Ontario Health
Cancer Care Ontario

**Guideline 19-7**

## A Quality Initiative of the Program in Evidence-Based Care (PEBC), Ontario Health (Cancer Care Ontario)

# Fear of Cancer Recurrence Guideline

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**PUBLICATIONS RELATED TO THIS REPORT**

- Cancer Care Ontario Person-Centred Care Guideline: Endorsement and Adaptation of CG 138: Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. 2015 May 2015. Person-Centred Care Program
- Li M, Kennedy EB, Byrne N, Gerin-Lajoie C, Green E, Katz MR, et al. The management of depression in patients with cancer. Toronto (ON): Cancer Care Ontario; 2015 May 11. Program in Evidence-based Care Guideline No.: 19-4.

# Table of Contents

# Fear of Cancer Recurrence Guideline

## Section 1: Recommendations

*This section is a quick reference guide and provides the guideline recommendations only. For key evidence associated with each recommendation, see Section 2.*

### GUIDELINE OBJECTIVES

To make recommendations based on evidence-based strategies and/or interventions to screen, assess, and manage fear of cancer recurrence (FCR) in adults living with cancer and their care partners/family members to improve patient outcomes.

### TARGET POPULATION

Adults living with cancer and care partners/family members (≥18 years)

- Includes adult survivors of childhood cancer,
- Includes people currently in treatment and post treatment for cancer,
- Care partners include family members and other support people (i.e., friends) who provide unpaid care to cancer survivors.

### INTENDED USERS

The intended users of this guideline include oncology professionals, primary care providers, healthcare professionals working with cancer patients, psychosocial oncology professionals, and decision and policy makers in hospitals, clinics, and health systems in the province of Ontario.

### PREAMBLE

FCR presents on a spectrum of severity [1]. The definition of FCR is the fear, worry, or concern relating to the possibility that cancer will come back or progress [1]. The definition of clinical FCR, based on a Delphi study of FCR experts, stipulates that clinical FCR occurs regularly outside of predictable triggers such as annual visits to the cancer centre or waiting for test results, lasts a minimum of three months, and is accompanied by distress or impairment [2]. Moderate FCR is described as subclinical presentation of FCR determined by the presence of some but not all the symptoms of clinical FCR [3,4]. Low FCR is indicated by a patient having occasional or transient thoughts or worry about FCR accompanied by minimal distress or impairment [1].

There is strong evidence for the efficacy of high-intensity intervention for people with high levels of FCR. Specifically, interventions that directly target FCR have shown better results at reducing FCR than general broad band interventions aimed at improving distress and coping [5,6]. Modest evidence is available for those with moderate FCR, and weak evidence concerns people with low FCR. A matched care approach matches the intensity of intervention to the severity of FCR. A person with high or clinical FCR would be offered a high-intensity intervention and a person with low FCR would be offered a lower intensity intervention. Additional studies are necessary to support specific interventions for patients with moderate or low FCR.

Attention to preferences for intervention types and delivery options must also be considered when recommending available interventions to people with FCR.

The glossary that follows this preamble provides definitions for terms used throughout the guideline.

The supplemental information section that follows the recommendations provides links to webpages with tools to help with communication, interventions and programs that may be used with patients and care partners with FCR.

## Glossary

### Common Terms

*Care partner*

An individual who provides unpaid essential and on-going personal, social, psychological and/or physical support and care, as deemed important to the person requiring care. This can include support in decision-making, care coordination, care delivery and continuity of care. The term implies a two-way relationship with a shared purpose, and it includes people who are identified as family, chosen family, an informal caregiver, or a friend.

*Clinical or high FCR*

Clinically significant FCR that occurs regularly outside of predictable triggers such as annual visits to the cancer centre or waiting for test results, lasts a minimum of three months, and is accompanied by distress or impairment [2].

*Subclinical or moderate FCR*

Described as subclinical presentation of FCR determined by the presence of some but not all of the symptoms of clinical FCR.

*Minimal or low FCR*

Indicated by a patient having occasional or transient thoughts or worry about FCR accompanied by minimal distress or impairment.

*FCR screening*

Questionnaires to identify FCR in patients or care partners to indicate a need for further assessment. Screening questionnaires are usually brief and may consist of only one question.

*FCR assessment*

Questionnaires and/or clinical interview to quantify and evaluate the severity of FCR in patients or care partners.

*FCR Intervention*

Programs or processes to reduce the severity of FCR in patients or care partners.

## Interventions and Organization

### *Matched Care Approach for Intervention Organization*

The matched or stratified approach is a way to deliver care and intervention to patients and care partners. This approach tailors the FCR interventions to match with the severity of FCR [7]. Those deemed to have mild levels of FCR are referred to minimal interventions, those with moderate levels of FCR are referred to intermediate intensity interventions and those with high FCR are referred to high intensity interventions.

### *Cognitive Behavioural Therapy*

Cognitive behavioural therapy (CBT) interventions, including mindfulness-based stress reduction, acceptance and mindfulness, commitment therapy and compassion-based interventions [8]. Traditional CBTs focused on the contents of thoughts and aimed to identify and modify people's negative thoughts or biases to reduce dysfunctional emotions and promote psychological adjustment, whereas contemporary CBTs focused on mental processes and aimed to modify how people relate to their inner experiences [9].

### *Mind-body interventions*

Mind-body interventions include meditation, relaxation techniques, the use of the creative arts, mindfulness-based stress reduction (MBSR) and may also include elements of CBT [10].

### *Psychoeducational Program*

Psychoeducation refers to the process of providing education and information to those seeking or receiving mental health services, experiencing psychological symptoms or seeking medical care services and may combine the elements of CBT, group therapy, and education.

### *Non-mental Health Specialist*

Interventions delivered by non-mental health specialists including doctors, nurses, and radiation therapy technologists for FCR within the context of routine medical oncology follow-up clinics [11].

### *Telecoaching*

Telecoaching is the use of motivational interviews delivered over the telephone.

## Screening and Assessment Tools Descriptions

**Cancer Worry Scale (CWS-6)**

The CWS is a six-item self-report scale used for detecting high levels of FCR. Items are rated on a four-point Likert scale. The screening cut-off score for high FCR is equal to or over 10 and for severe FCR, a score of equal to or over 12 [84].

**Fear of Cancer Recurrence Inventory (FCRI)**

The FCRI is a 42-item self-report scale for assessing the FCR. Higher scores indicating greater fear of recurrence. The FCRI consists of seven subscales: Triggers, Severity, Psychological

Distress, Coping Strategies, Functioning Impairments, Insight, and Reassurance. There is no evidence for a cut-off score for the FCRI [12].

**Fear of Cancer Recurrence Inventory Short Form (FCRI-SF)**
The FCRI-SF is a short form of the FCRI that is the nine items of the severity subscale. A cut-off score of 13 or above indicates the possibility of clinical level FCR [13], a score of 16 or above indicates the likely presence of clinical level FCR and a score of 22 or above indicates a clinical severity of FCR that needs specialized intervention [4].

**Fear of Cancer Recurrence - 7 Item Version (FCR7)**
The FCR7 is based upon a set of seven questions that have been selected from extant measures within the literature to assess directly FCR [85]. There is no evidence for a cut-off score for the FCR7.

**Fear of Cancer Recurrence - one item measure (FCR-1)**
The one-item FCR-1 was modeled after the Edmonton Symptom Assessment System (ESAS) and measures the subjective level of FCR on a scale from 0 to 100 with a cut off score of over 45 indicating clinical FCR. There is an option of using a scale of 0-10 with a cut off score of over 4.5 to indicate clinical FCR [86].

**Fear of Cancer Recurrence Inventory-Caregiver (FCRI-Caregiver)**
The 42-item FCRI-Caregiver was revised from the FCRI (patient version) and examined seven general areas: triggers, severity, psychological distress, functional impairment, insight, reassurance, and coping strategy. Each question was rated on a Likert scale ranging from 0 (not at all or never) to 4 (a great deal or all the time), with a higher score indicating a greater FCR [14].

**Fear of Progression Questionnaire (FoP-Q)**
The FoP-Q is a 43-item questionnaire to measure the fear of progression in chronically ill patients. The scale comprised five factors: affective reactions (13 items), partnership/family (7 items), occupation (7 items), loss of autonomy (7 items) and coping with anxiety (9 items) [15]. There is no evidence for a cut-off.

**Fear of Progression Questionnaire – Short Form (FoP-Q-SF)**
The FoP-Q-SF consists of 12 items with four of the five subscales (excluding coping) from the original FoP-Q scale. The items are scored on a five-point Likert scale, ranging from 1 ("never") to 5 ("very often"). The resulting sum score of the FoP-Q-SF ranges from 12 to 60. A cut-off of 34 or over 34 for dysfunctional FoP has been derived in adult cancer patients [16].

**Fear of Progression Questionnaire Short Form Parent (FoP-Q-SF/PR)**
The FoP-Q-SF/PR represents four of the five subscales of the long form (affective reactions, partnership/family, occupation, and loss of autonomy). The items are scored on a five-point Likert scale, ranging from 1 ("never") to 5 ("very often"). The resulting sum score of the FoP-Q-SF/PR ranges from 12 to 60. A cut-off of ≥34 for dysfunctional FoP has been derived in adult cancer patients [17].

## RECOMMENDATIONS

The following recommendations are based on the expertise and opinion of the Working Group, informed by the available research evidence. There is a flow chart following the recommendations that summarizes the steps for screening, assessing, and managing FCR.

### Recommendations for Screening Fear of Cancer Recurrence

**Recommendation 1.1 - Patients**
It is recommended that a single-item screening tool be given to patients routinely to scan for FCR. Specifically recommended is the FCR-1 with a cut-off score of 45 if using the 0 to 100 scale or a cut-off score of over 4.5 or more if using the 0 to 10 scale, both cut-offs signaling the potential presence of at least moderate FCR thus indicating a further need for FCR assessment.

**Edmonton Symptom Assessment System Fear of Cancer Recurrence Question:**

On a scale from 0-100, what is your subjective level of fear of cancer recurrence at this time?

**Please circle the number that best describes how you feel now:**
(FCR = fear that your cancer might come back or get worse)

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| No FCR | 0 | 10 | 20 | 30 | 40 | 50 | 60 | 70 | 80 | 90 | 100 | Worst possible FCR |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| No FCR | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible FCR |

**Qualifying Statements for Recommendation 1.1**

- This item is similar in wording to the Edmonton Symptom Assessment System (ESAS) questions and is designed to be embedded into the ESAS, which is routinely used at every visit to cancer centres in Ontario. Being screened at each visit would allow for fluctuations in individual variability [18].
- Completing a screening tool may make it easier for patients to have a conversation regarding FCR that they may otherwise be reluctant to have with their oncologist.
- Evidence has shown that screening for FCR had similar consultation times to regular follow-up appointments.
- The FCR-1 has been validated to be responsive to FCR changes over time. Still, additional studies need to be conducted to establish the optimum cut-off score to use. A similarly worded one-item screening tool (FCR-1r) using a scale of 0-10, has found a cut-off score of over 5 to signal the potential presence of FCR [87].
- Although overall FCR levels tend to be stable over time [19], clinicians should be aware that a visit to the cancer centre, and waiting for test results or documents are triggers that will elevate FCR in most patients, including those with low FCR, and therefore elevated scores on the screener need to be followed by a more in-depth questionnaire or clinical interview.

**Recommendation 1.2 - Care partners**
Care partners would benefit from FCR screening in the opinion of the Working Group and the existing literature.

**Qualifying Statements for Recommendation 1.2**
- More research needs to be conducted to create validated measures specific to care partners.

## Recommendations for Assessment of Fear of Cancer Recurrence

**Recommendation 2.1 - Patients**
It is recommended for assessment that the FCRI-SF, FoP-Q-SF, FCR7, or CWS be used to measure FCR in patients.

**Qualifying Statement**
- All of the above measures will assess for the presence or absence of clinical levels of FCR. Cancer centres that are interested in distinguishing between low, moderate or high levels of FCR should use the FCRI-SF.

**Recommendation 2.2 - Care Partners**
It is recommended that the FoP-Q-SF/PR and the FCRI-Caregiver be used to measure FCR in care-partners, until care-partner-specific measures are developed.

## Recommendations for Interventions for Fear of Cancer Recurrence

**Recommendation 3.1**
**Low-Intensity Interventions for Minimal or Low FCR**
3.1.1 An online (completely self-led or self-led with assistance when needed) FCR-specific intervention (e.g., CBT) should be offered for people with low-to-moderate FCR.
3.1.2 Low-intensity interventions that are not specific to FCR, such as exercise programs, could be offered to people with low FCR.

**Qualifying Statements for Recommendation 3.1**
- There is insufficient evidence to determine the optimum timing for FCR interventions (i.e., during or post treatment).
- Providing a general medical informational booklet on survivorship care to people with low-to-moderate FCR is not sufficient.
- Guidance and/or coaching in conjunction with self-led interventions can lead to better attendance and adherence to a treatment or follow-up protocol as well as increased participant satisfaction.
- Communication therapy with patients (i.e., teaching patients how to ask medical questions to the oncology team) does not appear to influence patient FCR. However, teaching oncologists how to introduce, discuss, validate, and respond to FCR may have a beneficial effect on the patients' concerns around FCR.
- In the absence of more studies, patients could be offered exercise programs that meet the suggested Canadian 24-Hour Movement Guidelines.
- Patients should be asked about their preferences for intervention types and delivery options.

**Recommendation 3.2**
**Intermediate-Intensity Interventions for Moderate FCR**

3.2.1 Those with moderate FCR could be offered a moderately intensive, general intervention, preferably in group format. Specifically, participation in either a psychoeducational program, relaxation training and/or professionally led support group is suggested for people with moderate FCR, although there is limited evidence on effectiveness at this time.

**Qualifying Statements for Recommendation 3.2**

- There is insufficient evidence to determine the optimum timing for these interventions (i.e., during or post treatment).
- Psychoeducational programs and support groups could be delivered by a range of mental health professionals with experience in oncology care.
- Psychoeducational programs should offer information regarding cancer management, survivorship, and symptoms surveillance, and could include information on FCR.
- Patients should be asked about their preferences for intervention types and delivery options.

**Recommendation 3.3**
**High-Intensity Interventions for high FCR**

3.3.1 Participation in an individual or group FCR-specific CBT or mind-body interventions (MBI) program, led by mental health professionals with experience in oncology care is indicated for people with high FCR (i.e., FCR occurs regularly outside of predictable triggers such as annual visits to the cancer centre or waiting for test results, lasts a minimum of three months, and is associated with impaired functioning or significant psychological distress).

3.3.2 A face-to-face or a blended format intervention (combination of face-to-face and video conferencing), with an average of six to seven sessions, is recommended.

**Qualifying Statements for Recommendation 3.3**

- Due to the absence of comparative studies, we cannot recommend one approach versus another; however, the evidence was strongest for various CBT and mindfulness-based approaches. Studies used several intervention strategies so we cannot comment on the usefulness of specific strategies.
- Studies have yet to report on the efficacy of interventions that are delivered entirely by video conferencing.
- No difference in FCR has been observed between sessions held during treatment compared with post treatment.
- There is insufficient evidence to show a benefit of high-intensity FCR interventions when delivered by a non-mental health specialist.
- Patients should be asked about their preferences for intervention types and delivery options.

**Recommendation 3.4**
**Caregiver Interventions**

3.4.1 There is insufficient evidence at this time to make recommendations about interventions for care partners. It is the opinion of the Working Group that care partners would benefit from existing interventions adapted to care partners.

3.4.2 More research needs to be done to develop and evaluate interventions for care partners with FCR given the evidence of almost 50% of care partners having moderate to high FCR.

**Qualifying Statements for Recommendation 3.4**

- Preliminary evidence has found that care partners have different experiences with FCR than patients and that proper adaptations of patient interventions for use with care partners can be satisfactory and acceptable to care partners.
- Care partners should be asked about their preferences for intervention types and delivery options.

## IMPLEMENTATION CONSIDERATIONS

The identification and treatment of FCR recommendations are very important to all patients and care partners. Patients have identified FCR as one of the top unmet needs [10] and the Working Group believe that these recommendations are acceptable and flexible and allow for conversations with the care provider so that the patients' treatment preferences will be known and met.

Asking the patient FCR screening questions at each follow-up visit would be easy to implement and has been shown to not add additional time to appointments [22]. (See Resource section for brief FCR intervention for oncologists [CIFeR]). Asking all patients at each visit will allow for the opportunity for more equitable identification and treatment of FCR. Screening care partners, while beneficial, would require more implementation efforts. Proper infrastructure for documenting personal health information of care partners (i.e., if a care partner is already in the care of a psychosocial oncology clinician and has their own chart) is necessary to be able to collect screening information for care partners. Additional resources may be needed to address the needs of care partners at some centres.

Adding a FCR screening question to the Ontario web-based ESAS platform will take some effort but may soon be achievable. Adding clearer pathways to interventions will allow providers to refer patients and care givers to the appropriate resources.

Some moderate-intensity interventions might already be available at some cancer centres, e.g., professionally led support group or psychoeducational group interventions such as survivorship classes.

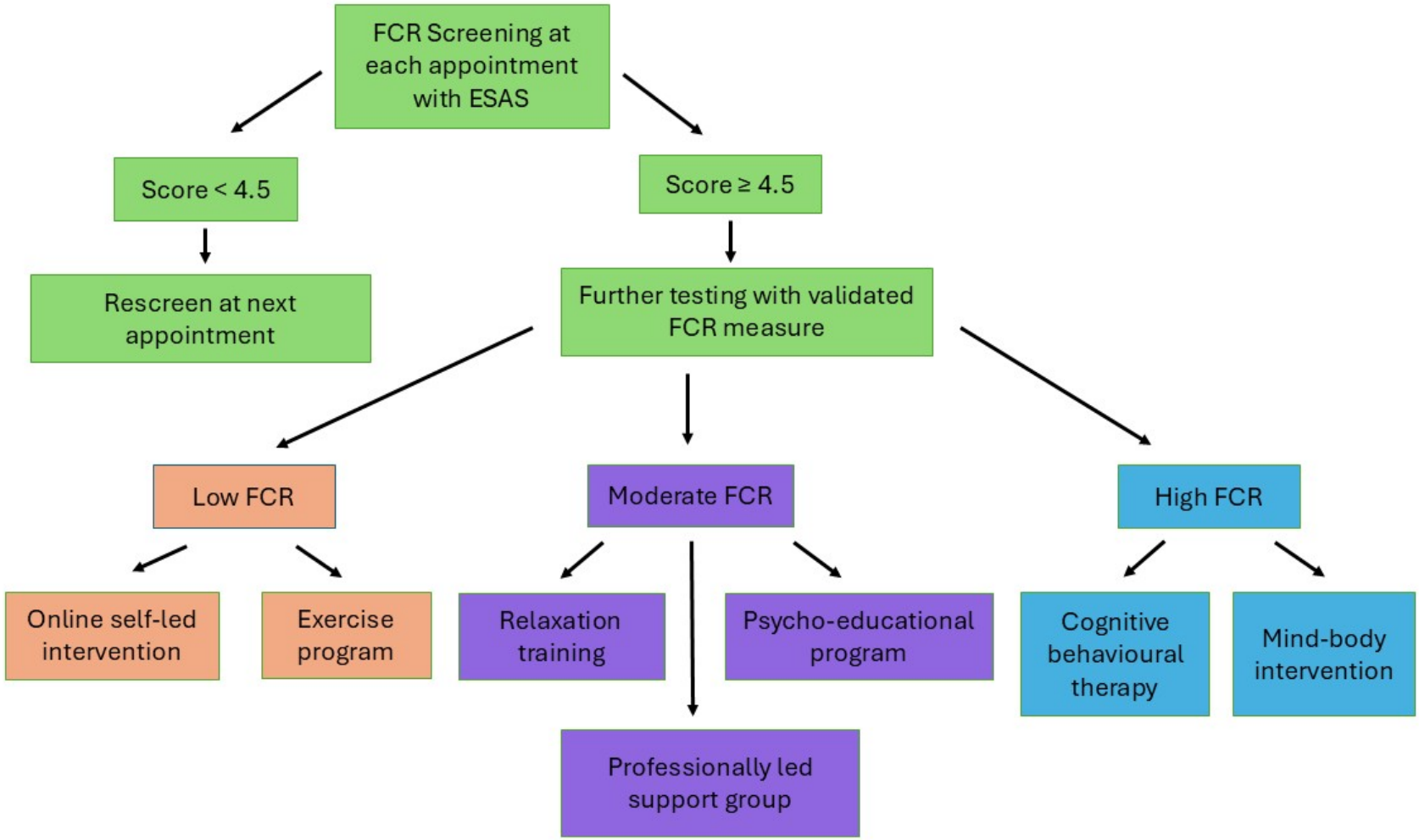
There are a growing number of evidence-based high-intensity FCR interventions that have been empirically established, including some with training material available for clinicians to readily implement (see Resources section). Promising online FCR interventions have already been tested in different countries and could be implemented in Ontario.

Knowledge of FCR, assessments and resources for all levels of FCR could come through education for health care specialists and patients. Education could come via online courses, webinars, and patient groups (see Resources section).

## RELATED GUIDELINES

- Cancer Care Ontario Person-Centred Care Guideline: Endorsement and Adaptation of CG 138: Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. 2015 May 2015. Person-Centred Care Program
- Li M, Kennedy EB, Byrne N, Gerin-Lajoie C, Green E, Katz MR, et al. The management of depression in patients with cancer. Toronto (ON): Cancer Care Ontario; 2015 May 11. Program in Evidence-based Care Guideline No.: 19-4.

## FCR Screening, Assessment, and Intervention Flow Chart



## Resources for Patients\Care Partners and Health Professionals

### Patient/Care Partners

**Canadian Cancer Society**

- Fear of cancer recurrence during COVID-19
- https://cancer.ca/en/cancer-information/resources/webinars/2020/fear-of-cancer-recurrence-during-covid-19

- Worrying that cancer will come back
- https://cancer.ca/en/living-with-cancer/life-after-treatment/worrying-that-cancer-will-come-back

- Community Services Locator
- https://cancer.ca/en/living-with-cancer/how-we-can-help/community-services-locator

- Talk to an Information Specialist
- https://cancer.ca/en/living-with-cancer/how-we-can-help/talk-to-an-information-specialist

- Spirituality
- https://cancer.ca/en/living-with-cancer/coping-with-changes/spirituality

**Canadian Association of Psychosocial Oncology**

- Coping with Cancer
- https://www.copingwithcancer.ca/

**Canadian Cancer Survivor Network**

- Educational activities for cancer survivors, patients and care partner
- https://survivornet.ca/news/did-you-miss-our-webinar-fear-of-cancer-recurrence-5-ways-to-lessen-your-anxiety/

**OH (CCO) Managing Symptoms**

- Talk to your oncologist and nurses to find close places for help near you
- OH (CCO) Recommended resources for anxiety: https://www.cancercareontario.ca/en/symptom-management/3981

**Wellspring Cancer Support**

- Resources, programs, brochures and community links for emotional, physical and practical challenges for cancer patients and care partners
- https://wellspring.ca/online-programs/programs/all-programs/

**Mindfulness Based Cognitive Therapy for Cancer**

- Mindfulness based courses available for people with cancer. Includes links to courses and on-line mindfulness recordings and practices.
- https://www.inspirationsolutions.com/mindfulness.html

**Alberta Health Services**

- After Treatment: Information and Resources to Help You Set Priorities and Take Action
- https://www.albertahealthservices.ca/assets/info/cca/if-cca-after-treatment-for-cancer.pdf

**Peter MacCallum Cancer Centre**

- Coping with the fear of cancer coming back (fear of cancer recurrence)
- https://www.petermac.org/sites/default/files/media-uploads/ACSC_Factsheet_FearOfCancerComingBack.pdf

**Fred Hutchinson Cancer Research Centre**

- How to deal with FCR – patient treatment and support
- https://www.fredhutch.org/content/dam/www/research/patient-treatment-and-support/survivorship-program/survivorship-health-links/Fear%20of%20Recurrence.pdf

**Maggie's – Everyone's home of cancer care**

- Fear of cancer returning
- https://www.maggies.org/cancer-support/managing-emotions/fear-cancer-returning/

**Dana Farber Cancer Institute**

- Your emotions after treatment – Dana Farber Cancer Institute
- https://www.dana-farber.org/for-patients-and-families/for-survivors/caring-for-yourself-after-cancer/your-emotions-after-treatment/

**Mayo Clinic: Adult Health**

- Cancer survivors: managing your emotion after cancer treatment
- https://www.mayoclinic.org/diseases-conditions/cancer/in-depth/cancer-survivor/art-20047129

- Connect with other patients who have fear of cancer recurrence
- https://newsnetwork.mayoclinic.org/discussion/connect-with-other-patients-who-have-fear-of-cancer-recurrence/

- Consumer Health: Life after cancer
- https://newsnetwork.mayoclinic.org/discussion/consumer-health-life-after-cancer-2/

**Cancer Council Victoria**

- Life after treatment – fear of the cancer coming back
- https://www.cancervic.org.au/living-with-cancer/life-after-treatment/fear-of-the-cancer-coming-back

**American Cancer Society**

- Life after Cancer
- https://www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/life-after-cancer.html

- Preventing cancer, signs and symptoms, and coping
- https://www.cancer.org/cancer/survivorship/long-term-health-concerns/recurrence/can-i-do-anything-to-prevent-cancer-recurrence.html#:~:text=Eating%20right%2C%20exercising%2C%20and%20seeing,be%20as%20healthy%20as%20possible.

**Fox Chase Cancer Center**
- 'Is My Cancer Coming Back?' How to Cope with the Fear of a Recurrence
- https://www.foxchase.org/blog/2018-03-23-how-to-cope-with-the-fear-of-a-cancer-recurrence

**Cancer*Care***
- Coping with fear of cancer recurrence
- https://www.cancercare.org/publications/253-coping_with_the_fear_of_recurrence#

**Breast Cancer Network Australia**
- FCR – Fact sheet
- https://www.bcna.org.au/resource-hub/articles/fear-of-breast-cancer-recurrence/

**Cancer.Net: Coping with Fear of Recurrence**
- Coping with fear of cancer recurrence, knowing when to seek help and prompting questions to ask healthcare team.
- https://www.cancer.net/survivorship/life-after-cancer/coping-with-fear-recurrence

**Harvard Health Blog**
- Fear of cancer recurrence: Mind-body tools offer hope
- https://www.health.harvard.edu/blog/fear-of-cancer-recurrence-mind-body-tools-offer-hope-2019030716152

- Mindfulness apps: How well do they work?
- https://www.health.harvard.edu/blog/mindfulness-apps-how-well-do-they-work-2018110615306

**Cleveland Clinic**
- Coping With Fear of Cancer Recurrence
- https://health.clevelandclinic.org/fear-of-cancer-recurrence/

**Health Professionals**

**CIFeR**
- Clinician Intervention Fear of Cancer Recurrence: CIFeR is a short eight-minute doctor-led intervention to help you to address fear of cancer recurrence when seeing your breast cancer patients in clinic.
- https://cifer.thinkific.com/courses/2021

**FORT**

- Fear of Recurrence Therapy resources and manuals
- https://drive.google.com/drive/folders/1cn_oK0loAhJzp-sTP0CiFg2FUJXiRKVv?usp=share_link

**CANO/ACIO**

- Adult Cancer Survivorship Manual — A Self Learning Resource for Nurses
- https://www.cano-acio.ca/page/survivorship_manual

**Cancer Network**

- Fear of Cancer Recurrence: A Practical Guide for Clinicians
- https://www.cancernetwork.com/view/fear-cancer-recurrence-practical-guide-clinicians

**User Manual**

- Treating Fear of Cancer Recurrence with Group Cognitive-Behavioural Therapy: A Step-by-Step Guide
- https://link.springer.com/book/10.1007/978-3-031-07187-4

**Alberta Health Services**

- Fear of Cancer Recurrence (FCR) Pathway
- https://www.albertahealthservices.ca/assets/info/hp/cancer/if-hp-cancer-primary-care-fcr-pathway.pdf

**Cancer Nurses Society of Australia**

- **Online Webinar**
- https://www.youtube.com/watch?v=1Ud5qIKmiMI

**Psycho-oncology Co-operative Research Group**

- Fear of Cancer Recurrence: Resource Hub
- https://www.pocog.org.au/content.aspx?pagetype=public&page=fcrhub&version=1&search=*

**Articles**

- Primer for primary care providers: Assessing and managing patient fear of cancer recurrence
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7491663/

# Fear of Cancer Recurrence Guideline

## Section 2: Guideline – Recommendations and Key Evidence

**GUIDELINE OBJECTIVES**

To make recommendations based on evidence-based strategies and/or interventions to screen, assess, and manage fear of cancer recurrence (FCR) in adults living with cancer and their care partners/family members to improve patient outcomes.

**TARGET POPULATION**

Adults living with cancer and care partners/family members (≥18 years)

- Includes adult survivors of childhood cancer
- Includes people currently in treatment and post treatment for cancer
- Care partners include family members and other support people (i.e., friends) who provide unpaid care to cancer survivors

**INTENDED USERS**

The intended users of this guideline include oncology professionals, primary care providers, healthcare professionals working with cancer patients, psychosocial oncology professionals, and decision and policy makers in hospitals, clinics, and health systems in the province of Ontario.

**PREAMBLE**

FCR presents on a spectrum of severity [1]. The definition of FCR is the fear, worry, or concern relating to the possibility that cancer will come back or progress [1]. The definition of clinical FCR, based on a Delphi study of FCR experts, stipulates that clinical FCR occurs regularly outside of predictable triggers such as annual visits to the cancer centre or waiting for test results, lasts a minimum of three months, and is accompanied by distress or impairment [2]. Moderate FCR is described as subclinical presentation of FCR determined by the presence of some but not all the symptoms of clinical FCR [3,4]. Low FCR is indicated by a patient having occasional or transient thoughts or worry about FCR accompanied by minimal distress or impairment [1].

There is strong evidence for the efficacy of high-intensity intervention for people with high levels of FCR. Specifically, interventions that directly target FCR have shown better results at reducing FCR than general broad band interventions aimed at improving distress and coping [5,6]. Modest evidence is available for those with moderate FCR, and weak evidence concerns people with low FCR. A matched care approach matches the intensity of intervention to the severity of FCR. A person with high or clinical FCR would be offered a high-intensity intervention and a person with low FCR would be offered a lower intensity intervention. Additional studies are necessary to support specific interventions for patients with moderate or low FCR.

Attention to preferences for intervention types and delivery options must also be considered when recommending available interventions to people with FCR.

The glossary that follows this preamble provides definitions for terms used throughout the guideline.

The supplemental information section that follows the recommendations provides links to webpages with tools to help with communication, interventions and programs that may be used with patients and care partners with FCR.

# Glossary

## Common Terms

### *Care partner*

An individual who provides unpaid essential and on-going personal, social, psychological and/or physical support and care, as deemed important to the person requiring care. This can include support in decision-making, care coordination, care delivery and continuity of care. The term implies a two-way relationship with a shared purpose, and it includes people who are identified as family, chosen family, an informal caregiver, or a friend.

### *Clinical or high FCR*

Clinically significant FCR that occurs regularly outside of predictable triggers such as annual visits to the cancer centre or waiting for test results, lasts a minimum of three months, and is accompanied by distress or impairment [2].

### *Subclinical or moderate FCR*

Described as subclinical presentation of FCR determined by the presence of some but not all of the symptoms of clinical FCR.

### *Minimal or low FCR*

Indicated by a patient having occasional or transient thoughts or worry about FCR accompanied by minimal distress or impairment.

### *FCR screening*

Questionnaires to identify FCR in patients or care partners to indicate a need for further assessment. Screening questionnaires are usually brief and may consist of only one question.

### *FCR assessment*

Questionnaires and/or clinical interview to quantify and evaluate the severity of FCR in patients or care partners.

### *FCR Intervention*

Programs or processes to reduce the severity of FCR in patients or care partners.

## Interventions and Organization

### *Matched Care Approach for Intervention Organization*

The matched or stratified approach is a way to deliver care and intervention to patients and care partners. This approach tailors the FCR interventions to match with the severity of FCR [7]. Those deemed to have mild levels of FCR are referred to minimal interventions, those with moderate levels of FCR are referred to intermediate intensity interventions and those with high FCR are referred to high intensity interventions.

### *Cognitive Behavioural Therapy*

Cognitive behavioural therapy (CBT) interventions, including mindfulness-based stress reduction, acceptance and mindfulness, commitment therapy and compassion-based interventions [8]. Traditional CBTs focused on the contents of thoughts and aimed to identify and modify people's negative thoughts or biases to reduce dysfunctional emotions and promote psychological adjustment, whereas contemporary CBTs focused on mental processes and aimed to modify how people relate to their inner experiences [9].

### *Mind-body interventions*

Mind-body interventions include meditation, relaxation techniques, the use of the creative arts, mindfulness-based stress reduction (MBSR) and may also include elements of CBT [10].

### *Psychoeducational Program*

Psychoeducation refers to the process of providing education and information to those seeking or receiving mental health services, experiencing psychological symptoms or seeking medical care services and may combine the elements of CBT, group therapy, and education.

### *Non-mental Health Specialist*

Interventions delivered by non-mental health specialists including doctors, nurses, and radiation therapy technologists for FCR within the context of routine medical oncology follow-up clinics [11].

### *Telecoaching*

Telecoaching is the use of motivational interviews delivered over the telephone.

## Screening and Assessment Tools Descriptions

**Cancer Worry Scale (CWS-6)**

The CWS is a six-item self-report scale used for detecting high levels of FCR. Items are rated on a four-point Likert scale. The screening cut-off score for high FCR is equal to or over 10 and for severe FCR, a score of equal to or over 12 [84].

**Fear of Cancer Recurrence Inventory (FCRI)**

The FCRI is a 42-item self-report scale for assessing the FCR. Higher scores indicating greater fear of recurrence. The FCRI consists of seven subscales: Triggers, Severity, Psychological Distress, Coping Strategies, Functioning Impairments, Insight, and Reassurance. There is no evidence for a cut-off score for the FCRI [12].

**Fear of Cancer Recurrence Inventory Short Form (FCRI-SF)**

The FCRI-SF is a short form of the FCRI that is the nine items of the severity subscale. A cut-off score of 13 or above indicates the possibility of clinical level FCR [13], a score of 16 or above indicates the likely presence of clinical level FCR and a score of 22 or above indicates a clinical severity of FCR that needs specialized intervention [4].

**Fear of Cancer Recurrence - 7 Item Version (FCR7)**
The FCR7 is based upon a set of seven questions that have been selected from extant measures within the literature to assess directly FCR [85]. There is no evidence for a cut-off score for the FCR7.

**Fear of Cancer Recurrence - one item measure (FCR-1)**
The one-item FCR-1 was modeled after the Edmonton Symptom Assessment System (ESAS) and measures the subjective level of FCR on a scale from 0 to 100 with a cut off score of over 45 indicating clinical FCR. There is an option of using a scale of 0-10 with a cut off score of over 4.5 to indicate clinical FCR [86].

**Fear of Cancer Recurrence Inventory-Caregiver (FCRI-Caregiver)**
The 42-item FCRI-Caregiver was revised from the FCRI (patient version) and examined seven general areas: triggers, severity, psychological distress, functional impairment, insight, reassurance, and coping strategy. Each question was rated on a Likert scale ranging from 0 (not at all or never) to 4 (a great deal or all the time), with a higher score indicating a greater FCR [14].

**Fear of Progression Questionnaire (FoP-Q)**
The FoP-Q is a 43-item questionnaire to measure the fear of progression in chronically ill patients. The scale comprised five factors: affective reactions (13 items), partnership/family (7 items), occupation (7 items), loss of autonomy (7 items) and coping with anxiety (9 items) [15]. There is no evidence for a cut-off.

**Fear of Progression Questionnaire – Short Form (FoP-Q-SF)**
The FoP-Q-SF consists of 12 items with four of the five subscales (excluding coping) from the original FoP-Q scale. The items are scored on a five-point Likert scale, ranging from 1 ("never") to 5 ("very often"). The resulting sum score of the FoP-Q-SF ranges from 12 to 60. A cut-off of 34 or over 34 for dysfunctional FoP has been derived in adult cancer patients [16].

**Fear of Progression Questionnaire Short Form Parent (FoP-Q-SF/PR)**
The FoP-Q-SF/PR represents four of the five subscales of the long form (affective reactions, partnership/family, occupation, and loss of autonomy). The items are scored on a five-point Likert scale, ranging from 1 ("never") to 5 ("very often"). The resulting sum score of the FoP-Q-SF/PR ranges from 12 to 60. A cut-off of ≥34 for dysfunctional FoP has been derived in adult cancer patients [17].

**RECOMMENDATIONS, KEY EVIDENCE, AND JUSTIFICATION**
The following recommendations are based on the expertise and opinion of the Working Group, informed by the available research evidence. There is a flow chart following the recommendations that summarizes the steps for screening, assessing, and managing FCR.

**Recommendations for Screening Fear of Cancer Recurrence**

**Recommendation 1.1 - Patients**
It is recommended that a single-item screening tool be given to patients routinely to scan for FCR. Specifically recommended is the FCR-1 with a cut-off score of 45 if using the 0 to 100 scale or a cut-off score of over 4.5 or more if using the 0 to 10 scale, both cut-offs signaling the potential presence of at least moderate FCR thus indicating a further need for FCR assessment.

**Edmonton Symptom Assessment System Fear of Cancer Recurrence Question:**

On a scale from 0-100, what is your subjective level of fear of cancer recurrence at this time?

**Please circle the number that best describes how you feel now:**
(FCR = fear that your cancer might come back or get worse)

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| No FCR | 0 | 10 | 20 | 30 | 40 | 50 | 60 | 70 | 80 | 90 | 100 | Worst possible FCR |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| No FCR | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible FCR |

**Qualifying Statements for Recommendation 1.1**
- This item is similar in wording to the Edmonton Symptom Assessment System (ESAS) questions and is designed to be embedded into the ESAS, which is routinely used at every visit to cancer centres in Ontario. Being screened at each visit would allow for fluctuations in individual variability [18].
- Completing a screening tool may make it easier for patients to have a conversation regarding FCR that they may otherwise be reluctant to have with their oncologist.
- Evidence has shown that screening for FCR had similar consultation times to regular follow-up appointments.
- The FCR-1 has been validated to be responsive to FCR changes over time. Still, additional studies need to be conducted to establish the optimum cut-off score to use. A similarly worded one-item screening tool (FCR-1r) using a scale of 0-10, has found a cut-off score of over 5 to signal the potential presence of FCR [87].
- Although overall FCR levels tend to be stable over time [19], clinicians should be aware that a visit to the cancer centre, and waiting for test results or documents are triggers that will elevate FCR in most patients, including those with low FCR, and therefore elevated scores on the screener need to be followed by a more in-depth questionnaire or clinical interview.

**Key Evidence and Justification for Recommendation 1.1**
Three studies show that a single-question assessment has very good concurrent and convergent validity with validated FCR scales [18,20,21]. A cut-off score of five or more out of 10 resulted in 95% sensitivity and 77% specificity for high FCR [18]. A score from 0-4 is considered low. The addition of FCR screening did not add extra time to appointments and allowed patients to talk about this issue [22], which allows for basic interventions by the healthcare team such as normalization of the concerns and provision of accurate medical information (e.g., on risk of recurrence, signs of recurrence etc.) [10,22]. The one-question screening tool can be the first step of a matched care approach to identify who should be further assessed on the frequency, severity, and impact of FCR on their functioning and psychological distress.

**Recommendation 1.2 - Care partners**
Care partners would benefit from FCR screening in the opinion of the Working Group and the existing literature.

**Qualifying Statements for Recommendation 1.2**
- More research needs to be conducted to create validated measures specific to care partners.

**Key Evidence for Recommendation 1.2**
Three systematic reviews examined FCR among care partners [23-25]. Two systematic reviews found that FCR was prevalent, persistent, and burdensome with an average prevalence of moderate-to-high FCR of 48% (range, 18-78%), which is equivalent to those in patients [24,25]. FCR scales intended for patients and adapted for care partners produced variable results. Insufficient evidence exists to make exact recommendations for FCR screening in care partners, but the Working Group believed that screening with adapted tools may be beneficial. Specific instruments for care partners need to be created.

**<u>Recommendations for Assessment of Fear of Cancer Recurrence</u>**

**Recommendation 2.1 - Patients**
It is recommended for assessment that the FCRI-SF, FoP-Q-SF, FCR7, or CWS be used to measure FCR in patients.

**Qualifying Statement**
- All of the above measures will assess for the presence or absence of clinical levels of FCR. Cancer centres that are interested in distinguishing between low, moderate or high levels of FCR should use the FCRI-SF.

**Key Evidence for Recommendation 2.1**
One systematic review evaluated 34 patient reported outcome measures and evaluated them using the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) criteria, which considers measurement properties of outcome instruments. They concluded that the FCR-1, FCRI-SF, FoP-Q-SF, FCR7, or CWS were effective choices for use in clinical screening and longitudinal assessment [88].

**Recommendation 2.2 - Care Partners**
It is recommended that the FoP-Q-SF/PR and the FCRI-Caregiver be used to measure FCR in care-partners, until care-partner-specific measures are developed.

**Key Evidence for Recommendation 2.2**
One systematic review found 12 different instruments that were developed for patients were used to measure care partner FCR and evaluated them using the COSMIN criteria. They found the FoP-Q-SF/PR met 67% of the COSMIN criteria and the FCRI-Caregiver met 47% [25].

**Recommendations for Interventions for Fear of Cancer Recurrence**

**Recommendation 3.1**
**Low-Intensity Interventions for Minimal or Low FCR**
3.1.3 An online (completely self-led or self-led with assistance when needed) FCR-specific intervention (e.g., CBT) should be offered for people with low-to-moderate FCR.
3.1.4 Low-intensity interventions that are not specific to FCR, such as exercise programs, could be offered to people with low FCR.

**Qualifying Statements for Recommendation 3.1**
- There is insufficient evidence to determine the optimum timing for FCR interventions (i.e., during or post treatment).
- Providing a general medical informational booklet on survivorship care to people with low-to-moderate FCR is not sufficient.
- Guidance and/or coaching in conjunction with self-led interventions can lead to better attendance and adherence to a treatment or follow-up protocol as well as increased participant satisfaction.
- Communication therapy with patients (i.e., teaching patients how to ask medical questions to the oncology team) does not appear to influence patient FCR. However, teaching oncologists how to introduce, discuss, validate, and respond to FCR may have a beneficial effect on the patients' concerns around FCR.
- In the absence of more studies, patients could be offered exercise programs that meet the suggested Canadian 24-Hour Movement Guidelines.
- Patients should be asked about their preferences for intervention types and delivery options.

**Key Evidence and Justification for Recommendation 3.1**
Six studies and one systematic review found that online self-guided CBT, online with physician-guided CBT, and online with technician-guided CBT all had short-term benefits [9,26-31]. One study found that Telecoaching (telephone-based motivational interviews) helped to increase adherence to an online program and increased satisfaction with the program [30]. A booklet-only intervention did not decrease FCR significantly [32]. Preliminary evidence from one randomized controlled trial (RCT) showed that exercise may be beneficial in people with low FCR such as high intensity training, but additional studies are needed [33]. One systematic review found that there was interest from mental health specialists as well as physicians and oncologists in FCR training [11]. There are new interventions being tested such as Clinician Intervention Fear of Cancer Recurrence (CIFeR), training oncologists to ask about and respond to FCR that could benefit patients [34].

**Recommendation 3.2**
**Intermediate-Intensity Interventions for Moderate FCR**
3.2.2 Those with moderate FCR could be offered a moderately intensive, general intervention, preferably in group format. Specifically, participation in either a psychoeducational program, relaxation training and/or professionally led support group is suggested for

people with moderate FCR, although there is limited evidence on effectiveness at this time.

**Qualifying Statements for Recommendation 3.2**

- There is insufficient evidence to determine the optimum timing for these interventions (i.e., during or post treatment).
- Psychoeducational programs and support groups could be delivered by a range of mental health professionals with experience in oncology care.
- Psychoeducational programs should offer information regarding cancer management, survivorship, and symptoms surveillance, and could include information on FCR.
- Patients should be asked about their preferences for intervention types and delivery options.

**Key Evidence and Justification for Recommendation 3.2**

Those with moderate FCR benefitted equally from the relaxation training control intervention as much as they did the high intensity FCR-specific interventions in RCTs [5,35]. Three studies found that psychoeducation may be beneficial for those with moderate FCR but may not be for those with high FCR [29,32,36]. Two systematic reviews found that interventions using group formats had greater decreases than studies using individual sessions [37,38]. Group formats are more scalable and cost-effective than individual sessions.

**Recommendation 3.3**

**High-Intensity Interventions for high FCR**

3.3.3 Participation in an individual or group FCR-specific CBT or mind-body interventions (MBI) program, led by mental health professionals with experience in oncology care is indicated for people with high FCR (i.e., FCR occurs regularly outside of predictable triggers such as annual visits to the cancer centre or waiting for test results, lasts a minimum of three months, and is associated with impaired functioning or significant psychological distress).

3.3.4 A face-to-face or a blended format intervention (combination of face-to-face and video conferencing), with an average of six to seven sessions, is recommended.

**Qualifying Statements for Recommendation 3.3**

- Due to the absence of comparative studies, we cannot recommend one approach versus another; however, the evidence was strongest for various CBT and mindfulness-based approaches. Studies used several intervention strategies so we cannot comment on the usefulness of specific strategies.
- Studies have yet to report on the efficacy of interventions that are delivered entirely by video conferencing.
- No difference in FCR has been observed between sessions held during treatment compared with post treatment.
- There is insufficient evidence to show a benefit of high-intensity FCR interventions when delivered by a non-mental health specialist.
- Patients should be asked about their preferences for intervention types and delivery options.

**Key Evidence and Justification for Recommendation 3.3**

Five systematic reviews [8-10,37,38] and 10 RCTs [6,27,28,30,35,39-43] examined high-intensity interventions to reduce levels of FCR in patients. Small to moderate effects were found immediately after the sessions and small effects at follow-up were noted for CBT and

MBI. There is some evidence that group interventions in people with high levels of FCR may be more efficacious than individual interventions [10]. However, individual sessions or a combination of individual and group sessions were also found to reduce FCR [8,9,27,36,39-41,43]. Systematic reviews of studies found CBT or MBI or a combination of the two to be efficacious [8-10,37,38]. For interventions delivered by non-mental health specialists, there is limited information available from two studies [29,36]. In both studies the interventions were variable due to patients attending few sessions [29] and there being no FCR measure for the baseline scores reported [36]. There was not enough evidence to make a recommendation at this time; however, there are some pilot studies ongoing.

**Recommendation 3.4**
**Caregiver Interventions**

3.4.3 There is insufficient evidence at this time to make recommendations about interventions for care partners. It is the opinion of the Working Group that care partners would benefit from existing interventions adapted to care partners.

3.4.4 More research needs to be done to develop and evaluate interventions for care partners with FCR given the evidence of almost 50% of care partners having moderate to high FCR.

**Qualifying Statements for Recommendation 3.4**

- Preliminary evidence has found that care partners have different experiences with FCR than patients and that proper adaptations of patient interventions for use with care partners can be satisfactory and acceptable to care partners.
- Care partners should be asked about their preferences for intervention types and delivery options.

**Key Evidence and Justification for Recommendation 3.4**

One systematic review studying the effects of FCR on care partners found only three studies evaluating FCR reducing interventions for care partners, one of which was an RCT [24]. However, while the intervention decreased FCR in the patient, it did not decrease FCR in the caregiver. Although it is clear that an average of 48% (range, 18-78%) of care partners experience levels of moderate-to-high FCR [20,21], there is insufficient evidence to support recommendations about interventions specifically for them. Preliminary evidence suggests that existing interventions can be adapted to care partners, since their experiences with FCR are similar to patients' experiences, but further research is needed [44,45].

**IMPLEMENTATION CONSIDERATIONS**

The identification and treatment of FCR recommendations are very important to all patients and care partners. Patients have identified FCR as one of the top unmet needs [10] and the Working Group believe that these recommendations are acceptable and flexible and allow for conversations with the care provider so that the patients' treatment preferences will be known and met.

Asking the patient FCR screening questions at each follow-up visit would be easy to implement and has been shown to not add additional time to appointments [22]. (See Resource section for brief FCR intervention for oncologists [CIFeR]). Asking all patients at each visit will allow for the opportunity for more equitable identification and treatment of FCR. Screening care partners, while beneficial, would require more implementation efforts. Proper infrastructure for documenting personal health information of care partners (i.e., if a care partner is already in the care of a psychosocial oncology clinician and has their own chart) is

necessary to be able to collect screening information for care partners. Additional resources may be needed to address the needs of care partners at some centres.

Adding a FCR screening question to the Ontario web-based ESAS platform will take some effort but may soon be achievable. Adding clearer pathways to interventions will allow providers to refer patients and care givers to the appropriate resources.

Some moderate-intensity interventions might already be available at some cancer centres, e.g., professionally led support group or psychoeducational group interventions such as survivorship classes.

There are a growing number of evidence-based high-intensity FCR interventions that have been empirically established, including some with training material available for clinicians to readily implement (see Resources section). Promising online FCR interventions have already been tested in different countries and could be implemented in Ontario.

Knowledge of FCR, assessments and resources for all levels of FCR could come through education for health care specialists and patients. Education could come via online courses, webinars, and patient groups (see Resources section).

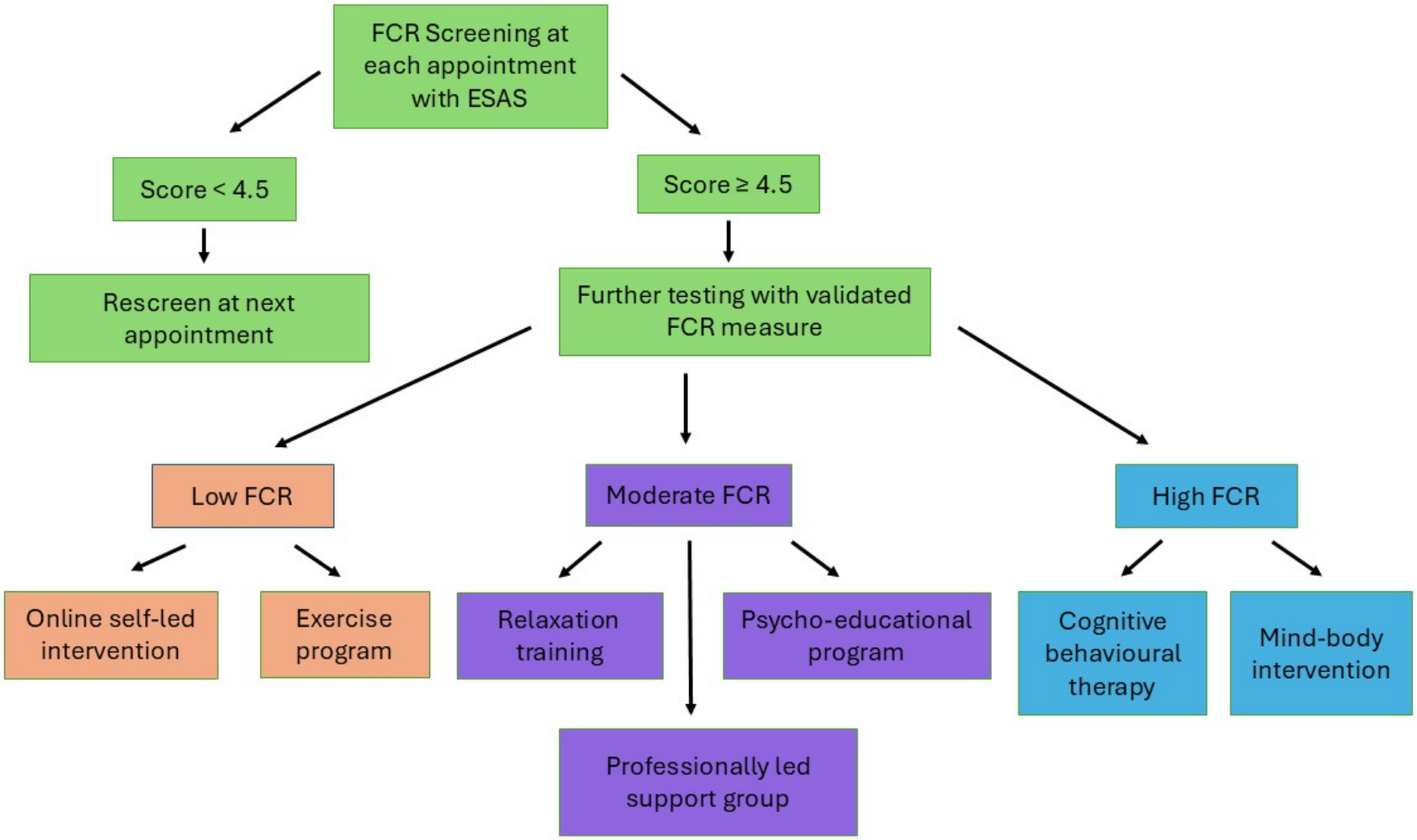
**RELATED GUIDELINES**

- Cancer Care Ontario Person-Centred Care Guideline: Endorsement and Adaptation of CG 138: Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. 2015 May 2015. Person-Centred Care Program
- Li M, Kennedy EB, Byrne N, Gerin-Lajoie C, Green E, Katz MR, et al. The management of depression in patients with cancer. Toronto (ON): Cancer Care Ontario; 2015 May 11. Program in Evidence-based Care Guideline No.: 19-4.

**FURTHER RESEARCH**

Further research is needed on implementing screening tools into clinical practice to see if they help with increasing referrals of patients to the appropriate services based on the severity of their fear. Additional research is needed on intermediate- and low-intensity interventions for patients, including general group MBI that could have an impact on low-to-moderate FCR such as relaxation techniques and approaches that include spirituality. Overall, cultural appropriateness and relevance of FCR interventions for diverse patient populations is poorly documented. The research to date on FCR has been mostly conducted with early-stage, disease-free, cancer *survivor*s rather than *patients*, who most often defined as those still in active treatment, or those with stage IV disease. For these groups of patients, the concept of fear of progression (FoP) may be more relevant than FCR. However, currently, the phenomenon of FoP is much less studied than FCR. For example, the widely cited 2013 systematic review of quantitative research on FCR included only 18 studies (13%) of the 130 that assessed FOP [19]. Similarly, a meta-analysis of RCTs for the treatment of FCR included only three of 23 (13%) studies that measured FOP as the outcome [38]. Some authors have argued that FoP and FCR are ‘nearly identical’ [46]; others have recently argued that they are different constructs and that FCR interventions may need to be adapted to address the needs of those living with advanced or metastatic cancer [47]. Last, additional efforts are needed to develop instruments to screen and assess FCR in care partners, as well as interventions specific to this group.

## FCR Screening, Assessment, and Intervention Flow Chart



## Resources for Patients\Care Partners and Health Professionals

### Patient/Care Partners

**Canadian Cancer Society**

- Fear of cancer recurrence during COVID-19
- https://cancer.ca/en/cancer-information/resources/webinars/2020/fear-of-cancer-recurrence-during-covid-19

- Worrying that cancer will come back
- https://cancer.ca/en/living-with-cancer/life-after-treatment/worrying-that-cancer-will-come-back

- Community Services Locator
- https://cancer.ca/en/living-with-cancer/how-we-can-help/community-services-locator

- Talk to an Information Specialist
- https://cancer.ca/en/living-with-cancer/how-we-can-help/talk-to-an-information-specialist

- Spirituality
- https://cancer.ca/en/living-with-cancer/coping-with-changes/spirituality

**Canadian Association of Psychosocial Oncology**

- Coping with Cancer
- https://www.copingwithcancer.ca/

**Canadian Cancer Survivor Network**

- Educational activities for cancer survivors, patients and care partner
- https://survivornet.ca/news/did-you-miss-our-webinar-fear-of-cancer-recurrence-5-ways-to-lessen-your-anxiety/

**OH (CCO) Managing Symptoms**

- Talk to your oncologist and nurses to find close places for help near you
- OH (CCO) Recommended resources for anxiety: https://www.cancercareontario.ca/en/symptom-management/3981

**Wellspring Cancer Support**

- Resources, programs, brochures and community links for emotional, physical and practical challenges for cancer patients and care partners
- https://wellspring.ca/online-programs/programs/all-programs/

**Mindfulness Based Cognitive Therapy for Cancer**

- Mindfulness based courses available for people with cancer. Includes links to courses and on-line mindfulness recordings and practices.
- https://www.inspirationsolutions.com/mindfulness.html

**Alberta Health Services**

- After Treatment: Information and Resources to Help You Set Priorities and Take Action
- https://www.albertahealthservices.ca/assets/info/cca/if-cca-after-treatment-for-cancer.pdf

**Peter MacCallum Cancer Centre**

- Coping with the fear of cancer coming back (fear of cancer recurrence)
- https://www.petermac.org/sites/default/files/media-uploads/ACSC_Factsheet_FearOfCancerComingBack.pdf

**Fred Hutchinson Cancer Research Centre**

- How to deal with FCR – patient treatment and support
- https://www.fredhutch.org/content/dam/www/research/patient-treatment-and-support/survivorship-program/survivorship-health-links/Fear%20of%20Recurrence.pdf

**Maggie's – Everyone's home of cancer care**

- Fear of cancer returning
- https://www.maggies.org/cancer-support/managing-emotions/fear-cancer-returning/

**Dana Farber Cancer Institute**

- Your emotions after treatment – Dana Farber Cancer Institute
- https://www.dana-farber.org/for-patients-and-families/for-survivors/caring-for-yourself-after-cancer/your-emotions-after-treatment/

**Mayo Clinic: Adult Health**

- Cancer survivors: managing your emotion after cancer treatment
- https://www.mayoclinic.org/diseases-conditions/cancer/in-depth/cancer-survivor/art-20047129

- Connect with other patients who have fear of cancer recurrence
- https://newsnetwork.mayoclinic.org/discussion/connect-with-other-patients-who-have-fear-of-cancer-recurrence/

- Consumer Health: Life after cancer
- https://newsnetwork.mayoclinic.org/discussion/consumer-health-life-after-cancer-2/

**Cancer Council Victoria**

- Life after treatment – fear of the cancer coming back
- https://www.cancervic.org.au/living-with-cancer/life-after-treatment/fear-of-the-cancer-coming-back

**American Cancer Society**

- Life after Cancer
- https://www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/life-after-cancer.html

- Preventing cancer, signs and symptoms, and coping
- https://www.cancer.org/cancer/survivorship/long-term-health-concerns/recurrence/can-i-do-anything-to-prevent-cancer-

recurrence.html#:~:text=Eating%20right%2C%20exercising%2C%20and%20seeing,be%20as%20healthy%20as%20possible.

**Fox Chase Cancer Center**
- 'Is My Cancer Coming Back?' How to Cope with the Fear of a Recurrence
- https://www.foxchase.org/blog/2018-03-23-how-to-cope-with-the-fear-of-a-cancer-recurrence

**Cancer*Care***
- Coping with fear of cancer recurrence
- https://www.cancercare.org/publications/253-coping_with_the_fear_of_recurrence#

**Breast Cancer Network Australia**
- FCR – Fact sheet
- https://www.bcna.org.au/resource-hub/articles/fear-of-breast-cancer-recurrence/

**Cancer.Net: Coping with Fear of Recurrence**
- Coping with fear of cancer recurrence, knowing when to seek help and prompting questions to ask healthcare team.
- https://www.cancer.net/survivorship/life-after-cancer/coping-with-fear-recurrence

**Harvard Health Blog**
- Fear of cancer recurrence: Mind-body tools offer hope
- https://www.health.harvard.edu/blog/fear-of-cancer-recurrence-mind-body-tools-offer-hope-2019030716152

- Mindfulness apps: How well do they work?
- https://www.health.harvard.edu/blog/mindfulness-apps-how-well-do-they-work-2018110615306

**Cleveland Clinic**
- Coping With Fear of Cancer Recurrence
- https://health.clevelandclinic.org/fear-of-cancer-recurrence/

**Health Professionals**

**CIFeR**
- Clinician Intervention Fear of Cancer Recurrence: CIFeR is a short eight-minute doctor-led intervention to help you to address fear of cancer recurrence when seeing your breast cancer patients in clinic.
- https://cifer.thinkific.com/courses/2021

**FORT**
- Fear of Recurrence Therapy resources and manuals
- https://drive.google.com/drive/folders/1cn_oK0loAhJzp-sTP0CiFg2FUJXiRKVv?usp=share_link

**CANO/ACIO**

- Adult Cancer Survivorship Manual — A Self Learning Resource for Nurses
- https://www.cano-acio.ca/page/survivorship_manual

**Cancer Network**

- Fear of Cancer Recurrence: A Practical Guide for Clinicians
- https://www.cancernetwork.com/view/fear-cancer-recurrence-practical-guide-clinicians

**User Manual**

- Treating Fear of Cancer Recurrence with Group Cognitive-Behavioural Therapy: A Step-by-Step Guide
- https://link.springer.com/book/10.1007/978-3-031-07187-4

**Alberta Health Services**

- Fear of Cancer Recurrence (FCR) Pathway
- https://www.albertahealthservices.ca/assets/info/hp/cancer/if-hp-cancer-primary-care-fcr-pathway.pdf

**Cancer Nurses Society of Australia**

- **Online Webinar**
- https://www.youtube.com/watch?v=1Ud5qlKmiMI

**Psycho-oncology Co-operative Research Group**

- Fear of Cancer Recurrence: Resource Hub
- https://www.pocog.org.au/content.aspx?pagetype=public&page=fcrhub&version=1&search=*

**Articles**

- Primer for primary care providers: Assessing and managing patient fear of cancer recurrence
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7491663/

# Fear of Cancer Recurrence Guideline

## Section 3: Guideline Methods Overview

*This section summarizes the methods used to create the guideline. For the systematic review, see Section 4.*

**THE PROGRAM IN EVIDENCE-BASED CARE**

The Program in Evidence-Based Care (PEBC) is an initiative of the Ontario provincial cancer system, Ontario Health (Cancer Care Ontario). The PEBC mandate is to improve the lives of Ontarians affected by cancer through the development, dissemination, and evaluation of evidence-based products designed to facilitate clinical, planning, and policy decisions about cancer control.

The PEBC supports the work of Guideline Development Groups (GDGs) in the development of various PEBC products. The GDGs are composed of clinicians, other healthcare providers and decision makers, methodologists, and community representatives from across the province.

The PEBC is a provincial initiative of OH (CCO) supported by the Ontario Ministry of Health (OMH). All work produced by the PEBC, and any associated Programs is editorially independent from the OMH.

**BACKGROUND FOR GUIDELINE**

One out of two Canadians will develop cancer during his or her lifetime and more than 60% of newly diagnosed cancer patients are expected to live five years or more [48]. This has led to the reconceptualization of cancer, in some cases, as a chronic illness, with the expectation that patients will need to manage their long-term physical and psychosocial concerns [49]. Abundant literature has shown that FCR is among survivors' top unmet needs (i.e., a supportive care need that is not currently addressed by the medical system), regardless of cancer type, sex, time since diagnosis, or stage of the disease [19]. The negative impact of FCR on both physical and psychosocial quality of life (QOL) have been well documented [19,50]. There is growing evidence that care partners experience just as much, if not more FCR than the survivors themselves, and that FCR is linked to negative psychological outcomes in this population as well [24,25]. Two meta-analyses and several systematic reviews have found that there are effective interventions to address FCR in cancer survivors [8-10,37,38]. However, these evidence-based interventions are not available in most clinical settings, and where they are available, only a minority of oncology healthcare providers refer patients with high FCR to these psychosocial services [51]. Appropriate coordination of care is thus essential, as well as making recommendations for the implementation of screening efforts, assessment using validated tools, and effective interventions so that psychosocial oncology professionals can support patients. Guidance will help providers plan for and advocate for the appropriate professional teams and resources to improve long-term outcomes of the growing number of cancer survivors, based on reported level of severity of FCR. This may reduce further healthcare utilization, as untreated patients with higher levels of FCR tend to report greater utilization of healthcare resources [52]. Without recommendations and guidance, patients' levels of FCR will not be appropriately identified and clinicians have insufficient information for screening, assessment, and intervention.

## GUIDELINE DEVELOPERS

This guideline was developed by the Fear of Cancer Recurrence GDG (Appendix 1), which was convened at the request of the Psychosocial Oncology Program.

The project was led by a small Working Group of the Fear of Cancer Recurrence GDG, which was responsible for reviewing the evidence base, drafting the guideline recommendations, and responding to comments received during the document review process. The Working Group members had expertise in psychosocial oncology, psychology, nursing, and health research methodology. Other members of the Fear of Cancer Recurrence GDG served as the Expert Panel and were responsible for the review and approval of the draft document produced by the Working Group. Conflict of interest declarations for all GDG members are summarized in Appendix 1 and were managed in accordance with the *PEBC Conflict of Interest Policy*.

Two patients/survivors/care partners also participated as active members of the Fear of Cancer Recurrence Working Group. The patient representatives attended and participated in Working Group meetings and teleconferences. They provided feedback on draft guideline documents throughout the entire practice guideline development process, communicating the perspective of patients and members of the public.

## GUIDELINE DEVELOPMENT METHODS

The PEBC produces evidence-based and evidence-informed guidance documents using the methods of the Practice Guidelines Development Cycle [53,54] . This process includes a systematic review, interpretation of the evidence by the Working Group and draft recommendations, internal review by content and methodology experts and external review by Ontario clinicians and other stakeholders.

The PEBC uses the AGREE II framework [55] as a methodological strategy for guideline development. AGREE II is a 23-item validated tool that is designed to assess the methodological rigour and transparency of guideline development and to improve the completeness and transparency of reporting in practice guidelines.

The currency of each document is ensured through periodic review and evaluation of the scientific literature and, where appropriate, the addition of newer literature to the original evidence-base. This is described in the *PEBC Document Assessment and Review Protocol*. PEBC guideline recommendations are based on evidence of the magnitude of the desirable and undesirable effects of an intervention or accuracy of a test, and take into account the certainty of the evidence, the values of key stakeholders (e.g., patients, clinicians, policy makers, etc.), and the potential impact on equity, acceptability and feasibility of implementation according to GRADE's evidence-to-decision framework [56]. A list of any implementation considerations (e.g., costs, human resources, and unique requirements for special or disadvantaged populations, dissemination issues, etc.) is provided along with the recommendations for information purposes. PEBC guideline development methods are described in more detail in the *PEBC Handbook* and the *PEBC Methods Handbook*.

### Search for Guidelines

As a first step in developing this guideline, a search for existing guidelines was undertaken to determine whether any guideline could be endorsed**.** Evidence-based guidelines with systematic reviews that addressed at least one research question (see Section 4) were considered. Guidelines older than three years at the time of the search (published before 2019) were excluded. Guidelines based on consensus or expert opinion were excluded. However, there was one guideline from Australia published in 2014 that was used in part (section on

interventions) as a starting point and updated: *Cancer Australia. Recommendations for the identification and management of fear of cancer recurrence in adult cancer survivors* [57].

The following sources were searched for guidelines on January 22, 2022, with the search term(s) fear of cancer recurrence, fear, cancer: National Institute for Health and Care Excellence Evidence Search, Canadian Medical Association Journal Infobase, American Society of Clinical Oncology, National Health and Medical Research Council – Australia Clinical Practice Guidelines Portal, and Cancer Council Australia – Cancer Guidelines Wiki**.** No guidelines were found as a result of the guideline search.

## GUIDELINE REVIEW AND APPROVAL

### Internal Review

For the guideline document to be approved, 75% of the content experts who comprise the GDG Expert Panel must cast a vote indicating whether or not they approve the document, or abstain from voting for a specified reason, and of those that vote, 75% must approve the document. In addition, the PEBC Report Approval Panel (RAP), a three-person panel with methodology expertise, must unanimously approve the document. The Expert Panel and RAP members may specify that approval is conditional, and that changes to the document are required. If substantial changes are subsequently made to the recommendations during external review, then the revised draft must be resubmitted for approval by RAP and the GDG Expert Panel.

### External Review

Feedback on the approved draft guideline is obtained from content experts and the target users through two processes. Through the Targeted Peer Review, several individuals with content expertise are identified by the GDG and asked to review and provide feedback on the guideline document. Through Professional Consultation, relevant care providers and other potential users of the guideline are contacted and asked to provide feedback on the guideline recommendations through a brief online survey.

## DISSEMINATION AND IMPLEMENTATION

The guideline will be published on the OH (CCO) website and may be submitted for publication to a peer-reviewed journal. The Professional Consultation of the External Review is intended to facilitate the dissemination of the guideline to Ontario practitioners. Section 1 of this guideline is a summary document to support the implementation of the guideline in practice. OH (CCO)-PEBC guidelines are routinely included in several international guideline databases including the CPAC Cancer Guidelines Database, the CMA/Joule CPG Infobase database, NICE Evidence Search (UK), and the Guidelines International Network (GIN) Library.

We have added a supplement to the recommendations the provides links to resources to interventions for FCR.

Implementation of guidelines developed by the PEBC may be undertaken by psychosocial program. At the time of publication, planned activities include adding question onto the ESAS.

## ACKNOWLEDGEMENTS

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- Sara Miller for copy editing.

# Fear of Cancer Recurrence Guideline

## Section 4: Systematic Review

**INTRODUCTION**

FCR is defined as the fear, worry, or concern that cancer may come back or progress [1]. FCR is among the top unmet needs of cancer survivors post cancer treatment [4]. It manifests itself on a continuum, from mild symptoms (41%) to clinically significant levels of FCR (59%), with one cancer patient out of five reporting the most severe form of this fear [19]. Clinical FCR tends to remain stable over time if unaddressed and is associated with negative outcomes, such as reduced QOL among cancer survivors and increased costs to the medical system [4,58-62]. For example, Lebel and colleagues found that higher levels of FCR were associated with more visits to the emergency room, to family physicians, and to oncology care providers among survivors of breast, colorectal, and prostate cancer [60]. A systematic review [24] of FCR in care partners of cancer patients found that care partners report equal or greater levels of FCR compared to cancer survivors [63-67]. FCR in care partners also tends to persist [65,68] and is associated with lower QOL [63,64,66], lower functioning [63,64,66], and higher psychological distress [65,66]. For example, recognising FCR as an unmet need was one of the strongest predictors of depression in care partners [69]. Moreover, studies of dyads found that FCR experienced by one partner influenced the level of FCR experienced by the other [10,66,68,70], suggesting that addressing FCR in care partners could also be beneficial to cancer survivors. There is now evidence that clinical FCR can be mitigated among cancer survivors by either group or individual interventions [8,71] with an average moderate effect size and evidence of sustained improvements at follow-up (on average 8 months post-therapy). These interventions also reduce intrusive thoughts, anxiety, and depression, and improve QOL [34,66,72,73]. Four studies to date addressed the cost of different FCR interventions and suggest that they can be cost-effective to conduct in that they can reduce FCR-associated burden on healthcare costs and improve QOL [52]. Reviewed treatments had an incremental cost-effectiveness ratio between AU$3,233 and AU$152,050 per quality-adjusted life year gained [52].

The Working Group of the Fear of Cancer Recurrence Expert Panel developed this evidentiary base to inform recommendations as part of a clinical practice guideline. Based on the objectives of this guideline (Section 2), the Working Group derived the research questions outlined below. This systematic review has been registered on the PROSPERO website (International prospective register of systematic reviews) with the following registration number CRD42023435619.

**RESEARCH QUESTIONS**

Research Question 1:

a. For patients who are living with cancer, are screening tools for FCR more effective for identifying patients and care partners who suffer from FCR than not screening?
b. For such a screening tool, is there improved capacity to identify patients who experience FCR compared to the current standard of care (i.e., ESAS, psychosocial support)?
c. Does the use of a screening tool increase referral to appropriate psychosocial resources?

Research Question 2:

a. For patients who are living with cancer, are assessment tools for FCR more effective for identifying the extent and nature of FCR in patients and care partners than usual care (e.g., ESAS)?
b. Does the use of an assessment tool lead to better management of FCR (e.g., referral to appropriate psychosocial resources)?

Research Question 3:

What are the most effective strategies/components for managing or reducing FCR?

**METHODS**

This evidence review was conducted in two planned stages, including a search for systematic reviews followed by a search for primary literature. These stages are described in subsequent sections.

In 2014, Cancer Australia published a guideline incorporating evidence up to 2012 on the identification and management of FCR in adult cancer survivors [57]. The Working Group decided to start the search after the search date of that systematic review.

**Search for Systematic Reviews**

A search was conducted for existing systematic reviews on January 22, 2022, and March 25, 2022. The databases searched were OVID MEDLINE, EMBASE, and Cochrane Database of Systematic Reviews for the years 2012 to March 2022. Systematic reviews were included if they met the following criteria: the review addressed at least one research question with similar inclusion/exclusion criteria, had a low risk of bias as assessed with the ROBIS tool [74], and was published after 2012. If more than one systematic review met the inclusion criteria, then one systematic review for each outcome or intervention was selected by the Working Group based on its age, quality, and the best match with our study selection criteria stated below.

**Search for Primary Literature**

For each outcome per research question, if no systematic review was included, then a search for primary literature was conducted. For any included systematic review, an updated search for primary literature was performed. If any included systematic review was limited in scope, then a search for primary literature to address the gap in evidence was conducted.

***Literature Search Strategy***

MEDLINE and EMBASE were searched for primary studies on January 22, 2022, and March 25, 2022. The databases searched were OVID MEDLINE and EMBASE beginning from January 2012. When a systematic review was included, the search for primary studies started at the end of the search timeframe from the included systematic review. Reference lists of papers and review articles were scanned for additional citations. Please see Appendix 2 for the full search strategy.

***Study Selection Criteria and Process***

*Inclusion Criteria*:

- Practice guidelines, systematic reviews, or meta-analyses relevant to the research questions
- Phase III RCTs with at least 30 patients
- Non-randomized comparative studies with at least 30 patients per group, where confounders were controlled for intervention studies
- Adults over the age of 18 years

*Exclusion Criteria*:

Letters, comments, editorials, abstract reports, papers published in a language other than English, because of a lack of resources for translation.

A review of the titles and abstracts was conducted by one reviewer (CZ) independently. If uncertainty existed for a given abstract, a second reviewer (SL) would review the paper in question.

For studies that warranted full-text review, one reviewer (CZ) independently reviewed each study. If uncertainty existed for a given study a second reviewer (SL) would review the paper in question.

***Data Extraction and Assessment of Risk of Bias***

All included primary studies underwent data extraction by CZ and FM, with all extracted data and information audited subsequently by an independent auditor.

Risk of bias per outcome for each included study was assessed using the Risk of Bias Tool 2.0 (RoB-2 tool) [75] for RCTs.

**Synthesizing the Evidence**

Meta-analysis was not planned due to the heterogeneity of the data for any of the outcomes.

***Assessment of the Certainty of the Evidence***

The certainty of the evidence was assessed per outcome for each intervention and/or research question, considering the risk of bias, inconsistency, indirectness, imprecision, and publication bias.

**RESULTS**

**Search for Systematic Reviews**

Of the 82 systematic reviews identified, 19 were considered for full-text review and 12 met inclusion criteria; the others were excluded for being not relevant to the scope of the guideline. The 12 remaining systematic reviews were chosen for relevancy to the topics and were assessed for quality using the ROBIS [74]. See Appendix 5 for systematic review quality assessment results.

**Search for Primary Literature**

A search for primary literature was conducted for all questions. A total of 1070 articles were found through the literature search. Of these, 166 articles underwent a full-text review and 22 were retained (Table 4-1). See Appendix 3 for PRISMA diagram of search results and Appendix 5 for the quality assessment results.

**Table 4-1. Studies selected for inclusion.**

| Topic | Studies |
|---|---|
| Screening for FCR in patients and care partners | 2 SRs, 1 RCT, 4 cross-sectional studies |
| Assessment of FCR in patients and care partners | 2 SRs (1 being published) |
| Interventions for FCR in patients and care partners | 13 SRs, 16 RCTs, 1 comparative |

**Abbreviations:** FCR: Fear of cancer recurrence; RCT: Randomized controlled trial; SR: systematic review

**Results from a previous guideline with a systematic review**

In 2014, Cancer Australia published a guideline incorporating evidence up to 2012 on the identification and management of FCR in adult cancer survivors [57]. The systematic review associated with the Australian guideline also produced 27 statements of evidence regarding prevalence, stability, unmet needs, demographic characteristics, cancer stage and treatment characteristics, psychological characteristics, QOL issues, healthcare factors, psychological correlations, and various interventions. From this evidence, they developed one recommendation and eight practice points. They recommended that where FCR is identified by either the patient or health professional as impairing social, emotional, or occupational functioning, consideration should be given to referring the patient to a psychological intervention to help address FCR. The practice points included providing information regarding FCR, including its likelihood, impact, and strategies for management to patients; the need for routine; proper assessment with validated tools and personnel; a list of the factors associated with FCR; and the need to provide support and psychological interventions to manage FCR. It is from this basic information that the Working Group started work on this guideline.

**Research Question 1:**

a. For patients who are living with cancer, are screening tools for FCR more effective for identifying patients and care partners who suffer from FCR than not screening?
b. For such a screening tool, is there improved capacity to identify patients who experience FCR compared to current standard of care (i.e., ESAS, psychosocial support)?
c. Does the use of a screening tool increase referral to appropriate psychosocial resources?

The evidence addressing the utility of using a screening tool to identify FCR in patients living with cancer was reported in five studies [18,20-22,76]. Rogers et al. found in a cross-sectional survey of 513 patients with head and neck cancer that a single-item FCR screening question had good convergent validity with University of Washington Quality of Life dysfunction, correlated strongly with the mean score of the seven items in the FCR subscales and overall QOL scores (Spearman $r=-0.82$, $p<0.001$) and was therefore suitable for identifying FCR [20]. Rudy et al. evaluated the ability of a single-item questionnaire (On a scale from 0 to 100, what is your subjective level of fear of cancer recurrence at this time?) on patients with breast and/or gynaecological cancer, the FCR-1, to measure FCR in 69 patients and found that the FCR-1 was statistically significantly correlated with the FCRI and FCRI-SF, and had good discriminant validity [21]. The area under the curve (AUC) was 0.85 (95% confidence interval [CI], 0.71 to 1.0, $p<0.001$), and with a cut-off score of ≥45/100, it had a sensitivity of 70% and a specificity of 89.5% [21]. Smith et al. reviewed the FCR-1 and modified its wording and scoring from 0-100 scale to a 0-10 scale (Describe how you feel now: no FCR=0, worst possible FCR=10) so that the question could be included in the ESAS, resulting in a one-item screening questionnaire called the FCR-1r [18]. The FCR-1r was evaluated in 107 patients who had completed cancer treatment and was found to have very good concurrent validity with FCRI-SF ($r=0.83$, $p<0.001$), and divergent validity with other variables. The AUC was 0.91 (95% CI, 0.85 to 0.97, $p<0.0001$)), and with a cut-off score of ≥5/10, it had a sensitivity of 95% and a specificity of 77% for detecting clinical FCR [18]. Smith at el. also compared the performance of the FCR-1r to the performance of the ESAS-r anxiety item performance (with a cut-off of

≥4/10) (using the FCRI-SF as a reference) and found that the ESAS-r anxiety item had a 91% sensitivity and 82% specificity (AUC=0.87, 95% CI, 0.77 to 0.98) for detecting clinical FCR [18].

Rogers et al., in an analysis of the main results of a cluster randomized trial of the Patient Concerns Inventory (PCI), found that the use of the PCI did not increase consultation time and allowed for the consultation to focus on those issues important to the patient. They also suggest that a question regarding FCR prompts the patient to talk about this aspect and seek reassurance or further information at the consultation or follow-up visit [22].

Deuning-Smit et al. evaluated the ability of the Distress Thermometer to detect FCR in 149 breast cancer and 74 colorectal cancer survivors, and found it had low sensitivity and specificity when comparing to the Cancer Worry Scale, making it not useful to detect FCR in routine care [76] (Appendix 4, Table 4-1).

The evidence regarding FCR screening in care partners is contained in two systematic reviews [23,24]. Smith et al. found in a review of 63 studies that FCR is prevalent in care partners, with almost 50% experiencing moderate or clinical FCR [24]. The meta-analysis by Webb et al. included 45 studies and found that 48% of care partners experience clinically significant FCR [25]. These systematic reviews included studies with longer and more extensive assessment tools (see Question 2) and did not report the use of any single-item screening tool with care partners.

### *Certainty of the Evidence*

The Cancer Australia guideline was assessed using the AGREE II tool [55] and scored 62% on the rigor of development domain indicating a high-quality guideline (a score of over 50% on the rigor of development domain). The systematic reviews were assessed using the ROBIS tool [74] and was a low risk of bias for both. The RCT was assessed using the RoB 2.0 [75] and the risk of bias was rated as some concerns. The four cross-sectional studies were assessed using the JBI Critical Appraisal Checklist for Analytical Cross-sectional Studies [77] and found to have a low risk of bias.

### Conclusions

Briefly, one-item screening tools are available for patients and have good psychometric properties. Their use in clinical care appears feasible in terms of time and may result in patients having more conversations around FCR with their medical team. Research on the implementation of FCR screening tools in clinical care is urgently needed. There is mixed evidence as to whether they outperform general distress or anxiety screening tools in terms of identification of clinical FCR and further research is needed to guide future implementation efforts. Despite the documented prevalence of clinical FCR in care partners, we could not identify a screening tool specific for this population.

### Research Question 2:

a. For patients who are living with cancer, are assessment tools for FCR more effective to identify the extent and nature of FCR in patients and care partners who suffer from FCR than usual care (e.g., ESAS)?
b. Does the use of an assessment tool allow for better management of FCR, e.g., referral to appropriate psychosocial resources?

A systematic review of 32 studies psychometrically evaluated 34 FCR assessment scales of patient reported outcomes (PROMs) using COSMIN criteria [88]. Maheu et al., found that 28 achieved Category A status. However, they determined that five PROMs, the FCR-1, FCRI-SF, FoP-Q-SF, FCR7, and the CWS were the most strongly supported measures for clinical use [88].

In a systematic review of 45 studies to examine FCR in care partners, Webb et al. found 12 different instruments that were used to measure care partner FCR but found that few had undergone appropriate testing [25]. Using the COSMIN criteria, they found that two measures, the FoP-Q-SF/PR and the FCRI-Caregiver, were psychometrically sound, but not specifically developed for care partners. The FoP-Q-SF/PR was found to meet 67% of the COSMIN criteria and the FCRI-Caregiver was found to have 47%; the FCRI-Parent had 40% [25].

**Research Question 3:**

What are the most effective strategies/components for managing or reducing FCR among the following interventions?

There are many different types of interventions than may reduce the level of FCR in patients. The review of the literature found 12 systematic reviews and 18 comparative studies evaluating different types of interventions, timing of interventions, settings, and specialists conducting the intervention.

Four systematic reviews and seven RCTs examined CBT [6,8,9,26,28,30,31,37,38,42,43]. All of the systematic reviews and RCTs found that CBT significantly decreased FCR in those with high FCR. However, there was a lack of specific information on such aspects as face-to-face, in-person, or group settings or who (type of professional) conducted the sessions to determine the superiority of one method over another.

Three systematic reviews and seven additional RCTs [10,26-28,35,37,39,41,42,78] examined MBI. The systematic reviews found a statistically significant decrease in FCR. Of the eight RCTs, six found a significant decrease in FCR [26,28,35,39,41,42].

Three studies evaluated psychoeducation; two lower-quality RCTs found no significant decreases in FCR but one found a significant difference [29,32,36]. Three Acceptance and Commitment Therapy (ACT) RCTs all found a significant decrease in FCR [35,40,42]. One RCT studied high-intensity exercise and found a decrease in FCR on a prostate cancer QOL FCR subscale but not on the FCRI-SF [33] (Appendix 4, Tables 4-2 and 4-3).

The interventions were inconsistent in settings, conductors, and modes with some interventions having more than one setting or approach such as face-to-face meetings as well as telephone support. This made it difficult to tease out the components, such as setting, the use of homework, and the length or duration of the interventions, that may be more beneficial than other components. As well, the levels of FCR at the start of each intervention was variable.

The length for the interventions ranged from three to 16 weeks. The amount of time for each session ranged from 15 to 150 minutes. The total number of sessions ranged from three to 36 times but the number of sessions occurring each week varied among interventions. One intervention occurred before treatment [33], one intervention occurred during treatment [41], 10 studies reported interventions occurring after treatment [6,26,29-32,35,36,42,43] and three studies reported interventions occurring during and after treatment [27,28,39]. For the studies that included a self-led component, two were entirely self-led [29,31] and five were self-led with assistance [26-28,30,32]. The length of follow-up ranged from one to 24 months [6,26,28-32,35,36,40-43], with three studies not reporting any follow-up [27,33,39].

Interventions were held in a variety of settings: fitness centre [33], hospital [6,27,35,36], cancer centre [35,40,42], university [39], home [27,41], local health service provider [28], and rehabilitation centre [29]. There were also on-line [26,28-30,40,41,43,79] and telephone [27,30-32,36] interventions. The interventions were conducted by both mental health specialists (e.g., social worker, clinical or counselling psychologist, or therapist) and non-mental health specialists (e.g., clinician, nurse, researcher, technician, or exercise physiologist). Ten studies used mental health specialists/combination of health specialists

[6,27,30,32,35,40-43,79]; five used non-mental health specialists [26,28,29,33,36]; and one study did not report the specialization of the person conducting the intervention [39].

**Matched Care Approach to Organizing FCR Care**

A recent review and synthesis of research on managing FCR discussed two models of care based on levels of intensity of interventions for levels of FCR: a matched-care approached and a stepped-care approach [80]. One comparative cohort study also used a matched-care approach in treating those patients with subthreshold FCR with a self-management intervention while patients with clinical FCR were provided with individual therapy [27].

A review by Pradhan et al. proposed a matched-care model to help manage FCR and determined that a matched-care approach could meet the needs of survivors and patients [80]. The model consists of four levels of increasing FCR severity and four levels of intensity of treatment. For the first three levels of FCR, there are three levels of lower-intensity treatments delivered by the healthcare team. Level 1 (low FCR level) may include psychoeducation and preventive interventions. Level 2 (low-to-moderate level) may include online interventions and self-help approaches. Level 3 (moderate-to-high FCR) may include nurse-led interventions. Level 4 (high FCR) may include high-intensity treatments delivered by a mental health specialist such as face-to-face evidence-based psycho-oncologist-delivered interventions [80].

The stepped-care approach enrols each patient with FCR (at any level) in a minimal intervention and after reassessment, if FCR levels are still high, then the intensity of the intervention could increase. This stepped-care approach has yet to be implemented and evaluated.

However, pilot data have recently been published on 61 melanoma patients who completed a matched-care program to manage their FCR [27]. In this study, Lynch et al. tailored the intervention received by the participants based on baseline FCRI-SF and FoP-Q-SF scores [27]. With a score of FCRI-SF ≤12 and FoP-Q-SF ≤23, indicating low FCR, the participant would receive treatment as usual. With a score of FCRI-SF 13-21 or FoP-Q-SF 24-33, indicating moderate FCR, the participant received a self-management treatment consisting of psychoeducation, a booklet, and telephone call support. If the participant had high FCR (FCRI-SF ≥22 or FoP-Q-SF ≥34), they received an individual FCR intervention known as *ConquerFear,* a contemporary CBT that included five sessions based on Meta-cognitive Therapy, the treatment associated with the Self-Regulation of Executive Function Model of emotional disorders, and components of ACT. The participants were re-assessed after five weeks. In both moderate and high FCR groups of participants, levels of FCR were decreased post-treatment [27]. Additional evaluations of this matched-care program are ongoing [81].

Applying the matched-care model, the Working Group organized the evidence on interventions into FCR intensity levels so as to make the interventions more usable and applicable to the people that require them.

Low-intensity level interventions included booklets, exercise, and remote interventions either self-led or guided. In a systematic review of 16 studies, Liu et al. found that consultation duration, empathy and clear information delivery helped decrease FCR and concluded that the provision of honest information about prognosis and recurrence risk was helpful to address FCR [11]. Dieng et al. used a booklet from the Australian Cancer Council, *Understanding Melanoma* (n=81, mean FCRI 59.35±27.79) as a comparison to psychoeducation (n=70, mean FCRI 55.5±27.96) and found that both groups had a reduction in FCR although the psychoeducation group had significantly lower FCR at 12 months postintervention than the control group (between-group difference, -1.41 in FCRI-SF [95% CI, -2.6 to -0.2], p=0.02) [32]. Kang et al. found that an exercise intervention (a high-intensity interval training program) was beneficial in reducing FCR when measured on the Memorial Anxiety Scale for Prostate Cancer fear of progression subscale (p=0.013) but not on the FCRI scale (baseline FCR=12.7, p=0.55) [33]. For

online/remote interventions, self-led CBT and CBT with guidance by either a physician or technician seem to reduce FCR in the short term [6,26,28-32,36,40,41,43,79]. Seven studies used self-led interventions as either a main intervention or as a comparison [26-32]. The systematic review by Cincidda et al. included both traditional and contemporary CBT remote interventions and reported that four of five studies showed a significant decrease in FCR [9]. Telecoaching helps to increase the adherence to the online program and increases satisfaction with the program [30].

Intermediate-intensity level intervention studies examined three areas: psychoeducation, support groups and interventions delivered by non-mental health specialists [26,28,29,33,36]. Three studies examined psychoeducation interventions [29,32,36]. Scores for FCR decreased significantly in one study [32]. However, two studies were of lower quality as one study did not have a baseline measure and therefore only compared one-month post-treatment with three-month post-treatment scores [36] and the other focused on psychoeducation around lymphedema and not FCR specifically [29]. Two systematic reviews found that interventions using group formats had greater decreases than studies using individual sessions [37,38]. There was limited information available for non-mental health specialists [11]. One study used nurses to conduct the intervention [36].

High-intensity level interventions included CBT, MBSR, mindfulness-based cognitive therapy (MBCT), Internet MBCT, ACT, and ACT/MBT or a combination [6,27,30,35,39-41,43]. All systematic reviews found that CBT interventions decreased FCR [8,9,37,38]. Cincidda et al. found that both contemporary and traditional CBT, face-to-face, remote and a blended intervention combining face-to-face, and videoconferencing were effective and proposed a program with of a combination of face-to-face and web-based interventions [9]. Park et al. found that approximately 66% of CBT interventions adopted a face-to-face group format with four to eight sessions, with at least a one-month intervention duration, and that these were more effective in reducing FCR scores than individual formats using brief online or telephone delivery methods [8]. Tauber et al. found significant moderators of effect including contemporary rather than traditional CBT, group rather than individual, and longer follow-up times had an effect on how much FCR can decrease but format, delivery, sex, or the number sessions did not [38]. However, this conclusion may be confounded by the fact that most studies having assessed traditional CBT were early trials, when FCR was less well known in terms of its determinants. Six RCTs found CBT using mental health professionals statistically significantly decreased FCR, whether in person or online [6,27,30,35,42,43]. Telecoaching increased the adherence to the online program as well as increased satisfaction with the program [30].

For MBSR/MBI, the systematic review by Chen et al. found that all MBSR studies reported a significant decrease in FCR [37]. The systematic review by Hall et al. found a significant pooled effect of 17 studies using MBI on reducing FCR from pre-treatment to post-treatment (Hedges' g, −0.36; 95% CI, −0.49 to −0.23; $p<0.001$) [10]. They found all MBI were effective and found no subgroup differences for groups versus individual; CBT versus no CBT; mindful mediation versus no mindful meditation, unimodal versus multimodal; post cancer treatment versus current cancer treatment; or six or fewer versus seven or more sessions [10]. Two RCTs found significant decreases in FCR using MBSR or MBCT face-to-face with mental health specialists [39,41]. One RCT examined an ACT intervention and found that this face-to-face, seven-week, group intervention (baseline Concerns about Recurrence Scale, 4.3±0.9) significantly reduced FCR [40].

For care partners, only one RCT was found in the systematic review by Smith et al. [24]. However, the dyadic intervention (side-by-side) only reduced FCR in the patient but not in the caregiver. It was proposed that some interventions may be possible to adapt for care partners, but such an approach still needs testing [24].

### *Certainty of the Evidence*

The systematic reviews were assessed using the ROBIS tool [74] and 11 had a low risk of bias and two had a high risk of bias. The RCTs were assessed using the RoB 2.0 [75] and the risk of bias for 17 studies had some concerns and one had a high risk of bias. The cohort study was assessed using the ROBINS tool [82] and found to have a moderate risk of bias. See Appendix 5 for results.

### Conclusions

There is a growing body of knowledge showing that brief (6-7 sessions) interventions, either face-to-face or blended, CBT or MBI, may benefit people who present with clinical FCR. Interventions delivered in group versus individual format may be more efficacious. These interventions have usually been delivered in research studies conducted by mental health specialists and there has been limited evaluation of their effectiveness in clinical settings or when delivered by non-mental health specialists. There has been much less research done on lower intensity interventions, except for self-led online interventions, which also seem to reduce FCR, especially when additional guidance is provided to patients. More general interventions such as psychoeducational groups may be beneficial for those with moderate FCR, but more research is needed. Caregiver-specific interventions are also currently lacking.

### *Ongoing, Unpublished, or Incomplete Studie*

A search for ongoing, unpublished, or incomplete randomized phase II, III, or IV trials was conducted on October 27, 2023, at clinicaltrials.gov using the terms “fear of cancer recurrence”. Seven trials were found, and the details are provided in Appendix 6.

## DISCUSSION

This guideline examined the existing evidence for screening, assessing, and managing FCR in patients and care partners. We acknowledge the documented impact of FCR on patients, care partners, and the healthcare system in general. The three systematic reviews that discussed care partners found that clinical FCR of care partners had a prevalence of almost 50%, was stable over time and detrimental, and was associated with the younger age of the care partner and the FCR level of the patient [23-25]. FCR may be associated with greater use of healthcare resources, but FCR treatments can be cost-effective and reduce costs on the family and healthcare system [52]. We also know that patients with FCR would like more information and communication about FCR and that health professionals would like more information or training on FCR management [11]. Thus, the current climate is ripe for a change in the way FCR is addressed in cancer centres.

With these guidelines, we aim to present cancer centres with practical recommendations around the comprehensive management of FCR. Matched or stepped-care approaches have yet to be fully evaluated but they have the potential to facilitate screening, assessment, and intervention considerations and for this reason, may be easier to implement in clinical care. Based on the reviewed evidence, we recommended the use of the FCR-1r because it has been worded to be accommodated into the ESAS and has good psychometric properties, for patients and survivors. Given that FCR is frequently heightened at certain predictable times such as waiting for test results, even among patients with low or moderate FCR, we recommend that screening for FCR be done at each encounter with the patient. For care partners, we were unable to identify screening tools and are aware of implementation barriers to get them routinely screened for FCR. However, we recommend the following instruments for assessment of FCR based on a systematic review that used the COSMIN criteria: the FoP-Q-SF/PR and the FCRI-Caregiver version for assessment of FCR.

Following a positive screening, we recommend that a thorough assessment be performed, after which patients and care partners should be offered an intervention that ideally matches the severity level of their FCR and their preferences. For patients with low FCR, such interventions may consist of psychoeducation, normalization, and appropriate reassurance from cancer specialists as well as a referral to non-specific interventions such as exercise programs. Specifically, healthcare providers can normalize the presence of minimal or low FCR following predictable triggers such as annual visits to the cancer centre or waiting for test results.

For those with low-to-moderate FCR, referrals to professionally led support groups that allow the exploration of the meaning and emotions associated with the experience of cancer or to a psychoeducational group that discusses the management of cancer during the survivorship phase may be helpful. Although the research evidence for these interventions is limited, such resources may already be available in some cancer centres or in the community and thus may be easier to implement as part of a matched care approach. If available, self-led CBT interventions for FCR can also be suggested even for those with severe FCR. We would recommend re-assessing patients after completion of these low- and moderate-intensity interventions to determine if their FCR scores still indicate a need for further interventions. Patients that still report moderate FCR after completing an initial more minimal intervention and those that scored in the clinical level of severity at baseline could be referred to more intensive treatment options. Compared to lower intensity treatment options, interventions for clinical FCR have been well-documented. Cancer centres have many evidence-based options to choose from in terms of format and theoretical approaches: face-to-face, blended, individual, group, CBT, ACT, MBSR, etc. Patient preference and availability of existing resources may guide the selection of the intervention in the absence of comparative trials assessing their differential efficacy. Unfortunately, currently, there is insufficient evidence of interventions to make recommendations for care partners, and we encourage researchers to design and test interventions for this population. Recent efforts by Lamarche et al. suggest that adapting existing FCR interventions may be acceptable to care partners and clinicians [45].

**CONCLUSIONS**

A large body of literature has clearly established survivors' desire for help with their FCR and the substantial prevalence, stability, and negative individual and systemic impacts of this fear. In the past decade, several FCR interventions for those with clinical FCR have been developed and tested through rigorous RCTs and can be implemented in cancer centres. Other interventions (e.g., psychoeducation groups, support groups, exercise) for patients presenting with low and low-to-moderate FCR may be beneficial and can be part of a comprehensive matched-care approach for addressing FCR.

# Fear of Cancer Recurrence Guideline

## Section 5: Internal and External Review

**INTERNAL REVIEW**

The guideline was evaluated by the GDG Expert Panel and the PEBC Report Approval Panel (RAP) (Appendix 1). The results of these evaluations and the Working Group's responses are described below.

**Expert Panel Review and Approval**

Of the 11 members of the GDG Expert Panel, 11 members voted and 0 abstained, for a total of 100% response in November 2023. Of those who voted, 11 approved the document (100%). The main comments from the Expert Panel and the Working Group's responses are summarized in Table 5-1.

**Table 5-1. Summary of the Working Group's responses to comments from the Expert Panel.**

| Comments | Responses |
|---|---|
| 1. Would it be worthwhile to include the threshold on the various assessment tools that are used to define levels of FCR? | We have added a list of assessment tools and thresholds into the glossary. |
| 2. Shouldn't healthcare professionals explain more about minimal or low FCR, because patients don't know when FCR is normal or clinically significant. There should be some clarification around the definition of low FCR and consider an expected level of FCR. | We have added a statement in the discussion regarding the normalizing of this reaction to predictable triggers in the discussion. |
| 3. The definition of telecoaching is too specific to one study. | We have modified the definition to be more generic. |
| 4. Should you talk about sensitivity and specificity here in Recommendation 1? | We have added sensitivity and specificity data to key evidence for Recommendation 1.1. |
| 5. Consider adding recommendations for when FCR is comorbid with psychiatric illness and guidance on developing an evidence-based treatment plan when FCR is present alongside major depression, for instance. | The Working Group feels that there is not enough information regarding this issue to provide recommendations. |
| 6. It needs to be indicated somewhere that most of the evidence supporting these guidelines is from people with early-stage cancer. | We have added this information into the discussion section. |
| 7. Should CBT be included in the definition of MBI? | The American Psychological Association states that there are elements of CBT in MBI, so we adjusted the definition to reflect that. |
| 8. If you are going to recommend a screening tool, you need to provide cut-offs that would determine which intervention recommendation (low, moderate, high) to apply. Right now, it is just suggested to use a cut-off of 5. What would be considered low or high? | This is a screening tool that clinicians can use to 'flag' people who need a bit more assessment. A score of 0-4 is considered low, 5 and above is a signal for most assessment to check again. We have clarified that in the document. |

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| 9. It would be helpful to have guidance on when to administer this item – before, during, or after oncology care visits. I am a bit concerned about the risk of false positives depending on the timing of item administration to patients (day before vs. in the waiting room vs. after the visit). | We have added that patients should be screened at each visit since there may be fluctuations in individual variability. |
| 10. How they would administer these questionnaires routinely, unless a care partner was already under their care/had their own chart This should either have different wording, or should include recommendations for how caregiver health data would be managed | We have added this detail into implementation section. |
| 11. Is there any evidence to support monitoring FCR symptoms without intervention, unless considered bothersome by the patient? | There is not any evidence to support this. The Working Group feels that the use of the screening tool at each appointment with help monitor flux in FCR. |
| 12. What about psychoeducation/education materials for people with low FCR? | The research showed psychoeducational materials were not effective in people with low FCR. |
| 13. You do not say anything about relaxation training in the recommendation. Should this be added based on this? | We have added relaxation training into the recommendation. |
| 14. Clarify that the presentation of FCR can vary by phase of survivorship/treatment status (recurrence vs. progression). Clarify that FCR can occur with or without a comorbid anxiety or depressive disorder. | We have added this information into the discussion section. |
| 15. Consider adding recommendations for when FCR is comorbid with psychiatric illness and guidance on developing an evidence-based treatment plan when FCR is present alongside major depression, for instance. | The Working Group feels this is not within the scope of the guideline. |
| 16. There was evidence from a review that contemporary CBT was more effective than traditional CBT approaches. Should we not be mentioning that here? | The Working Group feels that the ages of the studies of the different interventions affected the results of the review. For all interventions We state that the evidence does not support one method as superior over others. |
| 17. Consider adding resources provided by the Psycho-Oncology Co-operative Research Group (PoCoG) of Australia. | We have added these resources. |
| 18. I'm not sure this is how I would characterize ConquerFear sessions. More a mix of ACT and Metacognitive Therapy than MBI. | We have changed the description of the ConquerFear description to one provided by the ConquerFear group. |

**RAP Review and Approval**

Three RAP members reviewed this document in November 2023. The RAP approved, the document, November 2023. The main comments from the RAP and the Working Group's responses are summarized in Table 5-2.

**Table 5-2. Summary of the Working Group's responses to comments from RAP.**

| Comments | Responses |
|---|---|
| 1. Not sure what is meant by this statement "given the evidence for care partners having high FCR". Does it mean there is a high prevalence of FCR in this group implying that this is a significant problem?<br>In Recommendation 1.2, reference is made to an average of 48% but it is not clear in the sentence what the percentage refers to. Does it mean that 48% of care partners also suffer from FCR? | Yes, there is a significant problem with 48% of care partners having high FCR. We have clarified this statement in the document. |
| 2. Would it really need to be at each follow-up visit? Is this what was done in the studies? Is there a chance it would trigger more frequent investigations if it were to become a more standard question using the ESAS platform? | Patients should be screened at each visit since there may be variability and fluctuations in individual's experience.<br>We have added a statement in the discussion regarding the normalizing of this reaction to predictable triggers. |
| 3. Did the length of time since diagnosis and treatment make a difference in the recommendations? | There was not enough evidence to determine when an intervention worked the best. We have added a statement in the key evidence to clarify that. |
| 4. If the patient was transferred to a Wellness Program or to be followed by the family doctor, did the level of FCR change? Should new screening tools or interventions be performed? | The Working Group feels that screening should be completed at each visit with a health care provider. The level of FCR remains stable over time unless addressed. |
| 5. When the acronyms FCRI, FCRI-SF, FoP-Q-SF/PR and FCRI-C are introduced, there should be an annotation as a footnote, or they should be spelled out in the text. Please include more information on these scales perhaps in an appendix. | We have added a list of assessment tools and thresholds into the glossary and wrote out FCRI-Caregiver fully to avoid any misunderstandings with other FCRI-C acronyms. |
| 6. Could examples of low intensity interventions be included here to better inform the reader of what is meant by a low intensity intervention. | We have provided some examples of low intensity interventions into Recommendation 3.1. |

## EXTERNAL REVIEW

### External Review by Ontario Clinicians and Other Experts

#### *Targeted Peer Review*

Five targeted peer reviewers from Ontario, Quebec and Europe who are considered to be clinical and/or methodological experts on the topic were identified by the Working Group. Two agreed to review the guideline (Appendix 1). The results of the feedback survey are summarized in Table 5-3. The main comments from targeted peer reviewers and the Working Group's responses are summarized in Table 5-4.

**Table 5-3. Responses to nine items on the targeted peer reviewer questionnaire.**

| | Reviewer Ratings (N=2) | | | | |
|---|---|---|---|---|---|
| **Question** | Lowest Quality (1) | (2) | (3) | (4) | Highest Quality (5) |
| **1. Rate the guideline development methods.** | | | | | 2 |

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| **2. Rate the guideline presentation.** | | | | 1 | 1 |
| **3. Rate the guideline recommendations.** | | | | | 2 |
| **4. Rate the completeness of reporting.** | | | | | 2 |
| **5. Does this document provide sufficient information to inform your decisions? If not, what areas are missing?** | | | | | 2 |
| **6. Rate the overall quality of the guideline report.** | | | | | 2 |
| | Strongly Disagree (1) | (2) | Neutral (3) | (4) | Strongly Agree (5) |
| **7. I would make use of this guideline in my professional decisions.** | | | | | 2 |
| **8. I would recommend this guideline for use in practice.** | | | | | 2 |
| **9. What are the barriers or enablers to the implementation of this guideline report?** | **Enablers:**<br>Wide dissemination, including publication in a high-impact journal will be critical.<br>Financial resources and the will to reach out for a high standard of psychosocial care by the Chair and all health professions involved.<br><br>**Main barriers:**<br>Low number of specifically qualified psychotherapists for providing special treatments for patients with high FCR, lack of training in nursing staff and oncologists for providing low-intensity interventions for low to medium FCR. | | | | |

**Table 5-4. Summary of the Working Group's responses to comments from targeted peer reviewers.**

| Comments | Responses |
|---|---|
| A summary table that simplifies the decision-making process and choices for assessment and interventions would be helpful (e.g., Decision Tree?) | The Working Group agrees and will make a flow chart to allow for an easy way to follow the recommended steps. |
| There is no doubt about the completeness of the extant information. However, some attention might be put into how assessment of FCR integrates with symptom and distress screening overall and the possible overlaps. This would help clinicians be clearer about the specifics of the interventions recommended and more generic psychosocial issues which might impact FCR. | We have added a statement regarding the specificity of FCR interventions in the preamble. |
| Little information is given relating to possible harms and risks, but there is no empirical evidence available with regard to interventions for treating FCR. | There is currently no information published on harms or risks with FCR interventions that were recommended. |
| One minor critical point is that, as far as I understand, no physician/oncologist participated in the Working Group, and there was just one out of 11 in the expert panel. Thus, the medical profession might be a little bit underrepresented in the development of the guideline – but it is included. | The Working Group feels that the professional consultation included many different oncologists. As well, the RAP members are all oncologists. |

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| Some background information on available results relating to intervention acceptance and patient satisfaction might be helpful. | While high-intensity interventions have shown satisfaction and acceptance in pilot stages, there are no published data about their acceptability in real-life settings. |
| Preamble: The authors state that there is no consensus on the definition of clinical FCR. However, Mutsaers et al. Psycho-Oncology 2020;29:430-436 report on an international Delphi study that reached expert consensus on defining features of clinical FCR. The authors should clarify their statement. | We have clarified the statement. |
| Recommendation 1.1 – Patients: As there are several one-item screening questions on FCR, it might be useful to include a reference on the FCR-1r, so the graphical presentation of the single item could be clearly related to the relevant publication. | The Working Group agrees and have added a reference to the qualifying statement. |

### *Professional Consultation*

Feedback was obtained through a brief online survey of healthcare professionals and other stakeholders who are the intended users of the guideline. All nurses, nurse practitioners, advanced practice nurses, psychologists, radiation oncologists, primary care providers and medical oncologists in the PEBC database were contacted by email to inform them of the survey (n=620) Forty-six responses (8%) responses were received. Thirty-one stated that they did not have interest in this area or were unavailable to review this guideline at the time. The results of the feedback survey from 46 people are summarized in Table 5-5. The main comments from the consultation and the Working Group's responses are summarized in Table 5-6.

**Table 5-5. Responses to four items on the professional consultation survey.**

| | **Number of responses (%)** | | | | |
|---|---|---|---|---|---|
| **General Questions: Overall Guideline Assessment** | Lowest Quality (1) | (2) | (3) | (4) | Highest Quality (5) |
| **1. Rate the overall quality of the guideline report.** | | 3 (6) | 9 (20) | 22 (48) | 12 (26) |
| | Strongly Disagree (1) | (2) | (3) | (4) | Strongly Agree (5) |
| **2. I would make use of this guideline in my professional decisions.** | 2 (4) | 6 (13) | 10 (22) | 15 (33) | 13 (28) |
| **3. I would recommend this guideline for use in practice.** | 3 (7) | 5 (11) | 2 (4) | 22 (48) | 14 (30) |

4. **What are the barriers or enablers to the implementation of this guideline report?**

Practitioners listed enablers to the implementation of this guideline that included the following:

- Adding a simple one-question screen to initiate conversation is doable. Perhaps an addition to existing ESAS initiatives would take minimal effort.
- Ease of use and proven results.

- The knowledge that patients will be better supported and able to have a better QOL if their FCR is addressed.
- Patients would benefit from the interventions to alleviate FCR, which in turn may be cost-effective in the long term and would also increase their QOL.
- Could be done by a nurse or another person.
- Having support for treatments for FCR available makes it easier to initiate the conversation.

Practitioners listed barriers to the implementation of this guideline which included the following:

1. Time
   Several practitioners commented on the time it may take to complete an assessment, discuss the issue, and initiate any intervention.

2. Resources
   Many practitioners commented on the lack of resources to complete an FCR assessment in terms of people to do the assessments, and the lack of readily available programs for people of different levels of FCR. Comments also included the lack of people trained to provide programs. It was also mentioned how different areas have different access to interventions. Interventions that are helpful may not be available at all centres. Also, resources that are not covered by OHIP would not be accessible to many patients.

3. Education
   Some practitioners stated that education about FCR is lacking in front-end staff, healthcare workers and patients. Many lack awareness and knowledge of the importance of this issue. It was also stated there should be education on how to find resources for patients and care partners and that it is not as clear what the resources are for staff looking to increase their own knowledge and skillset to support patients.

4. Delivery
   Some practitioners stated that there may be a lack of consensus about when to introduce patients to FCR concepts and when to conduct any assessments. Also, there were questions regarding who should conduct the assessments and manage the results. There is a need to find leaders and motivators to encourage healthcare providers to use the guideline and to translate the recommendations into practice. The screening should be incorporated easily for the patient, but assessment of the care partners will be less so.

5. Access
   Practitioners commented that there are many marginalized persons who speak and understand neither official language and who are not able to do online activities because of financial poverty and inability to assess technologies.

**Table 5-6. Summary of the Working Group's responses to comments from professional consultants.**

| Comments | Responses |
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| Considering limited follow-up period within the cancer care system, issues associated with FCR would have to | The Working Group agrees and have added some sentences regarding education for all healthcare workers and |

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| be monitored largely within the primary care health system. This will require education and coordination.<br><br>A basic educational platform specific to patients in Ontario would be helpful so that resources/slide show could be shared with patient support groups. | patients in the Implementation Considerations Section.<br><br>However, it is important to note that people with FCR do not want to leave their oncologist. |
| There were some concerns that many of the recommendations are not evidence based and had some expert opinion due to insufficient evidence, lack of comparative studies, more research needs to be conducted etc.<br>This leads to a lack of confidence in recommendations, although they seem to have face validity/common sense. | The Working Group disagrees with the idea that the recommendations are not useful. The Working Group used evidence to develop the recommendations and where there was not enough evidence, the Working Group used expert opinion. The PEBC starts with evidence and where the evidence is lacking, uses expert opinion to try to guide practice. There are many studies, especially for high-intensity interventions, that show interventions work. There are also studies that show doing nothing does not resolve FCR. |
| Recommendation 3.3 touches on the use of CBT with specialists with more familiar understanding of oncologic care and oncologic needs, but the wide applicability of that is limited especially in community centres and so knowing what other options may exist for resource-limited environments is important - especially in consideration of the fact that mental health services are always a limited resource. | The Working Group has added a section on resources to help with that. As well, there are plans to try to promote the screening and assessment of FCR as well as interventions. |
| There is a recommendation for mindfulness practices, but which ones are better validated? Are there any that are subsidized for an oncology population? | There is no evidence showing one practice being better than another. We have added another resource with a mindfulness program. |
| I am not convinced it needs to be a question asked at every visit embedded in the ESAS tool for two reasons:<br>1. It is not clear to me from the evidence presented that screening with the current anxiety question is not enough and that an additional question is required. The anxiety algorithm was modified so that the first question in the focused assessment asks if the patient is anxious because of a situational or contributing factor. These include things such as test results, recurrence, other unmanaged symptoms.<br>2. I do not think this question should be asked at every appointment. With the Improving Patient Experience and Health Outcomes Collaborative study CCO participated in, I believe anxiety related to recurrence increased more than one year post treatment completion. I feel the question should be asked at the most relevant time periods and not necessarily every appointment starting with the initial consult. I would be willing to change my opinion if the evidence showed this, but I do not feel there is any strong evidence presented in this guideline to make such a big recommendation at this time. While the guideline does | Preliminary evidence has shown that the FCR item is more specific than the one item anxiety item [18].<br><br>The evidence points to the fact the FCR does not decrease over time [19] and does not correlate with time since diagnosis [4]. Based on this information, early detection would be beneficial so limiting screening of FCR only to key moments such as end of treatment or transition to primary care is not recommended. |

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| say at follow-up appointments, it is not clear whether this question would be added only during that phase of care or not.<br><br>I support all of the recommended interventions as this unmet need can be better addressed for patients and hopefully caregivers one day too. | |
| The population at risk is composed of persons at extremely high risk of recurrence along a spectrum to extremely low risk of recurrence. Recommendations and interventions should be specific to the risk level. | The Working Group feels that each person needs to be screened for FCR, it is an individual occurrence and not based on risk level. |
| If added to ESAS, how will this question be perceived by patients who already have cancer recurrence/progression? | The Working Group feels that the evidence has shown that asking a question regarding fear of recurrence does not upset those patients with recurrence. |
| The guideline seems more relevant to specialists in this area than to oncologists without specialist knowledge (reading this was hard going!). | The Working Group hopes that the flow chart and presentations of the information to cancer centres will help with the understanding and implementation of the recommendations. |
| There were some comments regarding grammatical errors. | These have been fixed. |
| Those scoring under 5 are considered to have low FCR. Those scoring above 5 require further assessment. Subsequent recommendations are made about low-intensity interventions for patients with low FCR, although this group appear not to be recommended to receive more detailed assessment tools. How can they be reliably assessed as having low FCR then? | People with scores under 5 are not considered to have FCR and do not need extra screening. The full assessment of FCR for those scoring above 5 on the screening tool will be given low, moderate, or high interventions. |
| There is a recommendation to screen care givers for FCR but little evidence to justify this. In reading the systematic review there appears to be significantly less literature for care givers, both screening tools and interventions. There is a recommendation that care givers would benefit from intervention. I do not think there is sufficient evidence to justify this, particularly as resources are likely not readily available for this. | There is evidence of care givers having FCR as shown in the two systematic reviews cited. There were, however, no screening tools found for this population, but there are assessment tools available. |
| Some degree of FCR is normal and, in fact, its absence generally indicates poor comprehension of the patient's situation or delusional denial except for a minority of patients with an exceptionally good prognosis. FCR can be an important motivator for patients to adhere to medications and lifestyle recommendations. There is also a significant shortage of mental health professionals in the province overall including cancer centres and most cancer centres are forced to triage patients and only treat the neediest. Given this situation as well as the fact that FCR increases normally at the time of appointment, it does not seem either practical or appropriate to offer any kind of intervention for patients with low to moderate FCR. | It is up to each cancer centre to focus on high FCR but many will have resources for moderate or low FCR and general well being.<br><br>It is important to recognize and refer patients to existing resources. There are many such resources listed in the supplemental information. |
| Review the FCR resource list. For example, is “Fear of cancer recurrence during COVID-19” still relevant in a guideline going to be published in 2024? | The resources have been reviewed by the Working Group and deemed to be relevant and useful. (COVID is still an |

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| | issue in 2024 and likely will be for some time) |
| Nothing else exists as far as I am aware of. This seems to apply mostly to specialty care. I would have liked something for primary care as well as we see the bulk of these patients once discharged from oncology and effectively deal with the FCR forever. There are two phases of this, I think: the acute phase and the more chronic phase, and I do not know that this has been addressed. It seemed to me that this was referring to patients who were in active oncology care but correct me if I am wrong. That was my impression | FCR does not decrease with time. The Working Group feels that there are roles for the cancer centre and primary care. Screening for FCR could be conducted at both locales and interventions prescribed at both. |
| I know this was addressing adults but there are other people in patient's families to think of and for me it would be difficult to implement without including patients' children who are integral parts of the family and have their own fears about mom/dad and cancer. | The definition of care partners includes the whole family. |
| I acknowledge that by providing a first step in recognizing this exists, we can then facilitate techniques/processes and study questions to find the answers that presently do not exist.<br><br>Thank you for this.<br><br>As a practitioner in a small remote clinic in Northern Ontario, in a community within adequate access to third-party payers/trained professionals to address our patients emotional and other needs for mental health, I would welcome opportunity to explore strategies and pilots which could be used. We are geography rich and population poor in Northern Ontario, and we are well versed in virtual care so I would be prepared to pilot virtual care projects at our site. | No action required. |
| I am a patient as well as a family doctor; I would certainly appreciate being asked about FCR at visits to the cancer clinic | No action required. |
| It would be interesting to review the impact of cancer support groups on FCR. Some of these groups are quite active, provide educational materials and some types of mental health support. Clearly that is not going to happen for the current guideline but is nonetheless quite relevant. | No action required. |
| Overall, the recommendations and strategies proposed will benefit patients/families living with cancer, there is a need for healthcare professionals, healthcare systems and organizations to incorporate more formally incorporate the recommendations outlined within this quality initiative.<br>May have to look in to creating patient champions for this project | No action required. |
| This is a very important aspect of patient and care partner experience for our system to better understand and address. Very pleased to see this guideline. | No action required. |
| The barriers would be compliance of screening patients at clinic appointments, but I also see this as the perfect | No action required. |

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| place for these guidelines to be implemented. I think also that anyone who has contact with the patient, i.e., nurses and radiation treatment therapists that build up a rapport with the patient, could refer the patient for screening if they felt that the patient had a high or concerning FCR.<br><br>I think that this a much-needed guideline and from knowing someone close who has gone through treatment and suffers every time there is bloodwork or other tests such as check-up MRIs or CT scans, I think this will be well received. I look forward to seeing it being implemented. | |

**CONCLUSION**

The final guideline recommendations contained in Section 2 and summarized in Section 1 reflect the integration of feedback obtained through the external review processes with the document as drafted by the GDG Working Group and approved by the GDG Expert Panel and the PEBC RAP.

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## Appendix 1: Affiliations and Conflict of Interest Declarations

In accordance with the PEBC Conflict of Interest (COI) Policy, the guideline authors, The Fear of Cancer Recurrence Guideline Working Group members, Expert Panel and internal and external reviewers were asked to disclose potential conflicts of interest.

**Table 1.1 Members of the Fear of Cancer Recurrence Guideline Working Group**

| Name | Affiliation | Declarations of Interest |
|---|---|---|
| Sophie Lebel<br>Psychosocial Oncology | University of Ottawa<br>Ottawa, ON | None |
| Laurie Freeman<br>Nursing/Psychosocial Oncology | University of Windsor<br>Windsor, ON | None |
| Jacqueline Galica<br>Nursing/Psychosocial Oncology | Queens University<br>Kingston, ON | None |
| Christine Maheu<br>Nursing/Psychosocial Oncology | McGill University<br>Montreal, QC | None |
| Rinat Nissim<br>Psychosocial Oncology | University Health Network<br>Toronto, ON | None |
| Josée Savard<br>Psychosocial Oncology | Université Laval<br>Québec City, QC | None |
| Lise Craig | Patient/Caregiver Representative | None |
| Randall Conrod | Patient/Caregiver Representative | None |
| Caroline Zwaal<br>Health Research Methodologist | Program in Evidence-based Care, McMaster University<br>Hamilton, ON | None |

**Table 1.2 Members of the Fear of Cancer Recurrence Guideline Expert Panel**

| Name | Affiliation | Declarations of interest |
|---|---|---|
| Aronela Benea<br>Advanced Practice Nurse | Women's College Hospital<br>Toronto, ON | None |
| Cristiane Bergerot<br>Psychologist | City of Hope Comprehensive Cancer Center, USA | None |
| Lori Bernstein<br>Psychologist | University Health Network<br>Toronto, ON | None |
| Phillis Butow<br>Psychologist | University of Sydney<br>Sydney, Australia | None |
| Daniel Hall<br>Psychologist | Harvard Medical School<br>Boston, MA, USA | None |
| Lynne Jolicoeur<br>Nurse Practitioner | The Ottawa Hospital<br>Ottawa, ON | None |
| Jennifer Jones<br>Survivorship | University Health Network<br>Toronto, ON | None |
| Danielle Petricone-Westwood<br>Psychologist | Toronto, ON | None |
| Judith Prins | Radboud University | None |

| | | |
|---|---|---|
| Psychologist | Nijmegen, the Netherlands | |
| Ben Smith<br>Psychologist | University of Sydney<br>Sydney, Australia | None |
| Amirrtha Srikanthan<br>Oncologist | The Ottawa Hospital<br>Ottawa, ON | None |

**Table 1.3 Members of the Report Approval Panel and Declarations of Interest**

| Name | Affiliation | Declarations of Interest |
|---|---|---|
| Jonathan Sussman | Juravinski Cancer Centre | None |
| Donna Maziak | Ottawa General Hospital | None |
| Bill Evans | Retired | None |

**Table 1.4 Members of the Targeted Peer Review and Declarations of Interest**

| Name | Affiliation | Declarations of Interest |
|---|---|---|
| Andreas Dinkel | Technische Universität München | None |
| Zeev Rosberger | McGill University | None |

**Appe**ndix 2: Literature Search Strategy

**Systematic Reviews**

1. Survivors/or Cancer Survivors/ or Neoplasm Recurrence, Local/ or "fear of cancer recurrence".mp. or Adult/ or Fear/
2. (systematic adj (review: or overview:)).mp.
3. (meta-analy: or metaanaly:).mp.
4. (pooled analy: or statistical pooling or mathematical pooling or statistical summar: or mathematical summar: or quantitative synthes?s or quantitative overview:).mp.
5. (exp review literature as topic/ or review.pt. or exp review/) and systematic.tw.
6. (cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinhal or cinahl or science citation index or scisearch or bids or sigle or cancerlit or pubmed or pub-med or medline or med-line).ab.
7. (reference list: or bibliograph: or hand-search: or handsearch: or relevant journal: or manual search:).ab.
8. or/2-7
9. (selection criteria or data extract: or quality assess: or jadad score or jadad scale or methodologic: quality).ab.
10. (stud: adj1 select:).ab.
11. (8 or 9) and review.pt.
12. 8 or 11
13. Cancer Survivors/ and Neoplasm Recurrence, Local/ and Adult/ and Fear/
14. fear of cancer recurrence.mp.
15. 13 or 14
16. 15 and 12
17. Patient Outcome Assessment/ or assessment.mp.
18. 15 and 17
19. screening.mp. or Mass Screening/
20. 15 and 19
21. 20 and 12
22. 18 and 12

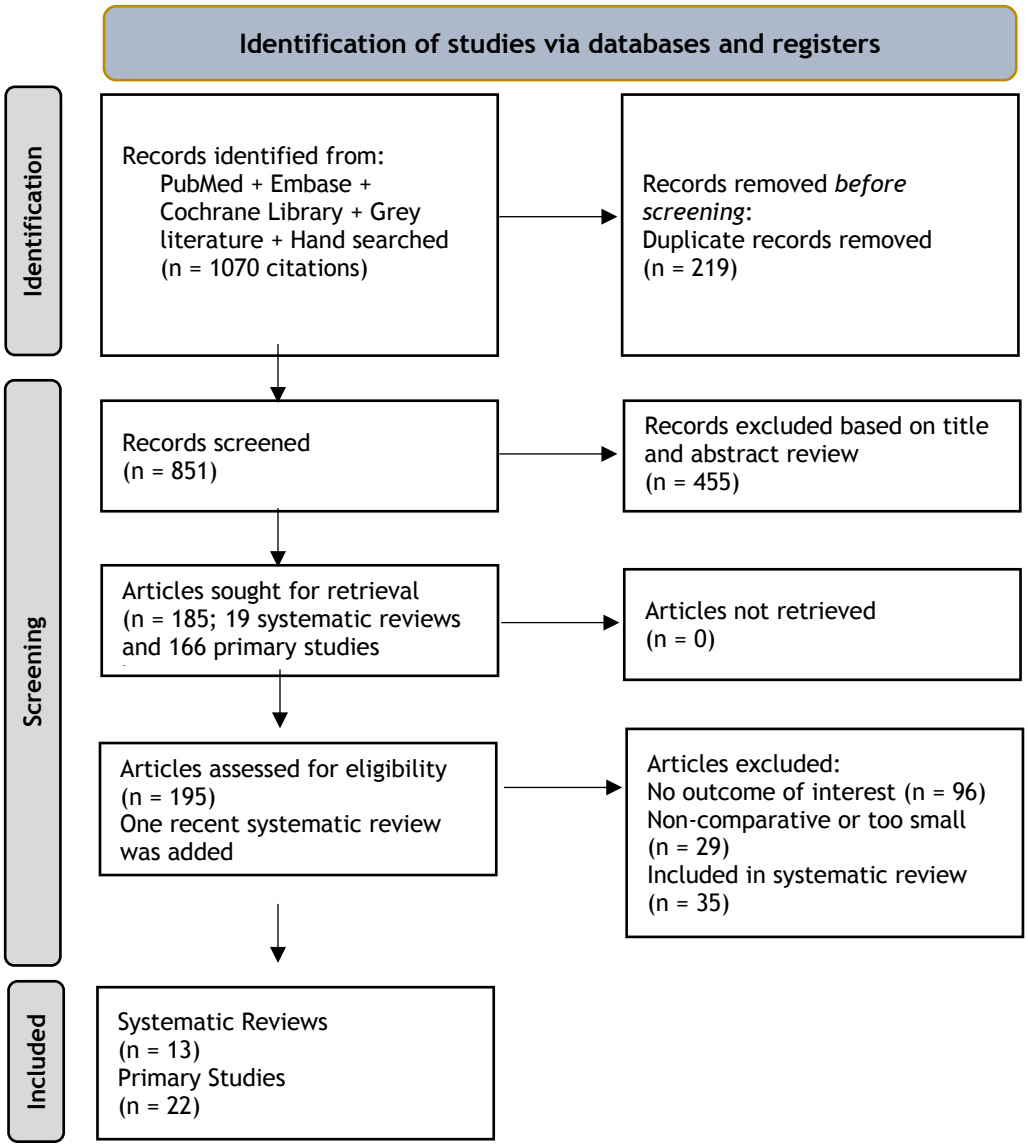
**Primary Literature**

1. (cancer or neoplasm or oncology or malignancy).mp.
2. ((anxiet* or worr* or fear* or concern) and (relapse or recur* or progress*)).mp.
3. Recurrence/ or Neoplasm recurrence, Local/
4. Fear/ or Anxiety/ or Stress, Psychological/ or exp Adaptation, Psychological/
5. 3 and 4
6. 5 and 1
7. screening.mp. or Mass Screening/
8. Symptom Assessment/ or assessment.mp.
9. 7 or 8
10. 6 and 9
11. 6 and 7
12. 6 and 8
13. 11 or 12
14. (comment or letter or editorial or note or erratum or short survey or news or newspaper article or patient education handout or case report or historical article).pt.
15. 13 not 14
16. 6 not 14

**Primary Literature of FCR Screening**

1. fear of cancer recurrence.m_titl.
2. fear of cancer recurrence.mp.
3. fear of cancer progression.m_titl.
4. cancer worry.m_titl.
5. screen.m_titl.
6. 1 or 2 or 3 or 4
7. screening.m_titl.
8. 5 or 7
9. 6 and 8
10. patient-reported outcome measure.mp.
11. 9 and 10
12. single item measure.mp.
13. 9 and 12
14. 11 and 12
15. measure.m_titl.
16. 9 and 15
17. remove duplicates from 16
18. limit 17 to yr="2012 -Current"
19. remove duplicates from 8
20. limit 19 to yr="2012 -Current"

## Appendix 3: PRISMA Flow Diagram



## Appendix 4: Data Tables

### Table 4-1. Fear of Cancer Recurrence Screening Studies

| Study | Study characteristics | Results |
|---|---|---|
| **Smith, 2023** [18]<br>Evaluation of the validity and screening performance of a revised single-item fear of cancer recurrence screening measure (FCR-1r)<br><br>Please circle the number that best describes how you feel now:<br>On a scale from 0-10: No FCR (0) to Worst possible FCR (10)<br>(FCR=fear that your cancer with come back or get worse) | • Two studies<br>• 107 patients<br>• Aged 55-74<br>• Mixed cancer types<br><br>1. Cross-sectional with consecutive patients<br>Embedded in ESAS-r<br>N=54<br><br>2. Single arm feasibility<br>Consecutive?<br>Part of stepped-care study<br>After FCRI-SF<br>N=53 | Concurrent validity:<br>• with FCRI-SF (r=0.83. p<0.0001)<br>Convergent validity:<br>• Correlation with anxiety: r=0.63 (p<0.0001)<br>• Correlation with IES-r: r=0.55 (p<0.0001)<br>Divergent validity:<br>• No statistically significant associations between FCR- 1r scores and annual income (p=0.40), marital status (p=0.78) or employment status (p=0.40)<br>AUC: 91 (95% CI, 0.85-0.97, p<0.0001)<br>Cut-off Score: ≥5/10<br>• 95% sensitivity<br>• 77% specificity |
| **Rudy, 2020** [21]<br>The FCR-1: Initial validation of a single-item measure of fear of cancer recurrence<br><br>"On a scale from 0 to 100, what is your subjective level of fear of cancer recurrence at this time?" | • 69 patients<br>• Between 29-83 years (mean =55.5 yr SD=11.3)<br>• Breast or gynecological cancer<br>• In FORT (6 sessions)<br>• with at least ≥13 on FCRI -SF and ≥24 on IES<br>Assessments:<br>• 2 weeks before intervention<br>• 1 week after<br>• 3-month post<br>• 6-month post | Convergent validity:<br>• Correlation with FCRI, r=0.39 (p=0.01) overall<br>• Correlation with FCRI-SF, r=0.32 (p=0.05) overall<br>• Correlation with MUII: r=0.49 (p =0.001)<br>• Correlation with IES, r=0.28 (p=0.08)<br>• Correlation with RQ, r=0.32 (p=0.04)<br>Discriminant validity:<br>• No statistically significant associations between FCR-1r scores and annual income (p=0.91), marital status (p=0.23) or employment status (p=0.47), ethnic background (p=0.87) or cancer stage (p=0.40)<br>AUC: 85 (95% CI, 0.71-1.0, p<0.001)<br>Cut-off Score: ≥45/100<br>• 70% sensitivity<br>• 89.5% specificity |
| **Rogers 2016** [20]<br>A single-item screening question for fear of recurrence in head and neck cancer<br><br>Fear of the cancer coming back (Tick one box): | • 513 patients<br>• Median=65 yrs (58-72)<br>• 71% male<br>• Head and neck cancer | Convergent validity:<br>• Correlation with UW QoL FCR questions: Spearman rs=-0.82, p<0.001<br>• Strong associations with aspects of dysfunction particularly anxiety and mood dysfunction, p<0.001 for both |

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| ◊ I have no fear of recurrence<br>◊ I have a little fear, with occasional thoughts but they don't really bother me<br>◊ I am sometimes having fearful thoughts, but I can usually manage these<br>◊ I get a lot of fears of recurrence, and these can really preoccupy my thoughts<br>◊ I am fearful all the time that my cancer might return, and I struggle with this | | |
| **Deuning-Smit 2023** [76]<br>Evaluating the capacity of the distress thermometer to detect high fear of cancer recurrence. | • 149 breast cancer<br>• 74 CRC survivors<br>• Mean age=56.3 years<br>• 82% female | Compared Distress Thermometer with cancer worry scale-6:<br>• ≥10 on CWS-6<br>• the DT score cut-off ≥4 in clinical guidelines had sensitivity of 65%, specificity of 67%, PPV of 75% and NPV of 56% for CWS-6 ≥10.<br>• For CWS-6 ≥12, the DT ≥4 cut-off had 72% sensitivity, 58% specificity, 47% PPV and 80% NPV<br>• Using the CWS-6 ≥10 cut-off, the sensitivity of the fears item was 29.3%, the specificity was 95.4%, the PPV was 90.7% and the NPV was 46.9%. |
| **Rogers, 2020** [22]<br>Improving quality of life through the routine use of the patient concerns inventory for head and neck cancer patients: main results in a cluster preference randomized controlled trial | • 188 head and neck cancer patients<br>• 140 completed the patient concerns inventory<br>• 148 control patients | • Fear of recurrence is frequently raised by patients on the PCI and is recognized as a major concern over many follow-up consultations.<br>• Hypothesized that the prompt allows the patient permission to talk about this aspect and seek reassurance or further information.<br>• Using the PCI might allow more passive HNC patients to take a more active role in medical consultations. |

**Abbreviations**: AUC: area under the curve; CRC: colorectal cancer; CWS-6: Dutch Cancer Worry Scale-6; DT: Distress Thermometer; ESAS-r: Edmonton Symptom Assessment System-revised; FCR-1r: single-item fear of cancer recurrence measure; FCRI: Fear of Cancer Recurrence Inventory; FCRI-SF: Fear of Cancer Recurrence Inventory Short Form; FORT: Fear of Cancer Recurrence Therapy; HNC: head and neck cancer; IES: Impact on Event Scale; IES-r: Impact of Event Scale-Revised; IES: Impact on Event Scale; MUII: Mishel Uncertainty in Illness Inventory; NPV: negative predictive value; PCI: Patient Concerns Inventory; PPV: positive predictive value; RQ: Reassurance Questionnaire; SD: standard deviation; UW QoL: University of Washington Quality of Life Questionnaire

## Table 4-2. Fear of Cancer Recurrence Intervention Systematic Reviews

| Study | Description | Interventions\Assessments | Main Findings |
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| **Screening** | | | |
| Webb, 2022 [25]<br><br>Systematic<br><br>Caregiver FCR: comparing FCR levels, and FCR measures | 45 studies | Studies with the aim to develop or validate a caregiver measure of FCR were evaluated with COSMIN<br>Meta-analysis comparing mean caregiver FCR with patient FCR with 24 studies<br><br>Caregiver versions:<br>FoP-Q-SF/PR, FoP-Q-SF/P, FCRI-Caregiver, FCRI-P | The overall combined difference in level of FCR between patient and caregiver FCR was not statistically significant (k = 24; g = 0.099; 95% CI −0.045–0.242, p=0.178) but heterogeneity was considerable (Q = 204.12, p<0.0001, $I^2$=85.79; 95% CI, -0.66-0.85).<br>Thirteen studies examined the level for caregiver FCR, and the mean was 48%, range 18-78%.<br>Twelve different instruments used to measure caregiver FCR were evaluated using the COSMIN criteria.<br>Twelve instruments were used to measure FCR in caregivers, although they were not developed for caregivers specifically.<br>The FoP-Q-SF/PR was found to have 67% of the COSMIN criteria and the FCRI-Caregiver was found to have 47%, the FCRI-P had 40%.<br>The others had much lower scores. |
| **Assessment and measurement** | | | |
| Maheu, 2025 [88] | 32 studies | Followed the COSMIN 10-step procedure and PRISMA 2020 guidelines to analyze patient reported outcome measures from 2011-2023. | Of the 34 measures evaluated, 28 achieved COSMIN Category A status, indicating sufficient psychometric quality for clinical or research use.<br>The FCR-1 was the only single-item measure to demonstrate responsiveness, supporting its use in both screening and longitudinal monitoring.<br>For practical guidance, five brief measures such as the FCR-1, FCRI-SF, FoP-Q-SF, FCR7, and CWS are the most strongly supported for use.<br>Full-length scales like the FCRI and FoP-Q are valuable tools for more comprehensive assessment. |
| **Interventions** | | | |
| **Overall** | | | |
| Chen, 2018 [37]<br><br>Systematic<br><br>Summarize psychosocial interventions for FCR | 10 RCTs<br>992 participants<br><br>**Types of cancers:**<br>7 breast<br>2 mixed<br>1 melanoma | **Types of interventions:**<br><br>MBSR: 3 studies (face-to-face)<br>CBT: 4 studies, (face-to-face)<br>1 psychoeducational intervention study, (booklet and phone calls)<br>1 gratitude intervention study (online)<br>1 communication intervention study (unsure) | All MBSR studies found a significant decrease in FCR<br><br>All CBT studies found a significant decrease in FCR (one was couples based)<br><br>The gratitude intervention found a decrease in FCR<br><br>The communication intervention did not find a significant decrease in FCR |
| **Cognitive Behaviour Therapy - 3 SRs** | | | |
| Cincidda, 2022 [9]<br><br>Scoping<br><br>Available psychological interventions for FCR based on traditional | 35 articles<br><br>**Study type:**<br>11 RCTS<br>3 cohort studies<br>10 pilot studies<br>9 study protocols<br>2 case studies<br><br>**Types of cancers:** | **Face-to-face psychological interventions:**<br>***Traditional CBT*** (n=7; 4 RCT, 1 longitudinal, 1 single arm, 1 feasibility)<br>Side by side, AFTER, CCI, 6-week and 4-week sessions<br>***Contemporary CBT*** (n=12, 6 RCT, 1 open trial, 2 pilot, 1 feasibility, 1 single arm, 1 protocol)<br>MBSR, ACT, ConquerFear, Takin-it-easy, 12-week session<br><br>**Remote psychological interventions:** | **Face to face:**<br>All interventions measured found a significant decrease in FCR except CCI<br><br>**Remote:**<br>All interventions measured found a significant decrease in FCR except the cancer recurrence self-help training trial<br><br>**Blended:**<br>All interventions measured found a significant decrease in FCR |

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| CBTs or contemporary CBTs | 14 breast cancer<br>2 breast or gynecological<br>1 gynecological<br>1 prostate<br>1 testicular<br>3 colorectal<br>13 mixed types | ***Traditional CBT*** (n=3, 2 RCT, 1 study protocol)<br>AIM-FBCR, The Cancer Recurrence Self<br>***Contemporary CBT*** (n=5, 1 RCT, 1 feasibility, 1 pilot, 2 study protocols)<br>MBCT, mMBSR, iNNOVBC, e-TC, iConquerFear<br><br>**Blended psychological interventions:**<br>***Traditional CBT*** (n=7, 2 RCT, 2 case study, 3 protocol)<br>SWORD, BLANKET, CORRECT<br>***Contemporary CBT*** (n=1 study protocol)<br>ConquerFear | Resulted in a suggested program structure - a combination of face-to-face and web-based |
| Park, 2022 [8]<br><br>Cognitive behavioural therapy for reducing FCR among breast cancer survivors: a systematic review of the literature | 17 RCTs<br>Breast Cancer | **Group-based:** 11 studies<br>**Individual based:** 6 Studies<br><br>**Measures:** FCRI (8 studies), CARS (6 studies), FoP-Q-SF (2 studies), QLACS-FCR subscale (1 study), CWS (1 study) (1 study used 2 scales) | • Three studies reported no significant between group differences in FCR across time. The common aspects of these studies were: telephone or online format and brief sessions of less than 1 hour.<br>• Seven studies reported both significant main effects in the intervention groups and significant group-by-time interaction effects on all FCR scores over time. In general, these interventions were in four to eight 60- to 120-min; face-to-face group sessions; over at least 4 weeks; with trained mental health care professionals.<br><br>**Summary:**<br>Revealed that the included interventions were:<br>• comparable to each other in terms of the study design and methodology of CBTs (not the best methodology in all studies)<br>• interventions differed considerably in overall intervention structure (e.g., length and intensity).<br>• two- thirds used a group format with four to eight sessions, and group treatment formats were shown to have better outcomes in reducing FCR scores than individual formats.<br>• most studies used face-to-face delivery methods.<br>• the included studies used various FCR measures.<br>• study findings showed the effectiveness of CBTs on FCR for BCSs and suggested specifically: face-to-face group sessions with at least a one-month intervention duration were more effective in reducing FCR scores than those with brief online or telephone delivery methods. |
| Tauber, 2019 [38]<br><br>Meta-analysis<br><br>Efficacy of psychological interventions in alleviating FCR | 32 controlled trials<br>23 included in meta-analysis<br>2965 participants<br><br>**Types of cancers:**<br>17 breast<br>8 mixed<br>2 breast and gynecological<br>2 prostate<br>1 melanoma | Follow-up data was 29 weeks on average<br>8 studies had FCR as primary target for intervention<br><br>**25 interventions**:<br>10 traditional CBT<br>9 contemporary CBT<br>6 with varied interventions<br><br>**Type**:<br>group based: n=13<br>individual based: n=12 | **Meta-analysis:**<br>• overall combined postintervention effect size was of small magnitude (g = 0.33; 95% CI=0.20 to 0.46; p<0.001)<br>• overall combined effect size at follow-up was slightly smaller than at postintervention (g = 0.28; 95% CI=0.17-0.40; p=0.001).<br>• statistically significant effect on FCR outcomes of a small magnitude (g = 0.33) immediately after intervention, which was largely maintained at follow-up (g = 0.28), on average 7 months<br><br>**Significant moderators of effect:**<br>**Therapy:** post-intervention: contemporary CBT compared with traditional CBT: (g=0.42 vs. g=0.24); N=18; ß= 0.22; 95% CI=0.04 to 0.41, p=0.018 |

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| | 1 gynecological<br>1 oropharyngeal | **Number of sessions**:<br>ranged from 1-15, mean=6.6<br><br>**Follow-up:**<br>varied from 6 - 78 weeks | **Format**: in follow-up: group compared with individual: N=18; ß= 0.18; 95% CI= 0.01 to 0.36; p=0.041<br>**Time to follow-up assessment:** in follow-up: weeks (range, 6-78): N=14; ß=20.01; 95% CI= 20.01 to 20.00; p=0.027<br><br>**Non-significant moderators of effect:** post-intervention:<br>cancer type, FCR primary target, FCR level inclusion, format, delivery, gender, time to post-intervention assessment, number of sessions, mean sample age, FCR measure (CARS or FCRI) |
| **Mind Body Interventions - 2 SRs** | | | |
| Hall, 2018 [10]<br><br>Meta-analysis<br><br>Calculate MBI pooled effects on decreasing FCR | 19 RCTs<br>2806 participants<br><br>**Types of Cancer**: 11 breast<br>3 prostate<br>3 mixed<br>1 gynecological<br>1 melanoma | **10 self-report measures used for FCR**: GTUS, MUIS, CARS, FCRI, FCRS, FoP, IUS-SF, MAX-PC-FCR<br><br>**Most common:** MUIS (n = 6); CARS (n = 5); FCRI (n = 4)<br><br>**Treatment:** active treatment (n=5); post treatment (n=14)<br><br>**Duration**: from 9 days to 12 months: (median 1.5 months; modal duration = 1 month, n=5)<br><br>**Sessions**: range: 4-17 sessions: median=6; mode=4<br><br>**Session length:** range: 10-165 minutes; median and mode: 120 minutes;<br>Typical duration: 720 minutes of content (6, 120-minute sessions)<br><br>**Delivery:** one-on-one interventions: n=8; group intervention: n=8; combination: n=3<br><br>**Medium of delivery**: in person visits: n=12; telephone calls: n=8; audio tapes or CDs: n=6; booklets: n=4; online forums, chats; or websites: n=3; multiple mechanisms: n=11<br><br>**Components:**<br>single mind-body technique: n=9; combination of multiple practices: n=10;<br>CB skills: n=11; Relaxation skills: n=4; Meditation: n=10; Seated meditation: n= 4; Other: n=5<br><br>**Control groups**: active control: n=9, book of mindfulness skills: n=1, inactive control: n=10 | **Effects from preintervention to postintervention (17 studies)**<br>• the length of time between baseline and postintervention assessment ranged from 9 days to 14 months (median = 2 months), (significant heterogeneity $I^2$ =47.99)<br>• significant pooled effect of mind-body interventions on reducing FCR from pre-treatment to post-treatment (Hedges' g = −0.36, 95% CI = −0.49, −0.23, p<0.001)<br><br>**Effects in studies preintervention to longest follow-up (14 studies)**<br>• length of time between baseline and the distal assessment ranged from 40 days to 24 months (median = 8 months) (significant heterogeneity $I^2$ =63.36)<br>• pooled effect size from baseline to the longest follow-up (Hedges' g = −0.31, 95% CI = −0.47, −0.16, p<0.001)<br><br>In both above analyses, both active and inactive control groups had a significant effect on FCR, but the active control groups had a smaller effect, although the difference was not significant between the groups<br><br>**No significant subgroup comparisons**:<br>• despite effect size differences, groups vs individual; CB vs no CB; MM vs. no MM, unimodal vs. multimodal; post cancer treatment vs. current cancer treatment; 6 or less vs. 7 or more sessions.<br>• trends toward group, multimodal, shorter interventions: delivery, content, number of mind-body components, treatment status, number of sessions did not show any significant difference |

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| Baydoun, 2021 [78]<br><br>Systematic<br><br>Summarize and appraise the literature on rates and correlates of adherence to mindfulness home practice | -21 articles (up to Oct 2020)<br>-5 studies examined FCR<br><br>**Types of cancer:**<br>3 breast<br>1 mixed<br>1 melanoma | Two measures used: CARS FCRI<br><br>**Lengacher 2009**:<br>• MBSR 6-weekly 2-hr<br>• home practice 15-45 min/day<br>• improvement in FCR, average: 25.6 min/day 57% adherence<br><br>**Lengacher 2018:**<br>• MBSR online 6-weekly 2 hr asynchronous<br>• home practice 15-45 min/day<br>• improvement in FCR (d=1.51), average 36 min/day 80% adherence<br><br>**Compen:**<br>• MBCT in person, 8 weekly 2.5 hr group sessions, 6 hr retreat; or individual and online for 8 weeks<br>• home practice daily diary<br>• improvement in FCR (d=0.27 (in person) and 0.53 (online)), average 29.6 min/day; adherence rate not available (no assigned time provided)<br><br>**Russell:**<br>• MBI 6-week web-based<br>• home practice daily<br>• improvement in FCR (d=1.01), average 13.7 min/day; adherence rate not available<br><br>**Park**:<br>• MBCT 8 weekly 2 hr classes,<br>• home practice 20-45 min/day<br>• improvement in FCR (d=0.43), average 24 min/day 53% adherence | The pooled adherence rate for all 21 studies participants' home practice was 60% of the assigned amount<br><br>**Factors influencing adherence:** 1 study examined FCR<br><br>**Compen:** comparing in-person vs. online MBCT, the average total daily home practice time did not differ significantly between groups (30.6 vs 28.7 min) |
| **Caregivers - 2 SRs** | | | |
| Smith, 2021 [24]<br><br>Systematic<br><br>FCR prevalence, severity, correlates, course, impact and interventions in caregivers | -63 studies (70 reports)<br>59 articles, 11 postgraduate theses<br><br>**Study type**:<br>2 RCTs<br>68 observational<br>30 cross-sectional<br>18 longitudinal<br><br>**49 quantitative**<br>**20 qualitative** | **Assessments:** most common:<br>FRQ (7/63, 11%)<br>SCNS-P&C (7/63, 11%)<br><br>**Full List:** FRQ, ASC, CARS-1, CaSPUN, CRCS, mCWS, FCRI-Caregiver, FoP-Q-SF-P, FCR7, QOL-F, QSC-R10, SCNS-P&C, WOCS, MAX-PC<br><br>**Prevalence:**<br>11 studies used validated measures or a single item from a validated scale<br>Prevalence ranged from 19-74.3%<br>unmet need ranged 10-43.4% | **Determinants: (21 studies)**<br>**Demographic characteristics:**<br>inconsistent associations with age, gender and education (12 studies, variable); no association with employment, relationship to survivor, children with survivor, years in relationship, sexual orientation, co-habitation (8 studies, variable); negative relationship between caregiver FCR and survivor age (2 studies)<br><br>**Disease, treatment and health issues:**<br>positive association with cancer severity (1 study); then variable positively associated with survivor comorbidities (2 studies)<br><br>**Patient caregiver relationship**: |

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| | **Types of cancers:**<br>20 breast<br>14 mixed<br>5 prostate<br>3 oesophageal<br>3 head and neck<br>2 lung<br>2 ovarian<br>1 brain<br>1 colon<br>1 melanoma | 7 of 10 studies reported FCR as one of top three unmet needs<br><br>**Severity**:<br>mean FCR was reported in 37 papers<br>FRQ range: 2.95-91.9%<br>CARS range: 11.79-13.79<br>SCNS-P&C range: 2.63 to 4.60<br>5 of 15 studies comparing severity scores between survivors and caregivers found significantly more sever in caregivers than survivors; 1 found more severe FCR in survivors. | inconsistent associations with caregiver communication; relationship satisfaction/quality and time spent caring for the survivor<br><br>**Psychological:**<br>cross-sectional studies: 10 found positive associations with caregiver and survivor FCR; and 3 studies found positive associations with depression/anxiety and FCR; 1 -cognitive processing, 1 -uncertainty and 1 -loneliness and 2 studies found negative association for meaning of illness<br>longitudinal studies: 2 found positive associations with survivor FCR and 1 -distress, and 1 -caregiver protective buffering<br><br>**Quality of Life**:<br>for caregiver: negative associations with; emotional/mental functioning -2 studies; role/social functioning, vitality, and general health -1 study; no association with physical function -2 studies<br><br>**Consequences of caregiver FCR (5 studies)**<br>Psychological and survivor-caregiver relationship issues and quality of life and cancer screening issues were found.<br><br>**Effects of Interventions: (1 RCT)**<br>Side by side: FCR declined significantly in female survivors, compared to female survivor control group participants. but male caregivers showed similar reductions in FCR in both intervention and control groups. |
| O'Rourke, 2021 [23]<br><br>Systematic<br><br>Factors Associated with Fear of Cancer Recurrence in Family Caregivers | 16 studies<br>(19 articles)<br><br>**Study type:**<br>9 cross-sectional 7 longitudinal surveys<br><br>**Cancer type**:<br>7 breast,<br>4 head and neck,<br>3 prostate,<br>2 mixed<br><br>**Focus:**<br>9 partners<br>7 caregivers | **Assessments:** FRQ, CARS, FCRI, Global FCR, WOCS, MAX-PC, CWS, adapted measures | **Total Numbers of studies and significant results for factors**<br><br>**Demographic Factors:**<br>**Age:** 12 studies; 1 weak negative; 5 positive associations<br>**Gender:** 4 studies; 1 female higher FCR than males<br>**Ethnicity**: 3 studies; 1 Latino partner significantly more worried than White partners, Black partner worry less -unvalidated scale<br>**Education**: 7 studies; 1 study found a weak negative association (but poorly done)<br><br>**Clinical Factors:**<br>**Treatment:**<br>-time: 8 studies, 2 studies -more recent, higher FCR<br>-type; 7 studies; 4 studies -chemo positive association; 1 study-anti-estrogen -positive association; 2 studies -surgery -negative association (not lasting at 12 months)<br>**Cancer stage:** 7 studies, 1 study found positive association<br>**Comorbidities**: 5 studies, mixed results, 2 studies found positive association<br>**Medical follow-up**: 2 studies, confusing, 2 found positive association<br><br>**Psychosocial Factors:**<br>**Emotional distress:** 3 studies -weak positive association<br>**Anxiety:** 3 studies: all positive association and 1 study found a strong association<br>**Interpersonal factors:** 9 studies -8 studies found weak to moderate associations between the relationship between the survivor and family caregiver<br>**Relationship quality:** 2 studies -1 study found a positive association<br>**Social support**: 3 studies -1 study found negative association |

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| | | | **Loneliness:**1 study - weak positive association<br>**Spousal negative affect:** 1 study -positive association<br>**Stress and coping:** 4 studies: all studies found positive association<br>**Quality of life:** 4 studies -all found significant, weak positive association between FCR and QoL<br>**Psychological beliefs:** 1 study: weak negative association with meaning of illness; 3 studies-illness perceptions -all found a positive association |
| **Health Specialists - 2 SRs** | | | |
| Deckx, 2021 [83]<br><br>Systematic<br><br>Role of general practitioners in interventions for psychosocial care | 33 studies were included overall<br><br>**For FCR:**<br>1 qualitative<br>6 observational<br><br>**Cancer type:**<br>3 breast<br>3 mixed<br>1 CRC | No scales provided. | **Studies reporting on the number of GP visits:**<br>**Thewes**: significant predictor for more unscheduled GP visits (adj regression coefficient = 9.9; 95% CI=2.3 to 17.4) not associated with unscheduled visits to the oncologist (adj regression coefficient = 3.9; 95% CI=-4.8 to 12.5)<br><br>**Mikkelsen**: 20% of the cancer survivors would discuss FCR with their GP, whereas 22% would discuss FCR with the hospital staff. Low confidence in GP competence and judgement a significant predictor for not contacting the GP (prevalence ratio = 2.12; 95% CI=1.02 to 4.42)<br><br>**Studies reporting on care provider:**<br>**Smith**: patients with FCR less likely to prefer GP-led cancer follow-up care compared with shared care (OR = 0.96, 95% CI=0.93 to 0.98)<br>**Smith:** 23% of breast cancer and 3% of GP had low confidence in GPs ability to manage FCR<br>**Brandenburg:** 22 CRC patients felt GP has reassuring role in FCR<br><br>Conclusion: patients with FCR prefer the oncologist as the health care provider for FCR |
| Liu, 2019 [11]<br><br>Systematic<br><br>Interventions from non-mental specialists | 16 articles (up to 2018)<br><br>**Study types**:<br>2 pilot RCTs<br>3 single arm studies<br>3 correlational studies<br>8 cross-sectional surveys<br><br>**Cancer types**:<br>6 breast<br>3 mixed<br>2 head and neck<br>2 CRC<br>1 esophageal<br>1 prostate<br>1 ovarian | 5 pilot RCTs: 2 with nurse-led interventions vs standard care for patients: 1 trained patients in discussing FCR with their specialist; 2 delivered supportive counselling and/or taught management strategies; and 1 for mixed health professionals to train them to manage FCR through normalisation, education and lifestyle strategies<br><br>8 cross-sectional surveys -5 with patients and 3 with specialists<br><br>WCS, CARS, FCRI, FOP-Q-SF | **RCTs**<br>1 study (phase II): AFTER intervention reduced FCR as assessed by WCS (p=0.039)<br>1 study (phase I): nurse delivered communication coaching -no FCR measure<br>1 study (single arm): nurse-led telephone follow-up, no pre/post FCR measures<br>1 study (single arm): training health care professionals<br>1 study (single arm): nurse-led telephone intervention: FCR scores of 12/16 patients decreased from baseline to 1-week follow-up (coefficient − 4.2, effect size 0.8 p=0.03).<br><br>**From 11 observations studies: 2 themes**<br>**1. Factors that influence FCR in the clinical encounter:**<br>**a. Information needs/provisions:** - 6 studies<br>4/5 patient surveys: patients would like detailed prognostic information; patients with the highest FCR want the most prognostic information (p=0.013) and were the most actively involved during the consultation (p<0.001)<br><br>**b. Provider-patient communication and relationship with FCR:** -3 studies<br>1 study: Patients unsatisfied with information provided during the consultation (p=0.001) and who experienced more interruptions during the consultation (p=0.008) had a lower decline in FOP; and a higher degree of perceived empathy conveyed by the doctor to the patient was also associated with less FOP reduction (p=0.013) |

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| | | | 1 study: no effect of consultation length on FOP levels.<br>1 study: external (upcoming appointments or scan, media, family/friend cancer diagnosis) and internal (worry about unexplained symptoms) trigger FCR<br>All studies: discussion of FCR by health professionals did not trigger increased FCR in patients.<br><br>**2. Strategies used to manage FCR: -**3 studies<br>1 study: 99% of health professionals (of whom 77/141 were doctor/nurses) expressed a desire for further training in managing FCR in their patient<br>1 study: 53% reported that FCR management was somewhat challenging with 32% rating it as moderately challenging and 11% as very challenging<br>1 study: 74% of surveyed medical oncologists and 64% of breast surgeons reported confidence in managing FCR, with oncologists consistently reporting higher confidence than surgeons in presenting risk information, identifying worry and managing worry.<br><br>**Conclusions:**<br>The majority (4/5) of the cross-sectional surveys of cancer patients indicated that provision of honest information about prognosis and recurrence risk information was helpful to address FCR.<br>Only 5 nurse-led interventions found and no doctor-led interventions in the context of oncology follow-up clinics found.<br>Correlational and cross-sectional surveys of patients and doctor/ nurses revealed a desire for better FCR discussions at follow-up clinics and the provision of prognostic and recurrence information by doctors. |
| **Resource Use - 1 SR** | | | |
| Williams, 2020 [52]<br><br>Systematic<br><br>FCR related healthcare use and intervention cost-effectiveness<br><br>MEDLINE, CINAHL and Cochrane PsycInfo, NHS-EED, AMED and EconLit,<br>01 September 2019 | 11 studies:<br>7 for costs of FCR, 4 for cost-effectiveness of FCR interventions<br><br>**Cancer types:**<br>7 mixed<br>2 breast<br>1 melanoma<br><br>**Study types:**<br>3 RCT<br>5 cross-sectional 2 longitudinal | FCRI -6 studies; FoP-Q-2 studies | **Results:** all studies reported associations between FCR and the use of various forms of healthcare, but did not change into monetary terms<br>2 studies -FCR predicts more visits and phone calls with primary care and oncology<br>2 studies -FCR predicts more visits to psychologists, psychosocial professionals, dieticians<br>2 studies -no association<br>1 study -association with increased outpatient and ER visits but not overnight stays<br>CAM -studies with and without associations<br>Medication use -1 study higher, 2 studies no association<br>Cancer screening -1 study less like to use formal screening programs<br>Economic evaluation of treatments – 3 studies. Incremental cost effectiveness ratio ranged from AU$3,23334 to AU $152,05035 per QALY gained, -AU$196,94233 to AU$8232 per unit of FCR reduced and AU$16,89535 per case of high FCR avoided<br><br>Probabilities of the interventions being cost-effective at different thresholds ranged from 35% to 76%, |

**Abbreviations:** ACT: acceptance and commitment therapy; Adj: adjusted; AFTER: 6 weekly sessions of traditional CBT individual therapy; AFTER: Adjustment to the Fear, Expectation or Treat of Recurrence; AIM-FBCR: Attention and Interpretation Modification for Fear of Breast Cancer Recurrence; AMED: Allied and Complementary Medicine Database; ASC: Assessment of Survivor Concerns; AU: Australian; AUC: area under the curve; BCS: breast cancer survivors;

BLANKET: blended care for fear of cancer recurrence; CAM: complementary and alternative medicine; CARS: Concerns about Recurrence Scale; CARS-1: Concerns About Recurrence Scale-Part 1; caSPUN: Cancer Survivors' Partners Unmet Needs; CB: cognitive-behavioural skills; CBT: cognitive behavioural therapy; CCI: coping and communication-enhancing intervention; CD: compact disc; CI: confidence interval; CINAHL: Cumulative Index to Nursing & Allied Health Literature; Cochrane: collection of databases in medicine and other healthcare specialties; ConquerFear: a manualized intervention focusing on reducing the impact of FCR based on metacognitive therapy, the Common Sense Model of illness, the Self-Regulation of Executive Function Model, and relational frame theory; CORRECT: colorectal cancer distress reduction; COSMIN: COnsensus-based Standards for the selection of health Measurement INstruments; CRC: colorectal cancer; CRCS: Cancer Related Challenge Scale; CWS: Cancer Worry Scale; CWS-6: The Dutch Cancer Worry Scale-6; EconLit: Essential Reference Tool for Economics Literature; e-TC: web-based intervention for survivors of testicular cancer; 6 interactive modules for 10 weeks; FCR: fear of cancer recurrence; FCR7: seven-question self-report scale to assess fear of recurrence; FCRI: Fear of Cancer Recurrence Inventory; FCRI-P: Fear of Cancer Inventory Parent; FCRS: Fear of Recurrence Scale; FoP: Fear of Progression Scale; FOP: fear of progression; FoP-Q-SF/P: Fear of Progression Questionnaire Short Form Partner; FoP-Q-SF/PR: Fear of Progression Questionnaire Short Form Parent; FoP-Q-SF: Fear of Progression Questionnaire Short Form; FOP-Q-SF-P: Fear of Progression Questionnaire-Short Form/Partner version; FORT: Fear of Cancer Recurrence Therapy; FRQ: Fear of Recurrence Questionnaire; GP: general practitioner; GTUS: Growth Through Uncertainty Scale; iConquerFear: web-based intervention based on the aforementioned ConquerFear therapy manual; IES: Impact of Events Scale; iNNOVBC: iNNOVBC: a guided Internet-delivered individually tailored acceptance and commitment therapy–influenced cognitive behavioural intervention to improve psychosocial outcomes in breast cancer survivors; IUS-SF: Intolerance of Uncertainty Scale-Short Form; MAX-PC: Memorial Anxiety Scale for Prostate Cancer; MAX-PC-FCR: Memorial Anxiety Scale for Prostate Cancer-Fear of Recurrence Subscale; MBCT: mindfulness-based cognitive therapy; MBI: mindfulness-based intervention; MBSR: mindfulness-based stress reduction; mCWS: Modified Cancer Worry Scale; MEDLINE: National Library of Medicine's (NLM) premier bibliographic database; MM: mindfulness meditation; mMBSR: mobile mindfulness-based stress reduction; MUIS: Mishel Uncertainty in Illness Scale; NHS-EED: NHS Economic Evaluation Database; OR: odds ratio; PsycInfo: The premier abstracting and indexing database covering the behavioural and social sciences from the authority in psychology; QALY: quality-adjusted life year; QLACS-FCR: Quality of Life in Adult Cancer Survivors – Fear of Cancer Recurrence; QoL: quality of life; QOL-F: Quality of Life-Family; QSC R10: Questionnaire on Stress in Cancer Patients; RCT: randomized controlled trial; RQ: Reassurance Questionnaire; SCNS-P&C: Supportive Care Needs Survey—Partners and Caregivers; SD: standard deviation; SR: systematic review; SWORD: Survivors' Worries of Recurrent Disease; Takin-it-easy: relaxation therapy with 5 face-to-face sessions over 10 weeks; WCS: Worry of Cancer Scale; WOCS: Worry of Cancer Scale-modified

## Table 4-3. Intervention Randomized Controlled Trials Data Table

| Author, Country | Sample size, Age (Years, Mean, SD), Sex, Cancer Type | Delivery Mode And Intervention Format | Session Number, Length, Duration | Provider and Location of Intervention | FCR Instrument and Assessment Times | Baseline FCR Level (SD) | Post FCR Level (SD) | Major Findings |
|---|---|---|---|---|---|---|---|---|
| Akechi, 2023 [31]<br><br>Japan<br><br>RCT<br><br>Smartphone-based problem-solving therapy and behavioural activation vs. TAU | 447<br><br>43.9±4.6<br>44.0±4.5<br><br>223 phone<br>224 TAU<br><br>Female<br><br>Breast cancer | Individual, PST App provides patients with a structured, five-step strategy for solving their problems.<br><br>The BA App had 6 sessions. | 8-week program period.<br><br>PST app -9 sessions;<br><br>BA app -6 sessions.<br><br>Each session for both apps took 10 minutes to complete.<br><br>Weekly automated emails | Smart phones | CARS-J at Baseline, 2, 4, 8 and 24 weeks<br><br>FCRI-SF at Baseline, 8 and 24 weeks | No baseline measure provided | At 8 weeks:<br><br>CARS-J<br>Control: 14.54 (95% CI, 14.17-14.92)<br><br>Intervention: 13.15 (95% CI, 12.75-13.55)<br><br>FCRI-SF<br><br>Control:<br>17.86 (95% CI, 17.35-18.37)<br><br>Intervention:<br>16.21 (95% CI, 15.64-16.78) | Statistically significant improvement in CARS-J scores at week 8 compared with the control group (difference –1.39, 95% CI, –1.94 to –0.85, p<0.001; ES=0.32)<br><br>Intervention group showed statistically significant improvement at week 8 in FCRI-SF scores (difference: –1.65; 95% CI, –2.41 to –0.89; p<0.001; ES=0.25)<br><br>There were no significant differences in the intervention group outcomes at weeks 8 and 24 in CARS or FCRI-SF<br><br>Comparing high FCR to low FCR:<br>both groups had significant improvement (week 0 to week 8),<br>greater improvement was observed among those with high FCR (difference –1.43; 95% CI, –2.05 to –0.80; p<0.001) compared with those with low FCR (difference –0.65; 95% CI, –1.21 to –0.08; p<0.05; subgroup interaction, p=0.0047<br><br>The degree of engagement with the apps was not significantly associated with the outcome (Kaiketsu-App: p=0.35; Genki-App: p=0.54) |
| Tauber, 2023 [43]<br><br>Denmark<br><br>RCT<br><br>ConquerFear - Group online vs. Relaxation online | 85<br><br>Intervention 54.1 (10.8)<br><br>Control 54.8 (10.8) years<br><br>54.5 (10.7)<br><br>Breast Cancer | Online<br><br>1 individual session<br><br>5 group sessions | 6 sessions<br><br>1- 11/2-hour individual session followed by 5 weekly 2-hour group sessions | Online<br><br>Psychologists | FCRI<br>FCRI-SF<br><br>Baseline, 1-week, 3- and 6-months | FCRI<br>Intervention: 94.5 (16.4)<br>Control: 87.9 (22.0)<br><br>FCRI-SF<br>Intervention: 24.8 (4.4)<br>Control: 23.8 (3.9) | 1 week post:<br>FCRI:<br>Intervention: 83.6 (±16.3)<br>Control: 82.8 (±14.4)<br><br>FCRI-SF<br>Intervention: 21.7 (±3.5)<br>Control: 21.4 (±4.0)<br><br>6-month FU | Compared with active controls, ConquerFear-Group participants reported statistically significant reductions in both FCRI from baseline to 6-month FU: (d=0.47, p=0.001) and FCRI-SF (d=0.57, p<0.001)<br><br>The changes in FCRI from baseline to 1 week post intervention was (d=0.45, p=0.081) and from baseline to 3-month FU was (d=0.45, p=0.013). |

| Author, Country | Sample size, Age (Years, Mean, SD), Sex, Cancer Type | Delivery Mode And Intervention Format | Session Number, Length, Duration | Provider and Location of Intervention | FCR Instrument and Assessment Times | Baseline FCR Level (SD) | Post FCR Level (SD) | Major Findings |
|---|---|---|---|---|---|---|---|---|
| | | | | | | | FCRI:<br>Intervention: 72.1 (±17.8)<br>Control: 77.8 (±19.1)<br><br>FCRI-SF<br>Intervention: 18.0 (±6.3)<br>Control: 20.7 (±3.2) | |
| Maheu, 2023 [6]<br><br>Canada<br><br>RCT<br><br>FORT vs. Control: LWWC | 164<br>84 FORT<br>80 LWWC<br><br>55.8 (9.9)<br>55.5 (11.3)<br><br>Female<br><br>Breast and gynecologic al cancer | Face to face<br><br>Group, Supervised<br><br>Weekly for 6 weeks | 6 sessions<br><br>90–120 min | Health professionals (clinical psychologists, nurses, and social workers<br><br>Cancer Care Hospitals | FCRI<br><br>Baseline, 3 and 6 months | Baseline:<br><br>Intervention: 93.1 (24.7)<br><br>Control: 92.2 (20.0) | T1:<br>Intervention: −11.03 points (95% CI, −19.40 to −2.66)<br><br>LWWC: −1.55 points (95% CI, −11.38 to 8.27) | Between group differences:<br><br>T1-T2: −9.48, 95% CI, −18.50 to −0.45, p=0.0393, d= −0.530<br><br>T1-T4: −1.89, 95% CI, −4.95 to 1.18, p=0.2302, d=−0.564<br><br>Recommended the use of a booster session to maintain gains over the long term |
| Kang, 2022 [33]<br><br>Canada<br><br>RCT<br><br>HIIT vs. usual care | 52<br><br>Average 63.4±7.1<br><br>Male<br><br>Prostate cancer | Group, supervised<br><br>3× a week for 12 weeks | 36 sessions<br><br>28-40 mins<br><br>12 weeks | Clinical exercise physiologist<br><br>Behavioural Medicine Fitness Centre | MAX-PC, FCRI, CWS<br><br>Baseline, 12 weeks, 6-month FU, 12-month FU | MAX-PC (FOP): 4.2±3.3 vs. 4.6±2.6<br>FCRI: 11.9±6.9 vs. 13.5±5.9<br>CWS: 12.5±3.4 vs. 13.3±2.2 | MAX-PC (FOP): 2.6±2.1 vs. 4.7±3.2<br>FCRI: 11.0±5.7 vs. 11.6±5.4<br>CWS: 12.1±2.5 vs. 12.5±2.8 | For MAX-PC, HIIT significantly reduced fear of progression subscale (−2.0, 95% CI, −3.5 to −0.4, p=0.013, d=0.67) compared to the UC group.<br><br>No significant differences were observed for FCRI or CWS. |
| Frangou, 2021 [42]<br><br>UK<br><br>RCT | 107<br><br>59.5±9.88<br><br>Female | Individual, first two sessions were reviewed and supervised by a trained psycho- | 3 sessions<br><br>90 mins<br><br>4 weeks | Doctoral-level clinical or counseling psychologist<br><br>Patient's nearest | FOP-Q-SF<br><br>Baseline, 3, 6, 12, 15, 18, 24-month follow-ups | Control: 34.63±8.80<br><br>Intervention: 33.74±8.63 | 3-month total FOP<br><br>Control: 34.96±9.10 | FOP scores were measured 34.6 (SD, 8.9) in the control group, and 33.7 (SD, 8.6) in the intervention group at baseline.<br><br>The score worsened by 0.33 points in the standard-of-care arm but improved by −3.74 points in the intervention arm where |

| Author, Country | Sample size, Age (Years, Mean, SD), Sex, Cancer Type | Delivery Mode And Intervention Format | Session Number, Length, Duration | Provider and Location of Intervention | FCR Instrument and Assessment Times | Baseline FCR Level (SD) | Post FCR Level (SD) | Major Findings |
|---|---|---|---|---|---|---|---|---|
| CBT MBI, ACT vs. control | Ovarian cancer | oncologist, remaining two sessions were supervised as needed.<br><br>Usual care + 4 sessions over ~3 months | | Maggie's Centre | | T-test p-value: 0.7845 | Intervention: 30.00±9.00<br><br>T-test p-value: 0.0012 | it fell to 30.0 (SD, 9.0), with a significant difference in treatment effect between the two arms of −4.4 points [95% CI: (−7.57, −1.22), p=0.008].<br><br>Across all patients in the intervention arm, there was no sustained treatment effect beyond 3 months (−1.41 (95% C.I. -4.70, 1.88) p=0.401<br><br>Amongst those who scored ≥34 on the FOP score at baseline, there was a longer-term improvement in FOP score to 6 months, p=0.006 |
| Akechi, 2021 [36]<br><br>Japan<br><br>RCT<br><br>Collaborative care + TAU vs. TAU alone | 59<br><br>Collaborative care + TAU: 52±12<br><br>TAU: 56±13<br><br>Female<br><br>Breast cancer | Group, supervised<br><br>1× a week for 7 weeks | 4 sessions<br><br>30-90 min<br><br>12 weeks | Trained nurses<br><br>Two sessions in-hospital, two via telephone | CARS-J (Japanese version for the CARS)<br><br>1- and 3-months post-intervention | No baseline measurement taken.<br><br>1 month: Collaborative care + TAU: 15.1±4.6<br><br>TAU: 16.2±5.6 | 3 month: Collaborative care + TAU: 15.0±4.9<br><br>TAU: 15.2±5.8 | No significant differences were observed among fear of recurrence as assessed by CARS-J at 1- and 3-month assessments<br><br>1 month: 15.1±4.6 vs 16.2±5.6, p=0.31<br><br>3 months: 15.0±4.9 vs. 15.2±5.8, p=0.94 |
| Arch, 2021 [40]<br><br>USA<br><br>RCT<br><br>Valued living condition (ACT-based) vs. EUC | 134<br><br>56.14±11.57<br><br>Male: 16<br>Female: 118<br><br>Mixed Cancer type | One-on-one with interventionist<br><br>3x within a month | 7 sessions<br><br>2 hours<br><br>7 weeks | Social workers in community oncology clinics<br><br>Online and in-person at a conference room in cancer centres | CARS-overall fear<br><br>Baseline, 1, 2, 5, 8 months | Valued living: 4.30±0.94<br><br>EUC: 3.93±1.26 | Valued living: 3.46±1.08<br><br>EUC: 3.83±1.31 | Mid-treatment:<br>Valued living: 3.91±1.10<br>EUC: 3.90±1.41<br><br>3-month follow-up:<br>Valued living: 3.48±1.21<br>EUC: 3.39±1.25<br><br>6-month follow-up:<br>Valued living: 3.14±1.19<br>EUC: 3.47±1.37<br><br>Intercept at baseline (SE): 4.09 (0.09)<br><br>Condition differences at baseline b (SE): 0.14 (0.09), p=0.15 |

| Author, Country | Sample size, Age (Years, Mean, SD), Sex, Cancer Type | Delivery Mode And Intervention Format | Session Number, Length, Duration | Provider and Location of Intervention | FCR Instrument and Assessment Times | Baseline FCR Level (SD) | Post FCR Level (SD) | Major Findings |
|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Main effect of time b (SE): -0.19 (0.03), p<0.001<br><br>Condition by time interaction b (SE): -0.08 (0.03), p=0.003<br><br>Interaction effect size d=0.29 (95% CI, 0.10-0.47) |
| Wagner, 2021 [30]<br><br>USA<br><br>eHealth intervention (FoRtitude)<br><br>RCT<br><br>CBT (relaxation, cognitive restructuring, worry practice) vs. HMC<br><br>Telecoaching vs. no telecoaching | 196<br><br>Mean age at screening: 54.7±9.8<br><br>Mean age at diagnosis: 51.8±9.4<br><br>Female<br><br>Breast cancer | Individually completed (assigned in groups), online, modules, unsupervised, self-paced<br><br>Self-paced, new FoRtitude site content released 3 times per week<br><br>Telecoaching included 4 weekly telephone-based motivational interviews to promote FoRtitude site use adherence | Each module had 3 sections: lesson 1, interactive tool, lesson 2. Participants were encouraged to use the FoRtitude site several times per week for 4 weeks.<br><br>All lessons were similar in length for consistency and averaged 10-15 minutes to read. Interactive tools required approximately 5-15 minutes.<br><br>4 weeks | Intervention content was delivered independently from the study team via web-based FoRtitude site.<br><br>Psychologists trained in motivational interviewing provided telecoaching.<br><br>Online - eHealth | FCRI, CARS<br><br>Baseline (T0), 4 weeks (T1), 8 weeks (T2) | FCRI<br>Relaxation Yes (n=98): 54.5±17.9<br>vs.<br>Relaxation No (n=98): 51.7±16.9<br><br>Worry practice Yes (n=98): 53.3±15.4<br>vs.<br>Worry practice No (n=98): 52.9±19.3<br><br>Cognitive restructuring Yes (n=98): 53.3±17.4<br>vs.<br>Cognitive restructuring No (n=98): 52.8±17.5<br><br>Telecoaching Yes (n=97): 52.8±17.5<br>vs. | FCRI<br>Relaxation Yes (n=98): 42.4±16.0<br>vs.<br>Relaxation No (n=98): 41.4±16.5<br><br>Worry practice Yes (n=98): 44.0±15.2<br>vs.<br>Worry practice No (n=98): 39.9±16.9<br><br>Cognitive restructuring Yes (n=98): 43.8±16.4<br>vs.<br>Cognitive restructuring No (n=98): 40.3±15.9<br><br>Telecoaching Yes (n=97): 40.8±16.3<br>vs. | FCRI total score, our primary endpoint, decreased statistically significantly from T0 to T2 for all conditions, including attention control (T0 = 53.1 [SD, 17.4], T2 = 41.9 [SD, 16.2], p<0.001).<br><br>A statistically significantly decreased FCRI total score was also observed for all groups from T0 to T1 (T0 = 53.1 [SD, 17.4], T1 = 41.9 [SD, 16.2], p<0.001). Similarly, FCRI subscale scores decreased from T0 to T1<br><br>Final model indicates statistically significant decreases in FCRI score at T2 within all groups, independent of CBT or HMC content. Found no statistically significant "treatment effect" because of the comparable magnitude of decrease for each CBT vs HMC comparison.<br><br>Effect sizes for the decline T0-T2 ranged from 0.55 to 0.69. Differences in effect sizes (CBT components vs attention control) were small (0.09 to 0.14).<br><br>Change in FCRI total score T0 (SD, 17.8) to T2 of at least 8.9 points represented a minimal clinically important difference.<br><br>53.0% of BCS across CBT and HMC conditions improved, 41.8% remained stable, and 5.2% reported worsened FCR from T0 to T2.76<br><br>When time-varying change in BCSE from T0 to the relevant time point was included as a |

| Author, Country | Sample size, Age (Years, Mean, SD), Sex, Cancer Type | Delivery Mode And Intervention Format | Session Number, Length, Duration | Provider and Location of Intervention | FCR Instrument and Assessment Times | Baseline FCR Level (SD) | Post FCR Level (SD) | Major Findings |
|---|---|---|---|---|---|---|---|---|
| | | | | | | Telecoaching No (n=99): 53.4±17.3<br>CARS Relaxation Yes (n=98): 14.7±4.5<br>vs.<br>Relaxation No (n=98): 13.1±4.3<br><br>Worry practice Yes (n=98): 14.0±4.4<br>vs.<br>Worry practice No (n=98): 13.8±4.5<br><br>Cognitive restructuring Yes (n=98): 14.0±4.6<br>vs.<br>Cognitive restructuring No (n=98): 13.8±4.3<br><br>Telecoaching Yes (n=97): 13.8±4.6<br>vs.<br>Telecoaching No (n=99): 14.0±4.3 | Telecoaching No (n=99): 43.1±16.0<br>CARS Relaxation Yes (n=98): 12.1±4.1<br>vs.<br>Relaxation No (n=98): 10.9±3.8<br><br>Worry practice Yes (n=98): 12.2±4.1<br>vs.<br>Worry practice No (n=98): 10.9±3.9<br><br>Cognitive restructuring Yes (n=98): 12.0±4.1<br>vs.<br>Cognitive restructuring No (n=98): 11.1±3.9<br><br>Telecoaching Yes (n=97): 11.4±4.0<br>vs.<br>Telecoaching No (n=99): 11.7±4.0 | predictor, the magnitude of the T0-T2 decline in FCRI total score was attenuated by, on average, 23%, with effect sizes ranging from 0.39 to 0.5177<br><br>CARS severity score decreased statistically significantly from baseline to 4 and 8 weeks in all groups. |
| Ahmadiqaragezlou, 2020 [39]<br><br>Iran | 38<br><br>Intervention : 44.4±0.7 | Guided, group and individual components | 8 sessions<br><br>120 mins<br><br>8 weeks | NR<br><br>Held at the Faculty of | FCRI<br><br>Baseline (T0, pre-intervention | Subscales Trigger<br>MBSR: 7.9±0.7<br>Control: 8.9±1.2 | Subscales Trigger<br>MBSR: 1±0.3<br>Control: 8.2±1.2 | Leven test was used to measure the error variance equation in different stages including (F=0.889, p=0.352), in the post-test component of insight, (F=1.019, p=0.319) in the post-test component of |

| Author, Country | Sample size, Age (Years, Mean, SD), Sex, Cancer Type | Delivery Mode And Intervention Format | Session Number, Length, Duration | Provider and Location of Intervention | FCR Instrument and Assessment Times | Baseline FCR Level (SD) | Post FCR Level (SD) | Major Findings |
|---|---|---|---|---|---|---|---|---|
| RCT<br><br>MBSR vs. control | Control: 48.4±9.7<br><br>Male: 8<br>Female: 30<br><br>Colorectal: 16<br>Breast: 22 | 1× a week for 8 weeks | | Rehabilitation at a University | , post-allocation)<br><br>Post-intervention (T1) | Severity<br>MBSR: 16.6±0.9<br>Control: 16.8±1<br><br>Psychological distress<br>MBSR: 6.9±0.5<br>Control: 6.8±0.5<br><br>Coping strategies<br>MBSR: 11.6±1<br>Control: 9.7±1.1<br><br>Dysfunction<br>MBSR: 8.1±0.96<br>Control: 6.9±1.3<br><br>Insight<br>MBSR: 1.7±0.46<br>Control: 1.8±0.62<br><br>Reassurance<br>MBSR: 5±0.52<br>Control: 4.53±0.5 | Severity<br>MBSR: 6±0.6<br>Control: 15.8±1<br><br>Psychological distress<br>MBSR: 2.3±0.6<br>Control: 7.6±1<br><br>Coping strategies<br>MBSR: 4±0.5<br>Control: 9.4±1.3<br><br>Dysfunction<br>MBSR: 1.4±0.22<br>Control: 6.7±0.7<br><br>Insight<br>MBSR: 0.5±0.2<br>Control: 0.9±0.5<br><br>Reassurance<br>MBSR: 2.3±0.6<br>Control: 4±0.4 | psychological distress, (F=3.611, p=0.065) in the post-test component of triggers, (F=2.569, p=0.118) in post-test component of severity, (F=3.722, p=0.062) in the post-test component of reassurance it was determined that the variance of the error of the various components of the test, except for the dysfunction component (F=4.638, p=0.038), and coping strategies (F=9.616, p=0.004) is similar in the post-test.<br><br>No interaction and regression lines that do not interrupt each other, and the slope is homogeneous. (p=0.59),<br><br>There was a significant difference between the experimental and control groups in all subscales of FCR inventory in the post-test, except insight (p=0.245).<br>MBSR had the greatest effect on the trigger and dysfunction.<br>There is a significant difference (p=0.001), between the two groups in the post-test. |
| Dieng, 2020 [32]<br><br>Australia<br><br>RCT | 151 (analyzed sample, outcomes imputed for 8 participants who completed | Self-led for psychoeducation booklet, one-on-one for telephone sessions<br><br>Psychoeducational booklet + | 3 sessions<br><br>Session 1: 90 mins<br><br>Sessions 2 and 3: 50 mins | Psychologists<br><br>At home | FCRI (severity scale of a modified, melanoma-specific version) | Baseline<br>Psychoeducation (n=70): 55.51±27.96<br><br>Usual care (n=81): 59.35±27.79 | Change at 1 month<br>Psychoeducation (n=67): -7.45±17.30<br><br>Usual care (n=76): -3.04±16.69 | Average score difference: -1.40 (-6.13, 3.32) p=0.56<br><br>Participants in the intervention group reported significantly lower fear of cancer recurrence at 12 months postintervention compared with participants in the control group. |

| Author, Country | Sample size, Age (Years, Mean, SD), Sex, Cancer Type | Delivery Mode And Intervention Format | Session Number, Length, Duration | Provider and Location of Intervention | FCR Instrument and Assessment Times | Baseline FCR Level (SD) | Post FCR Level (SD) | Major Findings |
|---|---|---|---|---|---|---|---|---|
| Psychoeducation (Melanoma Care Program) vs. usual care | 6-month but not 12-month questionnaires)<br><br>58.5±11.9<br><br>Male: 55%<br>Female: 45%<br><br>Skin cancer | 3 telephone sessions:<br>Session 1: approximately one week before each participant's next full dermatological appointment at the HRC | 4 weeks (Unclear what week participants are given the booklet, so 4 weeks at least) | | Baseline (T0, 6 weeks prior to next full dermatological consultation at the HRC), T1 (4 weeks after HRC consultation), T2 (1 week after subsequent full HRC consultation 6 months later), T3 (12 months later) | Between group difference: -3.83 (-5.15, 12.82) | Between group difference: -4.41 (-1.22, 10.03)<br><br>Change at 6-months Psychoeducation (n=70): -7.87±16.78<br><br>Usual care (n=80): -5.98±20.34<br><br>Between group difference: -1.90 (-4.17, 7.96)<br><br>Change at 12-months Psychoeducation (n=65): -5.62±21.11<br><br>Usual care (n=74): -6.62±23.97<br><br>Between group difference: -0.45 (-6.81, 5.91) | The between-group mean difference was -1.41 for FCR severity (95% CI -2.6 to -0.2; p=0.02) and -1.32 for FCR triggers (95% CI -2.6 to -0.02; p=0.0479.<br><br>In a complete case (sensitivity) analysis in which the eight imputed outcomes were removed, the between-group mean difference was –1.16 for FCR severity (95% CI –2.39 to 0.08; p=0.06.<br><br>When FCR severity was analyzed using a cut-off score of ≥13, the overall difference between groups was not statistically significant, with 54% of participants in the intervention group and 63% of participants in the control group scoring above the cut-off [odds ratio (OR) 0.59, 95% CI 0.30–1.14, p=0.1279.<br><br>When the more recently published cut-off score of ≥22 was applied, the overall difference between groups adjusted for baseline scores remained nonsignificant, with 19% of participants in the intervention group and 20% of participants in the control group scoring above the new cut-off (OR 0.73, 95% CI 0.35–1.52, p=0.3979. |
| Dirkse, 2020 [26]<br><br>Canada<br><br>RCT | 86<br><br>50.80±13.17<br><br>Male: 14<br>Female: 69 | Self-guided with weekly contact with a technician | 5 sessions<br><br>Self-guided lessons, choice between | Self-guided, weekly contact with technician for intervention group | FCRI-SF<br><br>Baseline (week 1), post-intervention | Self-guided: 22.62±5<br><br>Technician-guided: 23.27±5.9 | Self-guided: 19.00±6<br><br>Technician-guided: 18.41±6.5 | Percentage change from pre-treatment: post-treatment<br>Self-guided: 16%<br>Technician-guided: 21% |

| Author, Country | Sample size, Age (Years, Mean, SD), Sex, Cancer Type | Delivery Mode And Intervention Format | Session Number, Length, Duration | Provider and Location of Intervention | FCR Instrument and Assessment Times | Baseline FCR Level (SD) | Post FCR Level (SD) | Major Findings |
|---|---|---|---|---|---|---|---|---|
| Technician-guided ICBT vs. self-guided ICBT<br><br>Also included MBI | Mixed Cancer Type | 5× over the course of 8 weeks | weekly phone calls (10-min max) or secure emails with technician<br><br>8 weeks | Online | (week 8), 1-month follow up (week 12) | | 1-month follow-up<br>Self-guided: 17.59±5.6<br><br>Technician-guided: 17.91±6.5 | Percentage change from pre-treatment: 1-month follow-up<br>Self-guided: 22%<br>Technician-guided: 23%<br><br>Within-group effect sizes: post-treatment<br>Self-guided: 0.65 [0.63, 0.66]<br>Technician-guided: 0.78 [0.76, 0.79]<br><br>Within-group effect sizes: 1-month follow-up<br>Self-guided: 0.93 [0.91, 0.94]<br>Technician-guided: 0.85 [0.84, 0.86]<br><br>Between-group effect sizes: post-treatment: 0.09 [0.08, 0.11]<br><br>Between group effect sizes: 1-month-follow-up: 0.05 [0.04, 0.06]<br><br>Within-group effect sizes: 1-month follow-up<br>The GEE analyses revealed statistically significant time effects for the FCRI-SF (Wald's $X^2$ = 67.77, p<0.001).<br><br>For both treatment groups, medium effect sizes were observed on the FCRI-SF at post-treatment (d range, 0.65–0.78), yet increased to large effects by 1-month follow-up.<br><br>Significant percentage change in symptoms was observed from pre- to post-treatment for both the self-guided and technician guided groups on the FCRI-SF (range, 16–21%).<br><br>FCR had the lowest reliable improvement rates, with 29% of self-guided and 35% of technician-guided participants demonstrating reliable improvement. |

| Author, Country | Sample size, Age (Years, Mean, SD), Sex, Cancer Type | Delivery Mode And Intervention Format | Session Number, Length, Duration | Provider and Location of Intervention | FCR Instrument and Assessment Times | Baseline FCR Level (SD) | Post FCR Level (SD) | Major Findings |
|---|---|---|---|---|---|---|---|---|
| | | | | | | | | FCR demonstrated small recovery rates of 10% and 18% for self-guided and technician-guided groups, respectively. |
| Lynch, 2020 [27]<br><br>Australia<br><br>Fear-less (MBI)<br><br>Prospective cohort<br><br>No FCR vs. Subthreshold FCR vs. Clinical FCR | 61<br><br>61.4±11.6<br><br>No FCR: 69.2±9.6<br>Subthreshold FCR: 60.0±10.7<br>Clinical FCR: 50.3±5.4<br><br>Male: 67% (41/61)<br>Female: 33% (20/61)<br><br>No FCR<br>Male: 73% (16/22)<br>Female: 27% (6/22)<br><br>Subthreshold FCR<br>Male: 70% (19/27)<br>Female: 30% (8/27)<br><br>Clinical FCR<br>Male: 50% (6/12)<br>Female: 50% (6/12)<br><br>Metastatic melanoma | SM: self-led, individual, checked in with intervention provider<br><br>IT: individual, delivered by clinical psychologist<br><br>SM: self-paced with some interventionist delivery<br><br>IT: 5 sessions | Session number<br>SM: self-paced, 7 lessons (75% completion considered acceptable)<br><br>IT: 5 sessions<br><br>Length<br>SM: On average, the self-management intervention took 20.62 min (SD, 9.77) of clinician time to deliver<br><br>IT: 60-90 mins<br><br>Duration<br>NR<br><br>Approx. 5 weeks | SM: Psychology researcher or clinical psychologist<br><br>IT: clinical psychologist<br><br>SM: At-home and by phone<br><br>IT: Hospitals | FCRI-SF<br>FoP-Q-SF<br><br>Pre-intervention, post-intervention | FCRI-SF<br>SM: 17.67±6.03<br>IT: 24.29±4.19<br><br>FoP-Q-SF<br>SM: 29.14±8.21<br>IT: 37.29±8.56 | FCRI-SF<br>SM: 16.90±7.69<br>IT: 20.57±6.35<br><br>FoP-Q-SF<br>SM: 29.00±7.79<br>IT: 33.71±7.87 | SM:<br>The majority of participants (13/21, 62%) read ≥50% of the booklet with 10 participants (48%) reading ≥75% of the booklet.<br>Thirteen participants (62%) reported that they would recommend the self-management intervention to others.<br>One-third of participants (7/21, 33%) were unsure whether they would recommend it with some preferring a face-to-face or online delivery and others reporting they believed they did not need the intervention.<br>33% (7/21) reported subjective improvements in FCR after the intervention.<br>Eight participants (38%) completed ≥3/7 activities and seven (33%) did not complete any. Participants identified that the most helpful activities were keeping a relaxation diary (7/21, 33%), goal setting (6/21, 29%) and identifying what was within their control (6/21, 29%).<br><br>Post-intervention rescreening indicated that 62% of participants (13/21) had a reduction in FCR post-intervention compared to pre-intervention. After five weeks of self-management, all 21 participants were offered additional supports to manage FCR. However, 90% reported that they did not require any further support (two participants were uncontactable).<br><br>Of the 10 participants who read ≥75% of the booklet, 8 showed a reduction in FCR. The two participants who did not show any improvement attributed the lack of change |

| Author, Country | Sample size, Age (Years, Mean, SD), Sex, Cancer Type | Delivery Mode And Intervention Format | Session Number, Length, Duration | Provider and Location of Intervention | FCR Instrument and Assessment Times | Baseline FCR Level (SD) | Post FCR Level (SD) | Major Findings |
|---|---|---|---|---|---|---|---|---|
| | | | | | | | | in FCR to life stressors (e.g., a family member dying of or being diagnosed with terminal cancer prior to rescreening).<br><br>IT:<br>All six participants who completed five sessions reported that they would recommend the individual therapy to others. Participants' qualitative responses identified that the most useful aspects of individual therapy were detached mindfulness (4/7) and being listened to and validated (3/7). All six participants who completed the intervention reported subjective improvements in FCR levels and all attributed this change to therapy.<br><br>At the completion of individual therapy, 5/7 participants had a reduction in their FCR compared to pre-intervention. No participants who completed five sessions required further support for their FCR. |
| Murphy, 2020 [28]<br><br>Australia<br><br>iCanADAPT Early<br><br>RCT<br><br>iCBT vs. TAU<br><br>Also included MBI | 114<br><br>53.29±9.65<br><br>Female: 89% (101/114)<br><br>Male: 11% (13/114)<br><br>Mixed | Online, individual, self-managed<br><br>Participants allowed to access their family doctor and/or local (mental) health services as required.<br><br>Self-managed, 8× over 16 weeks | 8 sessions<br><br>Clinician time spent per group iCBT: 64.3 minutes<br><br>TAU: 17.6 minutes<br><br>16 weeks | Intervention was self-managed. Clinician monitored responses on all measures. Research team member contacted for inquiries.<br><br>Online and participants local family doctor and/or local (mental) health services | FCRI<br><br>Pre-treatment (baseline, post-randomization), midpoint, posttreatment, 3-month FU | iCBT: 91.48±18.53<br><br>TAU: 85.84±18.23 | iCBT: 73.80±19.31<br><br>TAU: 81.33±19.20 | Significant group-by-time interactions for all secondary outcome measures total scores occurred.<br><br>Between-group effect sizes were small for fear of recurrence (FCRI-Total, g=0.39, with subscale variation).<br><br>For iCBT, there was a large and significant within-group reduction for total scores on each secondary measure: FCRI-Total, g=1.09.<br><br>In the within-group analysis of iCBT, five of the FCRI-subscales showed significance increases, with FCRI -Coping Strategy showing a significant decrease.<br><br>For secondary measures in TAU, significant but small reductions were only found for FCRI-Total (g=0.20). This was driven |

| Author, Country | Sample size, Age (Years, Mean, SD), Sex, Cancer Type | Delivery Mode And Intervention Format | Session Number, Length, Duration | Provider and Location of Intervention | FCR Instrument and Assessment Times | Baseline FCR Level (SD) | Post FCR Level (SD) | Major Findings |
|---|---|---|---|---|---|---|---|---|
| | | | | | | | | through two of the FCRI-subscales (Severity and Functioning Impairment). |
| Omidi, 2020 [29]<br><br>Iran<br><br>RCT<br><br>GE vs. SNE vs. control | 105<br><br>GE: 52.47±10.62<br><br>SNE: 50.44±8.81<br><br>Control: 50.23±8.90<br><br>Female<br><br>Breast cancer | GE: Researcher-moderated, groups of 5<br><br>SNE: Online channel on Telegram messenger, individual<br><br>Control: In-person provided by lymphedema specialist, and self-led at home<br><br>Control+ GE: 5 sessions, 2x a week, over 3 weeks<br><br>Control+ SNE: Content uploaded 2x a week over 3 weeks<br><br>Control: All patients underwent routine lymphedema treatments, including. | Session number<br>GE: 5 sessions<br><br>SNE: 5 sessions<br><br>Control: 20 sessions<br><br>Length<br>GE: 60-90 minutes<br><br>SNE: NR<br><br>Control: NR<br><br>Duration<br>GE: 3 weeks<br><br>SNE: 3 weeks<br><br>Control: 2-3 weeks + maintenance phase (3 months later) | GE: Researcher<br><br>SNE: Self-led, channel admin notified when content was received<br><br>Control: Lymphedema specialist + patient-led<br><br>GE: Quiet room in the clinic<br><br>SNE: Online<br><br>Control: In clinic and at home | FoPQ-SF<br><br>GE and SNE: before the beginning of the study (T0), immediately after the 3 weeks of interventions (T1), 3 months later (T2)<br><br>Control: before the beginning of the study (T0), immediately after the end of the acute phase of treatment (2-3 weeks) (T1), 3 months later (T2) | T0<br>GE (n=32): 34.37±12.28<br><br>SNE (n=34): 36.28±12.43<br><br>Control (n=31): 36.60±11.12 | T1<br>GE: 31.78±11.01<br><br>SNE: 36.23±12.24<br><br>Control: 36.29±10.31<br><br>T2<br>GE: 31.81±11.92<br><br>SNE: 35.56±12.62<br><br>Control: 35.03±11.88 | Mean score of FCR changed: 34.4 to 31.8 in the GE group, 36.3 to 35.6 in the SNE group, 36.6 to 35 in the CO group.<br><br>Results indicated that the main effect of time and group was not significant (p=0.084, p=0.380, respectively).<br><br>Interaction of time and group effect on FCR mean score changes did not show significant correlation (p=0.568).<br><br>Comparison of the FCR scores at the end of the study, after adjusting the baseline value and group effect by ANCOVA test, did not show a significant difference (p=0.520). |
| Sharpe, 2019 [35]<br><br>Australia | 152<br><br>52.82±10.07 | Therapist-led, individual | 5 sessions<br><br>60-90 mins | Therapist<br><br>Hospitals/cancer centres | FCRI | NR | NR | Correlations:<br>There were no significant correlations between any baseline medical variables |

| Author, Country | Sample size, Age (Years, Mean, SD), Sex, Cancer Type | Delivery Mode And Intervention Format | Session Number, Length, Duration | Provider and Location of Intervention | FCR Instrument and Assessment Times | Baseline FCR Level (SD) | Post FCR Level (SD) | Major Findings |
|---|---|---|---|---|---|---|---|---|
| RCT<br><br>ConquerFear vs. relaxation training<br><br>MBI and CBT | Male: 7<br>Female: 145<br><br>Breast cancer: 140<br>Other: 12 | 5 sessions over a period of 10 weeks, sessions are weekly/fortnightly | 10 weeks | | Baseline, 3-month FU, 6-month FU | | | (e.g., type of treatment, stage, time since diagnosis) and FCRI at FU<br><br>Younger age (r=− 0.299), female gender (r=0.232) and higher baseline FCRI (r=0.687) were associated with higher levels of FCR at follow-up<br><br>Moderation analysis:<br>Perceived risk of recurrence (F(6,123) = 3.919; p=0.0532), metacognitions (F(6,123) = 0.0701, p=0.792) and intrusions (F(6,123) = 2.152, p=0.145) did not moderate treatment efficacy<br>baseline FCRI total score did moderate the relative efficacy of ConquerFear versus relaxation (F(15,113) = 4.36, p=0.039).<br><br>In tests of simple difference:<br>no between-group differences found for those scoring with levels of FCRI one standard deviation below the mean (i.e., ≤ 56) (p=0.745)<br>for those scoring within one standard deviation of the mean (57–112) (p=0.0033) or scoring one standard deviation above the mean (> 112) (p=0.0005) on the total FCRI, ConquerFear was significantly more efficacious than relaxation, even when controlling for other baseline characteristics.<br><br>Mediation analysis:<br>those in ConquerFear reported greater reductions in unhelpful metacognitions (F(6,136) = 2.337, p=0.0353), and intrusions (F(6,136) = 4.375, p=0.0002). model did not predict perceived likelihood of recurrence (F(6,136) = 0.977, p=0.444) or therapeutic alliance (F(6,136) = 1.143, p=0.341).<br>Treatment group significantly predicted FCRI at follow-up in univariate analyses (t=3.717, p=0.0003). |

| Author, Country | Sample size, Age (Years, Mean, SD), Sex, Cancer Type | Delivery Mode And Intervention Format | Session Number, Length, Duration | Provider and Location of Intervention | FCR Instrument and Assessment Times | Baseline FCR Level (SD) | Post FCR Level (SD) | Major Findings |
|---|---|---|---|---|---|---|---|---|
| Cillessen, 2020 [79]<br><br>Netherlands<br><br>Secondary analysis of Compen 2018 MBCT or eMBT vs. TAU)<br><br>RCT<br><br>MBCT vs. eMBCT vs. TAU | 125<br><br>52±10.2<br><br>Nonusers (n=17): 49.4±11.4<br><br>Users (n=108): 52.2±10.1<br><br>Nonusers Female: 100% (17/17)<br><br>Users Female: 85% (92/108) Male: 15% (16/108)<br><br>Breast cancer: 60.8% (76/125)<br><br>Other: 39.2% (49/125) | Completed online, individually, therapists provided feedback<br><br>1× a week for 9 weeks | 9 sessions<br><br>Self-paced but each lesson was intended to be completed within 1 week<br><br>The intervention was designed to be completed in 9 weeks; however, the average time to complete the program was 10.4±4.0 weeks | Therapist<br><br>Online | FCRI<br><br>Baseline | Nonusers: 91.5±18.7<br><br>Users: 78.1±20.3<br><br>Test value: 2.27 (df=118) P=0.03 d=0.69 | NR | Nonusers had higher levels of baseline fear of cancer recurrence compared with users ($t_{118}$=2.27, p=0.03). This effect was of a medium to large size (D=0.69). There were no other differences between users and nonusers at baseline.<br><br>Besides fear of cancer recurrence and conscientiousness, no other predictors of usage of eMBCT were found |
| Cillessen, 2018 [41]<br><br>Netherlands<br><br>(FU of Compen 2018 MBCT or eMBT vs. TAU)<br><br>RCT | 245<br><br>MBCT: 120<br><br>eMBCT: 125<br><br>MBCT Age: 51.5±11.1<br><br>eMBCT Age:51.8±10.2 | MBCT: sessions were groups of max. 12 and therapist-led, at-home was completed individually<br><br>eMBCT: individual, guided by therapist, | 8 sessions<br><br>MBCT: 150 mins for each session + 45 mins for at-home practice<br><br>eMBCT: self-paced but each session should be | Qualified mindfulness therapist<br><br>MBCT: NR + at home<br><br>eMBCT: online, at home | FCRI<br><br>T0 (baseline, after randomization), T1 (directly after intervention), T2 (3-month FU), | MBCT: 21.2±6.6 eMBCT: 21.1±6.3 | T1 MBCT: 17.9±6.7 eMBCT: 17.0±7.5<br><br>T2 MBCT: 16.7±5.4 eMBCT: 16.3±5.5<br><br>T3 | FCR did not significantly change over time. There were no differences between MBCT and eMBCT on the secondary outcomes.<br><br>Results linear mixed models<br>T0-T1 FCRI: F=272.0, df=1196, p<0.001<br><br>Time: F=1.2, df=1157, p=0.282<br>Intervention: F=1.6, df=1191, p=0.201<br><br>Effects of change in fear of cancer recurrence/rumination/mindfulness on |

| Author, Country | Sample size, Age (Years, Mean, SD), Sex, Cancer Type | Delivery Mode And Intervention Format | Session Number, Length, Duration | Provider and Location of Intervention | FCR Instrument and Assessment Times | Baseline FCR Level (SD) | Post FCR Level (SD) | Major Findings |
|---|---|---|---|---|---|---|---|---|
| MBCT vs. eMBCT) | MBCT<br>Male: 15.8% (19/120)<br>Female: 84.2% (01/120)<br><br>eMBCT<br>Male: 12.8% (16/125)<br>Female: 87.2% (109/125)<br><br>MBCT<br>Breast: 62.5% (75/120)<br>Other: 37.5% (45/120)<br><br>eMBCT<br>Breast: 60.8% (76/125)<br>Other: 39.2% (49/125 | participants received session info online (1× per week) and were encouraged to complete it (info+exercises) over one week<br><br>MBCT: 1× a week for 8 weeks + 45 mins a day 6x a week<br><br>eMBCT: 1× a week for 8 weeks | completed within 1 week<br><br>8 weeks | | T3 (9-month FU) | | MBCT:<br>17.3±6.4<br>eMBCT:<br>16.3±6.7 | psychological distress at the three-month follow-up with hierarchical linear regressions<br><br>FCR:<br>Step variable: Step 2 - Residual change score fear of cancer recurrence T0/T1<br>F=6.42, Df=1, 125, p=0.013<br>Adjusted $R^2$=0.033, B=1.40, t=2.53, p=0.013 |

**Abbreviations:** ACT: acceptance and commitment therapy; BA: behavioural activation; BCS: breast cancer survivors; BCSE: Breast Cancer Self-Efficiency Scale; CARS: Concerns about Recurrence Scale; CARS-J: Concerns about Recurrence Scale – Japanese Version; CBI-D: Cancer Behaviour Inventory; CBT: cognitive behavioural therapy; CI: confidence interval; CO: control; CWS: Cancer Worry Scale; eMBCT: online/internet mindfulness-based cognitive therapy; EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; EUC: enhanced usual care; FCR: fear of cancer recurrence; FCRI: Fear of Cancer Recurrence Inventory; FCRI-SF: Fear of Cancer Recurrence Inventory Short Form; FOP: Fear of Progression; FoP-Q-SF: Fear of Progression Questionnaire Short Form; FoPR: fear of progression/recurrence; FoR: fear of recurrence; FORT: fear of cancer recurrence therapy; FU: follow up; GE: group-based education; GEE: general estimated equations models; HIIT: high-intensity interval training; HMC: health management content; HRC: high risk clinics; ICBT: internet-delivered cognitive behavioural therapy; IT: individual therapy; LWWC: Living Well With Cancer; MAX-PC: Memorial Anxiety Scale for Prostate Cancer; MBCT: mindfulness-based cognitive therapy; MBI: mind-body intervention; MBSR: mindfulness-based stress reduction; mins: minutes; NR: not reported; OR: odds ratio; PST: problem-solving therapy; RCT: randomized controlled trial; SD: standard deviation; SE: standard error; SM: self-management; SNE: social network-based education; TAU: treatment as usual; UC: usual care

## Appendix 5: Quality Assessments

**Table 5.1 AGREE II (Appraisal of Guidelines for Research and Evaluation) Instrument Scores**

| Guideline | Domain 1: Scope and Purpose | Domain 2: Stakeholder Involvement | Domain 3: Rigor of Development | Domain 4: Clarity of Presentation | Domain 5: Applicability | Domain 6: Editorial Independence |
|---|---|---|---|---|---|---|
| Cancer Australia 2014 [57] | 83% | 73% | 62% | 58% | 55% | 80% |

**Table 5.2 ROBIS (Risk of Bias in Systematic Reviews) Quality Assessment Scores**

| Study | Domain 1: Study Eligibility Criteria | Domain 2: Identification and Selection of studies | Domain 3: Data Collection and Study Appraisal | Domain 4: Synthesis and Findings | Overall Risk of Bias |
|---|---|---|---|---|---|
| Tauber 2019 [38] | Low | Low | Low | Low | Low |
| Park 2022 [8] | Low | Low | Low | High | High |
| Cinnicida 2021 [9] | Low | Low | High | High | High |
| Chen 2018 [37] | Low | Low | Moderate | Low | Low |
| Hall 2018 [10] | Low | Low | Low | Low | Low |
| Baydoun 2021 [78] | Low | Low | Low | Low | Low |
| Smith 2021 [24] | Low | Low | Low | Low | Low |
| O'Rourke 2021 [23] | Low | Low | Low | Low | Low |
| Deckx 2021 [83] | Low | Low | Low | Low | Low |
| Liu 2019 [11] | Low | Low | Low | Low | Low |
| Williams 2020 [52] | Low | Low | Low | Low | Low |
| Webb 2023 [25] | Low | Low | Low | Low | Low |
| Maheu 2025 [88] | Low | Low | Low | Low | Low |

**Table 5.3 Risk of Bias in Randomized Controlled Trials**

| Study | Domain 1: Randomization Process | Domain 2: Deviation from Intervention | Domain 3: Missing Outcome Data | Domain 4: Measurement of Outcome | Domain 5: Reported Result | Overall Risk of Bias |
|---|---|---|---|---|---|---|
| Akechi, 2023 [31] | Low | Low | Low | Some concerns | Low | Some concerns |
| Tauber, 2023 [43] | Low | Some concerns | Low | Low | Low | Some concerns |
| Maheu, 2023 [6] | Low | Some concerns | Low | Low | Low | Some concerns |
| Ahmadiqaragezlou 2020 [39] | Low | High | Low | High | Low | High |
| Akechi 2021 [36] | Low | Low | Low | Some concerns | Low | Some concerns |

| | | | | | | |
|---|---|---|---|---|---|---|
| Arch 2021 [40] | Low | Low | Low | Some concerns | Low | Some concerns |
| Cillessen 2018 [41] | Low | Low | Low | Some concerns | Low | Some concerns |
| Cillessen 2020 [79] | Low | Some concerns | Low | Some concerns | Low | Some concerns |
| Dieng 2020 [32] | Low | Low | Low | Some concerns | Low | Some concerns |
| Dirske 2020 [26] | Low | Some concerns | Low | High | Low | Some concerns |
| Frangou 2021 [42] | Low | Low | Low | Some concerns | Low | Some concerns |
| Kang 2022 [33] | Low | Some concerns | Low | Some concerns | Low | Some concerns |
| Murphy 2020 [28] | Low | Low | Low | Some concerns | Low | Some concerns |
| Omidi 2020 [29] | Low | Low | Low | Some concerns | Low | Some concerns |
| Sharpe 2019 [35] | Low | Some concerns | Low | Low | Low | Some concerns |
| Wagner 2021 [30] | Low | Low | Low | Low | Low | Some concerns |
| Rogers, 2020 [22] | Some concerns | High | Low | Some concerns | Low | Some concerns |

**Table 5.4 ROBINS (Risk of Bias in Non-randomized Studies) Quality Assessment Scores**

| Study | Domain1: Bias due to confounding | Domain 2: Bias due to selection of participants | Domain 3: Bias in measurement of interventions | Domain 4: Bias due to departure of interventions | Domain 5: Bias due to missing data | Domain 6: Bias in measurement of outcomes | Domain 7: Bias in selection of the reported results | Overall Risk of Bias |
|---|---|---|---|---|---|---|---|---|
| Lynch 2020 [27] | Moderate | Serious | Moderate | Low | Low | Some concerns | Low | Moderate |

**Table 5.5 JBI Critical Appraisal Checklist for Analytical Cross-Sectional Studies Quality Assessment Scores**

| Study | Domain 1: Bias due to selection of participants | Domain 2: Bias in measurement of interventions | Domain 3: Bias due to confounding | Domain 4: Bias in measurement of outcomes | Overall Risk of Bias |
|---|---|---|---|---|---|
| Smith, 2023 [18] | Low | Low | Low | Low | Low |
| Deuning-Smit, 2022 [76] | Low | Low | Low | Low | Low |
| Rudy, 2020 [21] | Low | Low | Low | Low | Low |
| Rogers, 2016 [20] | Low | Low | Low | Low | Low |

## Appendix 6: Ongoing, Unpublished, or Incomplete Studies

**Table 6.1 Ongoing, Unpublished or Incomplete studies**

| | |
|---|---|
| **Protocol ID:** | **NCT04965428** |
| Study Title | Fear-focused Self-Compassion Therapy for Young Breast Cancer Patients' Fear of Cancer Recurrence |
| Study Status | Recruiting |
| Interventions | Behavioural: Fear-focused Self-Compassion Therapy |
| Primary Outcome Measures | Fear of cancer recurrence (FCR). Fear of cancer recurrence will be assessed using 42-item Fear of Cancer Recurrence Inventory (FCRI). |
| Sponsor | Shaanxi Normal University |
| Enrollment | 160 |
| Study Type | Intervention |
| Completion Date | 2023-12 |
| | |
| **Protocol ID:** | **NCT04568226** |
| Study Title | The Effect of Metacognition-based, Manualized Intervention on Fear of Cancer Recurrence |
| Study Status | Recruiting |
| Interventions | ConquerFear Intervention\| |
| Primary Outcome Measures | Fear of cancer recurrence (FCR). Fear of cancer recurrence will be assessed using 42-item Fear of Cancer Recurrence Inventory (FCRI). The subscale, Severity will be used as a screening tool for high level of FCR. |
| Sponsor | The University of Hong Kong |
| Enrollment | 174 |
| Study Type | Intervention |
| Completion Date | 2024-12-31 |
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| **Protocol ID:** | **NCT05765916** |
| Study Title | An Online Psychosocial Intervention for Fear of Cancer Recurrence in Breast Cancer Survivors |
| Study Status | Recruiting |
| Interventions | Behavioural: Online mindfulness and acceptance intervention |
| Primary Outcome Measures | Fear of cancer recurrence (FCR). Fear of cancer recurrence will be assessed using 42-item Fear of Cancer Recurrence Inventory (FCRI). |
| Sponsor | National University of Singapore |
| Enrollment | 244 |
| Study Type | Intervention |
| Completion Date | 2023-12-30 |
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| **Protocol ID:** | **NCT04287218** |
| Study Title | Reducing Fear of Cancer Recurrence in Danish Colorectal Cancer Survivors |
| Study Status | Recruiting |
| Interventions | Behavioural: TG-iConquerFear/Behavioural: aTAU |
| Primary Outcome Measures | Fear of cancer recurrence (FCR). Fear of cancer recurrence will be assessed using 42-item Fear of Cancer Recurrence Inventory (FCRI). Change of total score on Fear of Cancer Recurrence Inventory (FCRI) |
| Sponsor | Vejle Hospital |
| Enrollment | 540 |
| Study Type | Intervention |
| Completion Date | 2025-09 |
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| **Protocol ID:** | **NCT05364450** |
| Study Title | Facilitating Adaptive Coping with Fear of Recurrence Among Breast Cancer Survivors |
| Study Status | Active: Not Recruiting |
| Interventions | Behavioural: Enhanced Usual Care/Behavioural: Acceptance Commitment Therapy/Behavioural: Cognitive Behavioral Therapy |
| Primary Outcome Measures | Fear of cancer recurrence (FCR). Fear of cancer recurrence will be assessed using 42-item Fear of Cancer Recurrence Inventory (FCRI). |
| Sponsor | Indiana University |
| Enrollment | 390 |
| Study Type | Intervention |
| Completion Date | 2025-01-01 |
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| **Protocol ID:** | **NCT03270995** |
| Study Title | Cognitive-Existential Group Therapy to Reduce Fear of Cancer Recurrence: A RCT Study |
| Study Status | Completed |
| Interventions | Behavioural: Cognitive Existential Therapy Group 1\|Behavioural: Supportive Therapy Group 2 |
| Primary Outcome Measures | Fear of cancer recurrence (FCR). Fear of cancer recurrence will be assessed using 42-item Fear of Cancer Recurrence Inventory (FCRI). |
| Sponsor | McGill University |
| Enrollment | 144 |
| Study Type | Intervention |
| Completion Date | 2020-02-01 |
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| **Protocol ID:** | **NCT04137575** |
| Study Title | ConquerFear-Group: A Psychological Intervention for Fear of Cancer Recurrence |
| Study Status | Completed |
| Interventions | Behavioural: ConquerFear-Group/Behavioural: Relaxation Training |

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| Primary Outcome Measures | Fear of cancer recurrence (FCR). Fear of cancer recurrence will be assessed using 42-item Fear of Cancer Recurrence Inventory (FCRI). |
| Sponsor | Aarhus University Hospital |
| Enrollment | 85 |
| Study Type | Intervention |
| Completion Date | 2022-06-22 |