.0, relevant strategies were mapped to support each need: offering opportunities for choice and personalization (autonomy), providing clear feedback and skill-building exercises (competence), and facilitating peer and intervention deliverer communication (relatedness). Consistent with the guidance from the MRC framework (Skivington et al., 2021), working with this theoretical foundation also involved development of a program theory to articulate hypothesized mechanisms of change, including how support of basic psychological needs may improve quality-of-life-related outcomes. The hypothesized role of basic psychological needs in potential effects of the Fex-Can 2.0 intervention will later be assessed in the RCT.

Designing and refining

Action *designing and refining* refers to generation of ideas relating to content, format and delivery of an intervention (O'Cathain et al., 2019). Consistent with the guidance by O'Cathain et al. (2019), ideas and suggestions for the intervention was generated in collaboration with PRPs. Although several intervention and study design components had been determined prior to their involvement, their input was instrumental in refining the intervention (Paper IV). Impact of PRPs contributions was reported across four broad domains: language and content, structure of texts, elements of the intervention design, and the future pilot trial. PRPs input informed changes that may ultimately enhance the inclusivity, accessibility and relevance of the intervention. This included addressing the use of difficult, technical, or value-laden terminology; providing feedback on the rationale for included content; and refining the program's structure to enhance interest and readability. Further, PRPs also suggested incorporating elements to increase content variety, such as brief teasers at the beginning of each new module, which were subsequently implemented. Similar impact of PPI on interventions have been reported in previous studies (Nissen et al., 2018; Svedin et al., 2025), where input from PRPs resulted in improvements to clarity, relevance and comprehensibility of materials.

Methodological discussion

Randomized controlled trials for internet-delivered interventions

RCTs are widely regarded as the gold standard for evaluating interventions due to their capacity to enhance internal validity through randomization and structured protocols, thereby reducing selection bias and enabling causal inference (Zabor et al., 2020). However, in the context of internet-delivered interventions, several limitations should be acknowledged.

Firstly, in contrast to pharmacological trials, blinding of participants and intervention providers is rarely feasible in internet-delivered interventions, which may introduce expectancy effects and researcher allegiance bias, potentially threatening internal validity (Tarquinio et al., 2015). In the evaluation of the Fex-Can (1.0) intervention (Paper I) and in the planned evaluation of the Fex-Can 2.0 (Paper III), intervention providers are not blinded due to their active involvement in intervention delivery and monitoring (Lampic et al., 2019). Second, inclusion of human-supported guidance in internet-interventions introduces additional complexities compared to unguided interventions, as interaction between providers and participants may introduce uncontrolled

factors that can influence outcomes (Tarquinio et al., 2015). This consideration is particularly relevant in the evaluation of the Fex-Can 2.0 intervention, where increased provider contact and guidance have been introduced to enhance engagement and enable greater tailoring to individual needs. Although tailored content is a key feature of many internet-delivered interventions, the resulting flexibility and individual adjustments may conflict with structured nature of randomized controlled trials. While such structure is essential for maintaining methodological rigor and control, it may be less compatible with the flexible and context-sensitive design of internet-delivered interventions

As recommended by the MRC framework, researchers should aim to adopt a broader perspective on evaluation that extends beyond efficacy and effectiveness alone (Skivington et al., 2021). This includes theorization about how intervention effects come about, what impact it may have beyond the intended primary outcome, and exploration of experiences, all of which can be used to support decision-making in real-world settings (Skivington et al., 2021). In the evaluation of Fex-Can 2.0, qualitative exploration of participant experiences will be incorporated to understand contextual factors and identify potential unanticipated effects. In addition, theory-driven medication analyses will be conducted to examine potential mechanisms of change. Together, these approaches aim to complement the RCT design by enhancing the understanding of how and why potential effects occur (Skivington et al., 2021).

Who are we reaching?

A key strength of the Fex-Can YA project is its population-based design, which ensured that all individuals in Sweden diagnosed with cancer within the specified age range and time period were invited to participate in the cohort study (Wettergren et al., 2020). This approach minimizes selection bias and further provided a broad, generalizable pool for subsequent recruitment into the RCT (Lampic et al., 2019). The sex distribution and representation of cancer types among participants who responded to the 1.5-year assessment were broadly aligned with national cancer indicate rates for young adults (Socialstyrelsen, 2025a). However, the response rate among individuals diagnosed with ovarian cancer was low, which may limit generalizability of study findings for that group.

Of the 1010 individuals who completed the survey at 1.5 years post-diagnosis, 356 met the criteria for sexual dysfunction and were approached for participation in the Fex-Can Sex program (Paper I). Of the 138 that accepted participation in the Fex-Can Sex, only 22 (16%) were male. The limited participation

rate among males is consistent with previous research, which has shown that males have lower uptake and engagement in internet-delivered interventions (Karyotaki et al., 2015; Maher et al., 2014; Reinwand et al., 2015; Ryan et al., 2019). However, in the present study, lower participation rates among males may not only reflect this general pattern of low engagement, but may also relate to diagnosis-specific factors that influence perceived need for support. Testicular cancer was the most common diagnosis among males, accounting for 64% of the male Fex-Can Sex sample. Although the impact of testicular cancer on sexual health has been documented previously (Kuiper et al., 2024; Ljungman et al., 2019), the relatively low treatment intensity typically associated with this diagnosis may have limited the severity of sexual problems, and in turn, the need for intervention. Previous research has shown that more intensive treatments or receipt of several treatment modalities is associated with greater risk for sexual dysfunction (Ospina Serrano, 2023; Vrancken Peeters et al., 2024; Wettergren et al., 2022). Additionally, the timing of the intervention (1.5 years post-diagnosis) may not have optimally aligned with testicular cancer survivors' needs, as many undergo surgery alone and may have experienced improvements of potential impact on sexual function at this stage of survivorship (Ljungman et al., 2019). More broadly, cancer trajectories differ by diagnosis, treatment and individual factors, which may influence both the nature and timing of potential sexual problems (Ospina Serrano, 2023). Accordingly, for Fex-Can 2.0, individuals are eligible for participation from diagnosis up to five years later, allowing participation at a time better aligned with individual needs.

Involving patient research partner in research

Evaluating patient and public involvement

Within normative arguments for the involvement of patients and the public in research, PPI is regarded as having intrinsic worth, grounded in democratic principles that position involvement as a fundamental right (Barber et al., 2012; Gradinger et al., 2015; Staley, 2015). From this perspective, PPI is not merely instrumental, but an end in itself, contributing to greater accountability of research. Consequently, when justified on a normative ground, evaluation of PPI efforts may seem unnecessary. However, other perspectives highlight the practical benefits of PPI, viewing it as valuable not only for ethical reasons but also as a means of improving research quality, by making studies more relevant, strengthening design and enhancing recruitment and dissemination (Gradinger et al., 2015). Importantly, these perspectives are not mutually exclusive, and it is possible to regard PPI as an end in itself, while also seeking

to meaningfully and usefully evaluate it to understand how to do it well and maximize its impact (Staley, 2015).

In Paper IV, we thus aimed to describe and evaluate our collaboration with PRPs in the refinement of the Fex-Can (2.0) intervention, in an effort to demonstrate impact and highlight practical approaches to PPI. While collaborations between PRPs and researchers are inherently context-dependent and experiential, providing detailed descriptions can contribute to a collective evidence base that supports meaningful involvement in future research (Brett et al., 2014; Staley, 2015). Findings indicated that structured working processes, clear feedback on how input was used, and a safe, respectful collaboration were particularly valued (Paper IV). These findings are consistent with prior research highlighting the importance of relationship-building, role clarity, and recognition of contributions in effective PPI (Green & Johns, 2019; Mathie et al., 2018; NIHR, 2024; Nissen et al., 2018).

Levels and stages of involvement

Patient research partners can be involved throughout the research cycle and at varying levels of involvement (Colomer-Lahiguera et al., 2023; NIHR, 2024). However, continuous involvement and involvement at high levels may not always be feasible or appropriate, given practical, health-related and resource-related constraints (Boivin et al., 2018). In refining the Fex-Can (1.0) intervention, PRPs provided input that directly influenced the intervention, and their input had impact on the decisions made in the larger Fex-Can research project group (Paper IV). However, PRPs joined the process after key elements were already established, and many components were further informed by the Fex-Can (1.0) intervention and prior PPI work (Hovén et al., 2020; Winterling et al., 2016). These factors, along with time constraints, limited the scope of changes that PRPs could influence. While PRPs were thus not involved in earlier stages such as priority setting and initial design, their contributions during development were significant. This reflects guidance that PPI can be flexible and adapted to different stages of the research cycle, rather than requiring continuous engagement throughout all stages of the research cycle (NIHR, 2024). To ensure clarity, PRPs were explicitly and continuously informed about what could and could not be changed, and why. Their feedback and comments were documented, acted upon, and progress was reported back at each meeting. In interviews and at meetings, PRPs expressed a sense of ownership and pride in seeing their contributions reflected in the final product. As such, despite the limitations, involvement or PRPs in Fex-Can 2.0 was meaningful and reflects a pragmatic balance, engaging PRPs in ways that are feasible, and ensuring that contributions have tangible effects.

Considerations in data collection and analyses

Interviewing patient research partners

Interviews with PRPs were conducted by an independent researcher who was not involved in the collaboration with PRPs or in the wider Fex-Can research program (Paper IV). Interviewees were informed that members of the shared working group would not have access to identifiable information or raw interview data. These procedures aimed to support open and honest reflections and to minimize discomfort linked to the dual roles PRPs may hold as collaborators and as potential study participants. PRPs were also briefed on the purpose and progress of the evaluation, and the distinction between their roles (Boivin et al., 2018).

Interviewees generally described the collaboration positively, consistent with observations recorded in field notes. However, previous research has noted several potential negative experiences of PPI, including burden and feelings of frustration (Lammons et al., 2025; Price et al., 2018). While such challenges were not raised in the current interviews, potential unvoiced concerns cannot be ruled out given the relational dynamic inherent to PPI (Mathie et al., 2018; Pearce, 2021). Importantly, PRPs who discontinued their involvement in the collaboration (n=2) were not interviewed and their perspectives are thus not represented in the interview data.

Analyzing discussion forum posts

Discussion forum posts constituted a qualitative data source generated within the Fex-Can (1.0) intervention (Paper II). These posts represent participants' written reflections and interactions, offering insight into how experiences were articulated and shared in the intervention setting. However, because the forum operated with a research and treatment context, where moderator presence was known, the environment may have shaped how participants expressed themselves. As the data consisted or pre-existing forum posts, opportunities for follow-up questions or clarification were not possible, which limited the depth of interpretation. Additionally, only a subset of participants actively contributed posts in the forum, meaning the data primarily reflect the experiences and voices of more engaged forum users. As a result, the data may not capture the diversity of experiences present in the broader sample.

The Body Image Scale

A majority of questionnaires used in the Fex-Can YA and in the papers included in this thesis are well-established instruments with documented psychometric validity and widespread use, which facilitates comparison with previous

research. Paper V focuses on the Body Image Scale (BIS) (Hopwood et al., 2001); a commonly used measure of cancer-related body image. The BIS is brief, which is advantageous given the need to minimize participant burden in studies employing multiple instruments. Although it captures affective, cognitive, and behavioral aspects of body image, it primary targets appearance-related concerns. This focus may limit its relevance for cancer types or treatments that result in fewer visible bodily changes. A cut-off score of ≥10 has been suggested as indicating clinically relevant body image disturbance (Chopra et al., 2021). However, because this threshold was validated in a psychiatric oncology context, its generalizability to broader cancer may be limited.

Reducing research waste

Research waste refers to research that fails to address relevant questions, uses suboptimal methodologies, or is inadequately reported or disseminated (Chalmers & Glasziou et al., 2009). In health research, such waste extends beyond inefficient use of resources and raises ethical concerns, as it can result in misallocation of funds and to patients not accessing potential beneficial treatments. Underreporting of negative or null results is a major contributor to research waste; and publication of such results is essential to mitigate bias in the evidence base by counteracting the selective reporting of positive outcomes (Chalmers and Glasziou, 2009). To address such challenges, strategies include systematic reporting of null results, adherence to established reporting guidelines, structured and iterative intervention development processes, and prospective registration and publication of study protocols (Bleijenberg et al., 2018; Chalmers and Glasziou, 2009).

By refining and improving the content and study design of the original Fex-Can (1.0) programs, the present work seeks to address identified shortcomings and continue the development of support for young adults experiencing sexual problems and/or fertility-related distress following cancer. Although the original Fex-Can (1.0) programs had limited effects, they were well-received by participants and addressed issues of considerable importance, supporting the value of continued development. Iterative refinement of complex interventions, particularly when conducted in collaboration with PRPs, has been proposed as an effective strategy for reducing research waste, by ensuring relevance and acceptability (Bleijenberg et al., 2018; Cristea & Naudet, 2019; Minogue et al., 2018). Additionally, the use of an internal pilot trial prior to a full-scale RCT may further reduce research waste by allowing early identification of feasibility issues while retaining

pilot data for final analyses, thereby enhancing efficiency and avoiding unnecessary recruitment (Avery et al., 2017).

Future directions

Exploring and understanding need

An increasing number of young adults are living with and beyond cancer (Miller et al., 2020); facing complex and diverse psychosocial challenges that may extend well beyond the treatment phase. Sexual and reproductive health concerns are particularly salient, and can significantly impact quality of life, identity and interpersonal relationships (Cherven et al., 2024; Hawkey et al., 2021). Findings from the broader Fex-Can YA project have contributed important knowledge regarding sexuality and fertility among individuals diagnosed with cancer in young adulthood (Bergström et al., 2023; Rodriguez-Wallberg et al., 2023; Wettergren et al., 2022; Wide et al., 2021). Adding to this body of work, the present thesis highlights body image as an additional and under-addressed concern following cancer in young adulthood. A substantial proportion of young adults in the Fex-Can cohort reported body image disturbance 1.5 years post-diagnosis, with body image disturbance remining prevalent at follow-ups (Paper V). Higher levels of body image disturbance were further observed among those who had received more intensive treatment and among those experiencing concurrent emotional distress, underscoring the importance of both clinical and psychological factors in body image outcomes. Future research should build on these findings through longitudinal studies with extended follow-up periods to better understand trajectories of body image perceptions over time, particularly among males and among cancer types such as brain tumor and lymphoma that remain underrepresented in the literature. In addition, qualitative and mixed-methods studies are warranted to explore how young adults experience and interpret body-related changes following cancer and treatment, including how such concerns intersect with identity, sexuality, and social relationships. Such approaches may help identify critical time points, mechanisms, and contextual factors relevant for intervention development and inform more tailored body image support for young adults diagnosed with cancer.

Developing and evaluating internet-delivered interventions

Given the diverse and intersecting sexual and reproductive health challenges experienced, as well as the geographical dispersion and life context of the young adult population, treatment and support following cancer requires

innovate and accessible approaches. As the organization of the Swedish healthcare system has increasingly shifted towards self-care, person-centeredness and digital solutions (Socialstyrelsen, 2025b), internet-delivered interventions present a promising approach to addressing the psychosocial needs of young adult cancer survivors. Internet-delivered interventions can provide flexible, scalable and individualized support for such needs, complementing the face-to-face care (Devine et al., 2018; McCann et al., 2019; Mostafa et al., 2025). Although previous studies have demonstrated feasibility and efficacy of internet-delivered interventions for sexual and reproductive health concerns following cancer (e.g., Gorman et al., 2022; Hummel et al., 2017; Meneses et al., 2010b), the Fex-Can (1.0) intervention showed no to limited statistical effects. Evidence from prior research suggest that internet-delivered interventions that incorporate of more guidance and opportunity for tailoring can enhance motivation and adherence, and further result in more efficacious interventions (Akdemir et al., 2024; Baumeister et al., 2014; Lustria et al., 2013; Musiat et al., 2022). Accordingly, strategies such as increased guidance and greater tailoring to individual participants' needs have thus been integrated into the updated Fex-Can (2.0) intervention. While these features may enhance engagement and activity in the intervention, they also require additional resources and may complicate future implementation. Future research, including pilot and feasibility studies, process evaluations and systematic syntheses, should therefore explore optimal level, type and format of guidance, as well as how flexible and person-centered approaches can be implemented and sustained in practice.

Additionally, internet-delivered interventions targeting sexual and reproductive health are inherently complex, and may operate through multiple interacting components, including its content, inclusion of guidance, and contextual factors. Consequently, the evaluation of such complex interventions should aim to assess not only whether an intervention achieves its intended outcomes, but also how and why those outcomes are produced (Skivington et al., 2021). Future research should therefore apply approaches such as mixed-methods and the embedding of process evaluations within efficacy and effectiveness evaluations to help elucidate how and why interventions works by examining mechanisms of impact, contextual influences and implementation processes (O'Cathain et al., 2014; Skivington et al., 2021). Such approaches can support more informed interpretation of findings and guide future intervention development and implementation.

Involving patient research partners

Involving patients and the public in the development of internet-delivered interventions will further be crucial to ensure relevance and usability for the target groups. Future research should continue to explore the process of meaningful involvement of PRPs in the development of complex interventions. While there will never be a one-size-fits-all approach, it is essential to transparently and rigorously describe and evaluate PPI efforts. Doing so can help build a practical toolkit of approaches for involvement, that supports both researchers and PRPs in their collaboration. PPI has the potential not only to improve interventions and studies by, for example, improving acceptability and relevance, but also provide intrinsic value by promoting principles such as empowerment and democracy of knowledge. Moreover, as current knowledge on PPI in later stages of complex intervention development and evaluation remains scarce (Colomer-Lahiguera et al., 2023), future research should aim to systematically explore and evaluate involvement and its impact in these later phases. This could, for example, be achieved through process evaluations embedded within broader evaluations of intervention quality and effects (Boivin et al., 2014; 2018). Such research can help identify strategies that sustain meaningful involvement throughout the research cycle and strengthen the evidence base regarding the impact of involvement on research processes and outcomes.

Conclusions

The overall aim of this thesis was to develop and evaluate internet-delivered interventions targeting sexual problems and fertility-related distress following cancer, with the ultimate goal of improving the quality of survivorship for individuals diagnosed with cancer during young adulthood. Overall, the findings provide important insights into the sexual and reproductive health challenges faced by young adult cancer survivors, and underscore the importance of involving the target group in intervention development. Although the original Fex-Can (1.0) intervention did not demonstrate significant effects on the targeted outcomes, this work offers guidance for the design and refinement of internet-delivered intervention for young adults diagnosed with cancer. Internet-delivered interventions continue to hold promise as an accessible and inclusive delivery-format that align with the preferences of this population. Future research should focus on optimizing such interventions through increased flexibility, tailoring, feedback, guidance and opportunities for peer support. Such elements may aid researchers in better addressing the diverse needs of this population, and enhance engagement with intervention content. This work therefore informs future research aimed at refining and evaluating internet-delivered interventions, and offers strategies for meaningful collaboration with patient research partners.

The main conclusions of this thesis are:

- The internet-delivered intervention Fex-Can Sex (1.0) did not yield greater reductions in sexual dysfunction than receiving standard care, and identified shortcomings were used to guide refinements incorporated into the development of Fex-Can 2.0.

- While discussion forums within interventions may be used sparsely, posters share detailed and intimate accounts of experiences and appreciate the support it provides. Intervention developers should consider the inclusion of discussion forums in larger internet-delivered interventions to support the basic psychological need for relatedness.

- Strategies such as structured meeting formats, continuous feedback, and clear definitions of roles and scope of involvement are key components in fostering successful and meaningful patient and public involvement.

- Collaboration with patient research partners can substantially influence the development of complex interventions, and has the potential to increase the relevance and acceptability of the Fex-Can 2.0 intervention for future study participants.

- Young adults experience significant impact on their body image following cancer, and while some report improvement over time, many continue to experience body image concerns that warrant attention in follow-up care.

- Young adults exposed to more intensive cancer treatments and those experiencing concurrent emotional distress may be especially vulnerable to adverse body image outcomes following cancer.

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