

# Fear of Cancer Recurrence

Lymphoma Coalition  
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# Introduction

Advances in cancer detection and treatment have led to increasing numbers of patients surviving and living with cancers for prolonged periods of time. Consequently, across cancer survivorship research, greater attention is being focused on quality-of-life issues, and how individuals adapt to chronic cancers.<sup>1-4</sup>

One area of focus is the fear of cancer recurrence (FCR); FCR is very common among cancer survivors, and studies suggest that it persists long after treatments are terminated.<sup>1,5-10</sup> The Lymphoma Coalition (LC) is interested in further investigating this topic as, year after year, the LC Global Patient Survey (GPS) has reported FCR to be a major issue for lymphoma patients. FCR is concerning not only because of the distress it causes patients, but also because of its negative impacts on quality of life, healthcare service use, and adherence to follow-up recommendations. Despite being a common experience for which cancer survivors seek professional help or support, studies indicate that FCR is one of the most frequently cited unmet needs. Though there is much research interest surrounding FCR, its definition and characteristics continue to lack widespread consensus.<sup>8,11</sup> Therefore, at a clinical level, the process of translating FCR knowledge into effective patient services continues to be hindered.<sup>11-13</sup>

Supporting patients through first evidence, and then tools to cope within this environment is critical. In recent years, targeted FCR interventions have shown to reduce FCR levels in sample populations, and have outlined steps that all members of a patient's cancer team can take to effectively address FCR and better support patients. Clear clinical pathways must be established to ensure that patients are receiving appropriate intervention and support for this issue.

This report will cover:

1. Defining and understanding FCR
2. Measuring FCR
3. Prevalence
4. Predictors
5. Comorbidities
6. Interventions and practical clinical guidance

Words highlighted in **bold** are defined in the glossary at the end of the report.

## Understanding Fear of Cancer Recurrence (FCR)

FCR is now commonly accepted as a multidimensional construct<sup>14-17</sup>, an understanding of which necessitates an understanding of the following pieces:

1. Definition(s)
2. Conceptual Framework
3. Clinical Features

## Definition(s)

The most widely cited definition of FCR remains, proposed by the work of Vickberg (2003)<sup>14</sup>, “*the worry that cancer will come back in the same place or in another part of the body*”. Despite being the most commonly cited across FCR literature, this definition is still not recognised by all studies and researchers.<sup>11</sup>

In order to address this gap, a group of expert researchers (Lebel et al.<sup>11</sup>), policy makers, and patient advocates specialising in FCR convened for a 2-day meeting in Ottawa, Canada in 2015. The meeting attendees were from countries around the world. They used a three-round **Delphi method** to produce a new definition of FCR: “*Fear, worry, or concern relating to the possibility that cancer will come back or progress*”.<sup>11</sup> This updated definition suggests that FCR may be a problem both for patients with a curable disease who fear recurrence, and for those with advanced disease who fear progression. This definition closely aligns with the LC’s interpretation of FCR and reflects the broad spectrum in which patients can experience it.

Despite some remaining ambiguity surrounding a principal FCR definition, the Lebel et al. definition is now widely recognised, and readily employed across research studies.

## Conceptual Framework

Beyond these definitions, research is also interested in the different factors or variables that make up FCR as a concept. This is termed the conceptual dimensionality. Presently, the multi-dimensional FCR conceptualisation by Lee-Jones et al.<sup>15</sup> is the most cited.

Their conceptual framework<sup>15</sup> proposes that FCR is comprised of cognitions, beliefs and emotions. Cognitions include the person’s knowledge base of cancer (i.e. cure and survival rates), their past experience with cancer and treatment, and their general beliefs surrounding cancer eradication. Beliefs refers specifically to a person’s beliefs about their personal risk for a cancer recurrence. Emotions include worry about cancer returning, anxiety about the cancer itself, and regret for not selecting a more aggressive treatment.<sup>15</sup>

Though research has aimed to define it, studies suggest that the conceptual dimensionality of FCR still requires further investigation.<sup>18,19</sup>

## Clinical Features

The majority of patients who exhibit clinically meaningful levels of FCR do not meet the criteria for thoughts or behaviours associated with a specific psychological disorder. As such, FCR is considered a unique and significant mental health issue in its own right.<sup>20</sup>

Building on the definitional and conceptual work surrounding FCR, studies have sought to identify common features associated with clinically-significant FCR. Patients can experience FCR along a spectrum ranging from mild to severe. Patients with mild FCR may have occasional thoughts about cancer with peaks of anxiety (lasting for a few days then resolving) that are triggered by external factors (i.e. follow-up appointments).<sup>20</sup> Patients with moderate to severe FCR may experience more frequent thoughts about cancer (+1 times a week, without triggers), a perceived inability to control these thoughts, and a strong sense of associated distress.<sup>20</sup> When severe, FCR

is considered clinically significant and is unlikely to remit without clinical intervention.<sup>20</sup>

The same Lebel et al.<sup>11</sup> Delphi method study that produced the updated FCR definition also proposed 5 possible characteristics of clinical FCR:

1. High levels of preoccupation, worry, **rumination**, or intrusive thoughts
2. **Maladaptive** coping
3. Functional impairments
4. Excessive distress
5. Difficulties making plans for the future

Following this, Mutsaers et al.<sup>21</sup> used the Lebel et al. FCR definition and findings to conduct a study analysing the features of clinical FCR. Their study revealed that clinically-significant FCR was associated with 10 features:

1. Death-related thoughts
2. Feeling alone
3. Believing that cancer would return
4. Experiencing uncertainty
5. Having cancer-related thoughts and imagery that were difficult to control
6. Daily and recurrent thoughts
7. Thoughts that lasted 30 minutes or longer
8. Experience of distress
9. Experience of increased distress over time
10. Impact on an individual's daily life

Respondents of the 2018 LC GPS<sup>22</sup> with FCR report the following more frequently: feeling out of control, overall fearful, fearful for the future, at a loss, and wanting to get into bed and hide.<sup>22</sup> Additionally, when asked if they had experienced certain changes as a result of their lymphoma, respondents with FCR more frequently reported that their lifestyle and independence had been affected.<sup>22</sup>

## Measuring FCR

FCR definitions, conceptualisations, and clinical features are the theoretical foundations behind the FCR measurement tools that have been developed.

There have been numerous attempts to design accurate FCR measures. Though FCR itself is accepted as multidimensional, the method of assessing FCR, either using multi or unidimensional measures, remains widely varied.<sup>13</sup>

Generally, approaches to measure FCR can be divided into two main types: single item scales or multi-item scales. Single item scales are easily administered and can be applied repeatedly over time; however, when measuring scale 'performance', some **psychometric** investigations show limitations on key parameters (i.e. reliability).<sup>13</sup> Multi-item scales are able to assess various features and qualities of FCR; however, they can be burdensome to complete and difficult to score and interpret.<sup>13</sup>

Though many FCR measurement tools demonstrate promising psychometric properties, several studies suggest that further refinement and validation is required.<sup>5,8,13</sup> Some issues with current scales as indicated by the literature:<sup>5,8,13,19,23</sup>

1. Lack of conceptualisation/accepted definition of FCR
2. Single-point designs
3. Lack of clinical cut-off point
4. Over-reliance on breast cancers
5. Cross-cultural validity

Tables 1 and 2 (Appendix) outline a body of validated assessment tools used in research and clinical practices to measure FCR. Both longer (10+ items) and shorter (2-10 items) scales are identified. The foundational theories and definitions behind each of these tools varies widely. There is no current consensus on which tool is most appropriate to measure FCR, and the applicability of any of these measurement scales is dependent on a range of considerations. Some of these considerations include: context of use, psychometric properties according to context, desired mode of administration, and respondent burden.<sup>13,19</sup>

Ideally, the employment of an FCR measurement scale should be supplemented by open-ended questions and observations of non-verbal and verbal cues from the patient.<sup>13,20</sup> Results of the screening tool should be shared with the patient. If FCR is detected using one of these scales, this information should be shared with the patient's healthcare team (with the permission of the patient).<sup>20</sup>

## FCR Prevalence

Fear of recurrence (FCR) is amongst the most commonly reported psychosocial issues for cancer survivors.<sup>5-7</sup> Studies suggest that FCR is likely a concern for all cancer patients; to date, FCR has been documented in patients with breast, colorectal, testicular, head and neck, lung, endometrial, and thyroid cancer; sarcoma; melanoma; and lymphomas.<sup>20</sup>

Reported prevalence rates of FCR vary widely across the literature; this may be explained by the use of various measurement tools (**single-item, multi-item, unidimensional, multi-dimensional**), and by the inconsistent psychometric properties across these tools.<sup>8,16,19,23</sup> Despite variation, many studies suggest that most cancer survivors will experience some level of FCR during their cancer experience. The studies examined in this review reported FCR prevalence rates ranging from 36% to 89%.<sup>1,7,11,16,19,24-28</sup> Data from studies with survivors of breast cancer, colorectal cancer, lung cancer, and prostate cancer was the most readily available. A commonly reported figure is that, on average, 49% of survivors report moderate to high levels of FCR.<sup>8,20,29-30</sup> Additionally, about 7% of survivors experience severe and highly disabling FCR.<sup>29-30</sup>

Specific to the lymphoma population, the 2018 LC GPS<sup>22</sup> indicated that 43% of respondents experienced FCR during treatment and 72% experienced FCR after treatment. Respondents' reports of FCR peaked immediately following treatment (27%) and 3-5 years (22%) after treatment, but it was also reported by some respondents (10%) at 8+ years after treatment completion.<sup>22</sup>

## FCR Predictors

A predictor variable is used to predict some other variable or outcome. Predictor variables are generally not manipulated by the researcher; the differences in the predictor variable across subjects are usually naturally occurring. Understanding the predictors of FCR is necessary to identify survivors with or at high risk of developing clinically-significant FCR. There have been three types of FCR predictors identified in the literature: 1) demographic, 2) clinical, and 3) psychosocial.

The FCR predictors included in table 3 below were sourced only from studies whose results were statistically significant and critically appraised. These predictors were also proven consistently across studies. While predictors (religion, ethnicity, race, etc.) outside of this table have been analysed, many studies presented conflicting results and so they were not included.

Table 3. Demographic, clinical and psychological predictors of FCR as determined by studies with statistically significant results

Category of Predictor	FCR Predictors
Demographic	<ul style="list-style-type: none"> <li>• Younger age* (either measured as age at diagnosis, or by age at the time of study assessment)<sup>25,28-29,31-33</sup></li> <li>• Female gender*<sup>26,33</sup></li> <li>• Young mothers<sup>34</sup></li> <li>• Socio-economic status: being from a lower social class, having a lower level of education, and experiencing economic/financial issues<sup>10,35</sup></li> </ul>
Clinical	<ul style="list-style-type: none"> <li>• Lesser sense of physical well-being ('the control or relief of symptoms and the maintenance of function and independence') and a higher number of comorbidities<sup>33,36-37</sup></li> <li>• Presence and severity of physical symptoms (i.e. fatigue, pain)<sup>29,31,33,35-36,38</sup></li> <li>• Severity of cancer or cancer stage<sup>33,35-36</sup></li> <li>• Type of cancer treatment (radiation, novel targeted therapies, adjuvant treatments)<sup>20,35-36,39-40</sup></li> </ul>
Psychosocial	<ul style="list-style-type: none"> <li>• Psychological and emotional distress* (depression, anxiety, loss of behavioural or emotional control, lesser psychological well-being, lower level of optimism)<sup>26,35</sup></li> <li>• General or cancer-related beliefs and illness perceptions (viewing cancer experience as chronic or cyclic, attributing any symptom to recurrence, illness representations and reminders)<sup>10,41</sup></li> <li>• Stress and certain coping techniques (avoidance coping, escapist coping, and some elements of active coping)<sup>42-44</sup></li> <li>• Lower social support and adverse social interactions, relationships and perceptions of social network/support<sup>35,45</sup></li> </ul>

\* Indicates the predictor was corroborated in LC 2018 GPS results.



Awareness of these known predicting factors is important in identifying those patients vulnerable to experiencing FCR. It is also important to recognise there are limits to these generalisations; the main being that many of these predictors have been identified with survivors in one disease type, breast cancer survivors. Every case should be approached with appropriate contextual consideration and sensitivity.

## FCR Comorbidities

FCR is prevalent, distressing and long-lasting, and as such has a number of negative correlates. Across comorbidity studies, FCR is consistently reported to be a predictor of overall quality of life, mental health-related quality of life, and physical health-related quality of life (QoL).

Significant negative associations are reported between FCR and psychological well-being; FCR is associated with lower overall health-related quality of life, lower social functioning and other functional impairments, psychological/psychiatric distress and morbidities, emotional distress, uncertainty, anxiety and depression.<sup>2,10,12,28-30,46-49</sup> Results of the 2018 LC GPS<sup>22</sup> indicated that FCR was associated with feelings of isolation, depression, and anxiety both during and after treatment. FCR is also reported to influence mood and ability to make plans for the future.<sup>19</sup> Studies examining FCR and physical health-related QoL suggest that high FCR can negatively impact health behaviours, adherence to follow-up recommendations, and medical and physical well-being.<sup>20,50</sup>

FCR is also associated with increased use of medical resources. Using multiple **regression analysis**, one study determined that higher FCR significantly predicted greater number of outpatient and emergency room visits in the past 6 months when controlling for education level and relationship status.<sup>51</sup> Other studies suggest that cancer survivors with high FCR have more unscheduled visits with physicians, conduct self-examinations more frequently than recommended guidelines, have higher expenditures on complementary and alternative medicines (CAM), and attend counselling and support groups more frequently.<sup>19,20,29-30</sup> Similarly, irrespective of perceived information level, the 2018 LC GPS<sup>22</sup> indicated that respondents with FCR felt less confident in sourcing/determining the trustworthiness of information about their condition and treatment choices, and less confident in determining the need for medical care versus handling a health problem on their own. Additionally, FCR has been associated with more negative interactions with the healthcare system. For example, some studies indicate that patients with high FCR report lower satisfaction with their treatment plan and communication with medical staff.<sup>49</sup> This was reflected in 2018 LC GPS<sup>22</sup> results; respondents with FCR (regardless of their perceived information level) less frequently reported having good conversations with their doctor about their care and treatment plan.

## FCR Interventions

Studies suggest that FCR is one of the most frequently cited unmet needs among cancer survivors. Survivors consistently report FCR to be among their top greatest concerns, irrespective of the level of severity at which they experience it (low, moderate, high).<sup>29,52-53</sup> Further, longitudinal studies of cancer survivors show that FCR is long-lasting, and without intervention it may not necessarily diminish over time.<sup>20</sup>

Evidence suggests that the majority of cancer patients express interest in receiving strategies, learning coping mechanisms, and engaging in discussion about FCR.<sup>27</sup> Despite this, FCR is often omitted from survivorship planning and discussions with healthcare professionals (HCPs).<sup>54</sup> The 2018 LC GPS indicated that 45% of respondents discussed their FCR with their doctor. However, only 29% felt it helped and 20% did not feel it helped alleviate the fear.<sup>22</sup> Further, of those who discussed their FCR with the doctor, only 37% were referred onto support.<sup>22</sup> Several other studies concluded that only the minority of clinical staff reported always referring patients with high levels of FCR to psychosocial (or other) support.<sup>24,27,29,53</sup>

FCR is associated with unmet supportive care needs across a wide range of domains including: medical, psychological, physical, spiritual/religious, and sexual.<sup>53</sup> It can be difficult for HCPs to determine how to manage or treat FCR because evidence-based strategies are not yet routinely available.<sup>8</sup> However, in recent years, studies have begun developing and evaluating interventions for FCR. Studies examining potential mechanisms for reducing FCR ('mediators') have been essential to the development of tailored interventions for survivors.

Mediators clarify the relationship between variables; normally, a dependent variable is statistically correlated with an independent variable. When a mediating variable is introduced, the statistical significance between the dependent and independent variables is lost (full mediator) or reduced (partial mediators).<sup>23</sup> In the case of FCR, studies<sup>23</sup> have identified the following statistically significant mediators (i.e. proven to help reduce FCR): self-efficacy (belief in one's own capabilities)<sup>55</sup>, methods of coping (active coping specifically)<sup>44</sup>, ease of understanding information, symptom management, and care co-ordination.<sup>37</sup> The majority of these studies were conducted using breast cancer populations, therefore further investigation is required for generalisability.

Beyond mediators, a review of evidence of current published interventions<sup>56</sup> suggests the following successful intervention focuses:

- Being mindful
- Addressing fears
- Managing uncertainty
- Gaining control
- Improving 'patient-provider' communication
- Handling stress through counselling

In recent years, there have been several models used to guide therapeutic interventions for FCR. Early models were based heavily on the Common-Sense Model of Illness Representations, which suggested that patients with a high emotional response to cancer, and who believed their cancer was more severe (long lasting, out of their control) were more likely to experience FCR.<sup>20</sup> More recent models have built upon this conceptualisation. For example, a model developed by Fardell et al.<sup>5</sup> that proposes that for some, normal worry about a recurrence activates an unhelpful style of cognitive processing which creates a vicious cycle (i.e. ruminating, focusing attention on symptoms, trying to suppress worrying thoughts) that increases the individuals FCR. There have been a growing number of therapeutic FCR interventions, based on these models, which have been proven effective in reducing FCR (table 4).

Table 4. Randomised control trials of psychotherapeutic interventions for patients with FCR

Study	Intervention	Control	Primary Outcome (Improved Score)	Significant Outcomes (Primary + Secondary Outcomes)
Herschbach et al. (2010) <sup>57</sup>	Group cognitive behavioural therapy (CBT) or group supportive-experiential therapy (SET). Delivered in 2 group therapy programs (4 sessions each).	Usual care	Fear of Progression Questionnaire (FoP-Q)	Improved scores of FoP-Q and the HADS
Humphris & Rogers (2012) <sup>58</sup>	AFTER intervention based on the Common-Sense Model of Illness Representations. Delivered in 6 individual sessions by trained specialist nurse.	Usual care	Anxiety subscale of the Hospital Anxiety and Depression Scale (HADS)	Improved scores on HADS (anxiety subscale) and the Worry of Cancer Scale (WOC)
Dieng et al. (2016) <sup>59</sup>	Psychoeducation pamphlet and 3, 1-hour telephone counselling sessions. Information on: risk information, question prompt sheet, care planning, support.	Care as usual	Fear of Cancer Recurrence Inventory (FCRI) severity subscale	Improvements in 2 subscales of FCRI: distress and trigger scores
Otto et al. (2016) <sup>60</sup>	Gratitude intervention. Weekly letter writing (10 mins) to someone whom participants were grateful.	Listing activities that patients engaged in during previous week	Concerns About Recurrence Scale (CARS)	Positive impact on score for death worry subscale of CARS
van de Wal et al. (2017) <sup>7</sup>	CBT: psychoeducation, cognitive restructuring, behavioural modification. Delivered in 5, 1-hour face-to-face sessions and 3, 15-minute online consultations.	Care as usual	FCRI	Improvements on all FCRI subscales
Lichtenthal et al. (2017) <sup>61</sup>	Cognitive bias modification. Combined modification of both attention and interpretation bias.	Placebo	CARS	Significant improvement in scores on health worries subscale of CARS
Butow et al. (2017) <sup>62</sup>	Conquer Fear: metacognitive therapy, acceptance & commitment therapy, attention training technique, detached mindfulness, behavioural contracts. Delivered in 5 face-to-face sessions over 10 weeks.	Relaxation therapy (5 sessions over 10 weeks)	FCRI	Improvement in many FCRI subscales: severity, coping, distress, triggers, anxiety, cancer-specific distress, health-related quality of life, meta-cognitions

Beyond underlying design models, the majority of interventions outlined in table 4 above employ delivery methodologies (i.e. CBT) which are adapted from various fields of behavioural and psychotherapy and tailored to address FCR in cancer survivors. These therapy types are described in table 5 below; trial interventions (or literature reviews studying many interventions) that achieved statistically significant FCR reduction in their sample population are included for each category of therapy.

Table 5. Categories of behavioural therapy and psychotherapy adapted for use in FCR interventions

Therapy Type	Description	Studies Employing the Therapy Type with Positive Results
Acceptance and Commitment Therapy (ACT)	Promotes forms of coping including: accepting cancer-related distress, reducing cancer-related avoidance, clarifying personal values, and committing to meaningful behaviour change.  Theorises that greater well-being can be achieved by overcoming negative thoughts and feelings. ACT is often conducted one-on-one with a therapist.	<a href="https://www.ncbi.nlm.nih.gov/pubmed/25100576">https://www.ncbi.nlm.nih.gov/pubmed/25100576</a>
Cognitive Behavioural Therapy (CBT)	Short-term, goal-orientated blend of psychotherapy and behavioural therapy. Takes a hands-on practical approach to problem solving. The goal is to change the patterns of thinking or behaviours that are behind patient's difficulties.  Works by focusing on the patient's cognitive processes (thoughts, images, attitudes, beliefs), and how these processes relate to the way they react or behave. CBT is usually conducted one-on-one with a therapist and is customised to the specific needs and personality of each patient.	<a href="https://www.ncbi.nlm.nih.gov/pubmed/29468568">https://www.ncbi.nlm.nih.gov/pubmed/29468568</a>
Blended Cognitive Behavioural Therapy (bCBT)	Same as CBT with the exception of the intervention delivery methodology. In bCBT only part of the therapy is delivered in face-to-face sessions, the remainder is offered to the patient in a different format (internet or web-based). Requires fewer face-to-face sessions, and continuous access to a web-format intervention facilitates skill acquisition and consolidation of in-session learning.	<a href="http://ascopubs.org/doi/full/10.1200/JCO.2016.70.5301">http://ascopubs.org/doi/full/10.1200/JCO.2016.70.5301</a>
Cognitive Existential (CE)	In the oncology context, developed to improve mood and mental attitude toward cancer. Can be individual or group setting. Some themes include: working through grief over losses, improve problem solving, develop cognitive strategies to maximise coping, body and self-image, sexuality, and relationships.	<a href="https://www.ncbi.nlm.nih.gov/pubmed/26838024">https://www.ncbi.nlm.nih.gov/pubmed/26838024</a> <a href="https://www.ncbi.nlm.nih.gov/pubmed/25555320">https://www.ncbi.nlm.nih.gov/pubmed/25555320</a> <a href="https://www.ncbi.nlm.nih.gov/pubmed/28150044">https://www.ncbi.nlm.nih.gov/pubmed/28150044</a> <a href="https://www.ncbi.nlm.nih.gov/pubmed/24756313">https://www.ncbi.nlm.nih.gov/pubmed/24756313</a>
Mindfulness Based Stress Reduction (MBSR)	Group intervention program (6-8 weeks) that focuses on the progressive acquisition of mindful awareness. Instruction in 3 formal techniques: mindfulness meditation, body scanning, and simple yoga postures.  Based on the following principles: non-judging, non-striving, acceptance, letting go, beginner's mind, patience, trust, and non-centring. Helps patients become more aware of habitual reactions and relate to themselves in a new way to interrupt this cycle and create more choice.	<a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3627743/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3627743/</a>
Communication Skills Training (CST)/ Survivorship care planning	A survivorship care plan refers to a written summary of the treatment received and recommendations regarding surveillance and management of late effects. CST programs are being developed for physicians in order to help them conduct survivorship-focused office visits using a survivorship plan with clear communication goals (beyond common discussions about nutrition, exercise, rehabilitation, etc.). CST programs can have many different focuses.	<a href="https://www.ncbi.nlm.nih.gov/pubmed/26622912">https://www.ncbi.nlm.nih.gov/pubmed/26622912</a> <a href="https://www.ncbi.nlm.nih.gov/pubmed/27697980">https://www.ncbi.nlm.nih.gov/pubmed/27697980</a>

Most of these published interventions have included face-to-face and group interactions, telephone discussions, and online sessions. Though effective, face-to-face psychological therapy

does present some limits; costs, resource intensive, and there are known patient-reported barriers such as stigma, investment of time, reluctance to return to a hospital setting, and indirect costs (time off work, travel, parking, etc.).<sup>7</sup> Further, outside of metropolitan areas, there can be a lack of suitably trained clinicians to deliver these specialised interventions.<sup>7</sup> Blended therapies (i.e. bCBT) may overcome some of these barriers; however, research suggests that further investigation is still needed to establish guidelines for assessment and management of FCR.

## Clinical Guidance

There are steps that all members of a patient's cancer team, from surgeons to oncologists, to nurses and allied health professionals, can take in order to effectively address FCR and better support patients. The following were sourced from numerous studies focused on the patient-provider communication aspect of FCR reduction, and provide practical suggestions for HCPs<sup>20</sup>:

- Assess and screen for FCR using validated measures
- Provide adequate information about prognosis
- Provide adequate information about signs and symptoms of a recurrence
- Discuss behavioural strategies for risk-reduction and follow-up
- Warn patients and families that FCR may be an issue in survivorship
- Normalise FCR and encourage patients to discuss it if it is a concern
- Avoid ordering extra tests to reassure an anxious patient (readiness to do so can indicate that the physician is also anxious/concerned about the risk)
- Refer patients onto appropriate support (psycho-oncology care, patient organisations, etc.)

It is recommended that screening for FCR (using validated measures) be conducted particularly at the end of treatment, as well as during follow-up appointments, as this is when patients begin to lessen their contact with the healthcare system. When treatment ends, patients lose the support provided by regular contact with oncology staff, and so experiencing some emotional upheaval is common.<sup>20</sup> Additionally, since natural fluctuations (incidence, severity) in FCR occur throughout the patient experience, it is important to complete repeat assessments. It may also be beneficial to verbally ask a patient about FCR at key follow-up consultations rather than request a complete questionnaire, as some patients may respond more readily to a direct question.<sup>20</sup>

It can be helpful to clearly acknowledge the emotional impact of a cancer diagnosis at the outset, and to respond to emotional cues from the patient and their family throughout their experience.<sup>20</sup> The response of HCPs to a patient's emotional cues has been proven to encourage patients to speak more freely about their feelings. For example, *'It sounds like you have been worrying a lot about what this cancer will mean for your future, can you tell me more about that?'* This may signal to a patient that attending to their concerns is an important and usual part of cancer care.<sup>20</sup>

The importance of talking about FCR should be emphasised; patients should not be made to feel like they need to adopt a 'positive outlook' or 'get back to normal'. Patients may have to develop a new 'normal' that incorporates the cancer experience into their lives. This should be reinforced with the patient's family and caretakers. For example, *'Many people whom I see worry a lot about their cancer coming back. This is normal and expected after a cancer diagnosis. But if the worry is distressing you, we should do something about it. There are things we can suggest to help you manage your worries. Has this been an issue for you?'* Acknowledging the normalcy of FCR will help to reduce stigma and patient denial of anxiety.<sup>20</sup>

Finally, those who experience FCR should be directed to appropriate resources. The patient's cancer team should assess the referral options in their local community as well as online in order to establish a clear clinical pathway. Some options include: booklets and online resources, referral to psycho-oncologist for select patients, referral to support groups, referral to patient organisations, etc.

# APPENDIX

\*In psychological research, 'reliability' refers to the consistency of a study or a measuring test. 'Internal consistency' reliability gauges how well a test or survey is actually measuring what it is intended to measure. Internal consistency is usually measured with Cronbach's alpha ( $\alpha$ ); a typical rule for describing the measurement is:

	Internal consistency
$\alpha \geq 0.9$	Excellent
$0.9 > \alpha \geq 0.8$	Good
$0.8 > \alpha \geq 0.7$	Acceptable
$0.7 > \alpha \geq 0.6$	Questionable
$0.6 > \alpha \geq 0.5$	Poor
$0.5 > \alpha$	Unacceptable

Table 1. Longer FCR measurement scales (10+ items)

Name of Measurement	Reference(s)	Country	Intended Population	Description	Number of Items/Structure	Reliability
Fear of Cancer Recurrence Inventory (FCRI & FCRI SF)	(Simard & Savard, 2009) <sup>16</sup>	Canada	Mixed cancers	Multidimensional self-report scale developed to include cognitive-behavioural conceptions of FCR.  Certain items inspired by DSM IV (Diagnostic and Statistical Manual of Mental Disorders) diagnostic criteria of anxiety and somatoform disorders to better assess the clinical significance of self-reported FCR.	<b>42 total items</b> [9- item short form available (SF)] divided into 7 subscales: 1. Triggers (8 items) 2. Severity (9 items) 3. Psychological distress (4 items) 4. Coping strategies (9 items) 5. Functioning impairments (6 items) 6. Insight (3 items) 7. Reassurance (3 items)  Measured using a 0 to 4 Linkert scale (0 not at all, 4 a great deal or all the time). <i>Higher scores indicate higher FCR</i>	Internal consistency: $\alpha = 0.95$
Fear of Progression Questionnaire (FOP-Q)	(Herschbach et al., 2005) <sup>17</sup>	Germany	Chronic illnesses (cancer, diabetes mellitus and rheumatic diseases)	Self-reporting multidimensional questionnaire.  Suitable for use for patients with all stages of disease, measures fear of progression not recurrence.  FOP and FCR are comparable and share many defining features.	<b>43 total items</b> [12- item short form available] divided into 5 subscales: 1. Affective reactions (13 items) 2. Partnership/family (7 items) 3. Occupation (7 items) 4. Loss of autonomy (7 items) 5. Coping with anxiety (9 items)  Measured using a 1 (never) to 5 (very often) point Linkert scale. <i>Higher scores indicate higher FCR</i>	Internal consistency: $\alpha = 0.95$ $\alpha = 0.87$ (for the 12-item short form)



Concerns About Recurrence Scale (CARS)	(Vickberg, 2003) <sup>14</sup>	USA	Breast cancer	A systematic assessment of the characteristics and nature of women's fears about possible breast cancer recurrence. Development based on Lazarus and Folkman's transactional model of stress and coping model.	30 total items divided into 2 main sections: 4 questions (frequency, potential for upset, consistency, intensity of fears) assessing overall FCR with a 6-point Linkert scale. 26 items assessing the nature of women's FOR on a Linkert scale of 1 (a little) to 4 (extremely). <i>Higher score indicates greater levels of worry about potential consequences of cancer recurrence</i>	Internal consistency: Overall fear $\alpha=0.87$ Subscales $\alpha=0.89-0.94$
Impact of Event Scale - Revised (IES-R)	(Weiss & Marmar, 1997) <sup>63</sup>	USA	Used with both ill and healthy adults exposed to any specific traumatic event. Can be administered repeatedly over time to monitor progress.	IES-R is the IES with 7 additional items. 6 of these items cover hyperarousal symptoms (irritability and anger, difficulty concentrating, heightened startle response). 1 new intrusion item discussing dissociative experiences of a true flashback. Compared to the IES, the IES-R better parallels the DSM-IV criteria for PTSD.	22 total items divided into 3 subscales: 1. Intrusion (8 items) 2. Avoidance (8 items) 3. Hyperarousal (6 items) Each item answered on a 5-point scale (0 not at all- 4 extremely) according to how often each has occurred in the past 7 days. <i>Higher combined score indicates higher subjective stress</i>	Internal consistency: Intrusion $\alpha= 0.87-0.92$ Avoidance $\alpha= 0.84-0.86$ Hyperarousal $\alpha= 0.79-0.90$
Hospital Anxiety and Depression Scale (HADS)	(Zigmond & Snaith, 1983) <sup>64</sup> (Herrmann, 1997) <sup>65</sup> (Mykletun, Stordal & Dahl, 2001) <sup>66</sup>	UK	Physically ill patients, general medical hospital outpatient clinics	Psychological screening tool (does not contain any confounding somatic items) that produces clinically meaningful results. Sensitive to changes during the course of the disease as well as to responses from various interventions (psychotherapeutic).	14 total items divided into 2 subscales: 1. Depression (HADS-D) (7 items) 2. Anxiety (HADS-A) (7 items) Each item answered on a 4-point (0-3) response category, so possible scores range from 0-21 for both HADS-D and A. <i>Score of 0-7 for either subscale regarded in 'normal range', score of 8-10 suggests presence of respective state, score of 11+ indicates probable presence of the mood disorder</i>	Internal consistency: HADS-D $\alpha= 0.80$ HADS-A $\alpha= 0.76$
Fear of Recurrence Questionnaire (FRQ)	(Northouse, 1981) <sup>67</sup>	USA	Breast cancer, but suitable for mixed cancers	First questionnaire designed to specifically assess FOR assessing worry about illness returning and health status, uncertainty, concerns of significant others, triggers, and impact on/attitudes towards future.	22 total items [6- item short form available] with patient and carer versions available. Measured using a 5-point Linkert scale (1 strongly agree, 5 strongly disagree). <i>Higher scores indicate higher FCR</i>	Internal consistency: $\alpha= 0.92$ (patients) $\alpha= 0.91$ (carers)
Impact of Event Scale (IES)	(Horowitz, Wilner & Alvarez, 1979) <sup>68</sup>	USA	Used with both ill and healthy adults exposed to any specific traumatic event.	Broadly applicable self-report measure that assesses symptoms relating to any specific traumatic experience.	15 total items divided into 2 subscales: 1. Intrusion (7 items, scores 0-35): intrusive thoughts, nightmares, intrusive feelings and imagery 2. Avoidance (8 items, scores 0-40): numbing of responsiveness, avoidance of feelings, situations, ideas Each item answered on a 4-point scale (0 not at all, 1 rarely, 3 sometimes, 5 often) according to how often each has occurred in the past 7 days. <i>Higher combined score indicates higher subjective stress</i>	Internal consistency: Overall $\alpha= 0.86$ Intrusion $\alpha= 0.79$ Avoidance $\alpha= 0.82$



Table 2. Shorter FCR measurement scales (2-10 items)

Name of Measurement	Reference(s)	Country	Intended Population	Description	Number of Items/Structure	Reliability
Fear of Cancer Recurrence Scale (FCR4 & FCR7)	(Humphris et al., 2018) <sup>13</sup>	Scotland, UK	Breast cancer, colorectal cancer, also suitable for mixed cancers	Unidimensional scales based upon a set of 7 questions selected from extant measures within the literature to directly assess FCR. The FCR4 is the FCR4 with 3 additional items.  FCR4 designed to feature anxiety, worry, and strong feelings coupled with return of the disease. FCR7 contains 2 cognitive processing items, and 1 behavioural response item.	<b>FCR4: 4 total items</b> <b>FCR7: 7 total items</b> Items 1-6 measured using a 1 (not at all) to 5 (all the time) Linkert scale. Item 7 measured using a 0 (not at all) to 10 (a great deal) Linkert scale.  <i>Higher scores indicate higher FCR</i>	Internal consistency: FCR4 $\alpha=0.93$  FCR7 $\alpha=0.93$
Concerns About Recurrence Questionnaire (CAR-Q-4)	(Thewes et al., 2015) <sup>69</sup>	Australia, Denmark	Breast cancer	Examines frequency, intrusiveness, degrees of distress, and risk perception.	<b>4 total items</b> Items 1-3 measured using an 11-point Linkert scale ('not at all' to 'a great deal'). The 4 <sup>th</sup> item is scored as a number (up to 100%).  <i>Higher scores indicate higher FCR</i>	Internal reliable and valid
Fear of Recurrence Scale B (FRSb)	(Franssen et al., 2009) <sup>70</sup>	Netherlands	Esophageal cancer patients, but also suitable for mixed cancers	Measures frequency of FCR, belief in cure, and fear of death.	<b>3 total items</b> Items measured using a 1 (very often, very much, very strongly) to 5 (not at all, never) Linkert scale. Items are reversed scored.  <i>Higher scores indicate higher FCR</i>	Internal consistency: $\alpha=0.66$
Worry of Cancer Scale Revised (WOC-R)	(Hodges, 2009) <sup>71</sup>	UK	Head and neck cancer patients and carers, but also suitable for mixed cancers	Modified from the Easterling and Leventhal CWS.  Examines frequency and degree of intrusiveness of FCR.	<b>2 total items</b> The 1 <sup>st</sup> item is measured using a 0 (not at all) to 10 (a great deal) Linkert scale. The 2 <sup>nd</sup> item is measured using a 0 (none of the time) to 4 (all of the time) Linkert scale.  <i>Higher scores indicate higher FCR</i>	Internal consistency: $\alpha=0.85$ (at 3 months) $\alpha=0.90$ (at 6 months)
Cancer Worry Scale B (CWS-B)	(Cameron et al., 2007) <sup>72</sup>	USA	Breast cancer	Examines worry about breast cancer recurrence and concern about breast cancer recurrence.	<b>2 total items</b> Items measured using a 0 (not at all) to 10 (extremely) Linkert scale.  <i>Higher scores indicate higher FCR</i>	Inter-item correlation: $r=0.86$

Assessment of Survivor Concerns Scale (ASCS)	(Gotay & Pagano, 2007) <sup>73</sup>	USA	Mixed cancers	Developed based on author's previous research with survivors. Examines worries about cancer (recurrence, new diagnosis, future tests) and worries about health (death, general health).	<p><b>5 total items</b> divided into 2 subscales:</p> <ol style="list-style-type: none"> <li>1. Cancer worry (3 items)</li> <li>2. Health worry (2 items)</li> </ol> <p>Items measured using a 1 (not at all) to 4 (very much) Linkert scale. <i>Higher scores indicate higher FCR</i></p>	Internal consistency: Cancer worry $\alpha=0.93$ Health worry $\alpha=0.72$
Cancer-related Worries Scale (CRWS)	(Deimling et al., 2006) <sup>74</sup>	USA	Mixed cancers	Examines concern about recurrence, worry about future tests, worry about recurrence, worry about other forms of cancer.	<p><b>4 total items</b></p> <p>Items measured using a 1 (strongly agree) to 5 (strongly disagree) Linkert scale. Items are reverse scored. <i>Higher scores indicate higher FCR</i></p>	Internal consistency: $\alpha=0.84$
Fear of Recurrence Scale A (FRSa)	(Rabin, Leventhal & Goodin, 2004) <sup>75</sup>	USA	Breast cancer	Developed as a modification of the of the Fears of Developing Ovarian Cancer Scale. Examines frequency of FCR, emotional impact, functional impact, and concern about FCR.	<p><b>4 total items</b></p> <p>Items measured using a 1 (rarely or never) to 4 (all the time or very concerned) Linkert scale. <i>Higher scores indicate higher FCR</i></p>	Internal consistency: $\alpha=0.82-0.84$ Test re-test: $r=0.50-0.62$
Fear of Relapse/Recurrence Scale (FRRS)	(Greenberg et al., 1997) <sup>76</sup>	USA	Leukaemia patients, but also suitable for mixed cancers	Examines inability to plan for future, perceived risk of recurrence, impact of FCR, fear of recurrence, and belief in cure.	<p><b>5 total items</b></p> <p>Items measured using a 1 (strongly agree) to 5 (strongly disagree) Linkert scale. The 5<sup>th</sup> item is reversed scored. <i>Higher scores indicate higher FCR</i></p>	Internal consistency: $\alpha=0.69-0.83$ (across 5 studies)
Fear of Recurrence Index (FRI)	(Lasry & Margolese, 1992) <sup>77</sup>	Canada	Breast cancer, but also suitable for mixed cancers	Examines patient's FCR, family/carers FCR, and worry about health.	<p><b>2 total items</b></p> <p>Items measured using a 1 (very much) to 4 (not at all) Linkert scale. Items are reversed scored. <i>Higher scores indicate higher FCR</i></p>	Inter-item correlation: $r=0.68$
Cancer Worry Scale A (CWS-A)	(Easterling & Leventhal, 1989) <sup>78</sup>	USA	Breast cancer with healthy controls, also suitable for mixed cancers	Examines the frequency of FCR, distress caused by FCR and 'intrusions'.	<p><b>3 total items</b></p> <p>Items 1 and 2 measured using a 0 (not at all) to 10 (a great deal) Linkert scale. Item 3 measured using a 0 (none of the time) to 4 (all of the time) Linkert scale. <i>Higher scores indicate higher FCR</i></p>	Internal consistency: $\alpha=0.81$

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# Glossary of Terms

**Delphi method:** means and method for consensus-building by using a series of questionnaires to collect data from a panel of selected subjects. Several rounds of questionnaires are sent out and the anonymous responses are aggregated and shared with the panel after each round; panel participants are allowed to adjust their answers in subsequent rounds. Since multiple rounds of questions are employed, the Delphi method seeks to reach the correct response through consensus.

**Maladaptive:** not adjusting (behaviours, actions, thoughts, tendencies) adequately or appropriately to the environment or situation.

**Multi-dimensional measurement scale:** measures constructs that consist of two or more underlying dimensions (i.e. academic aptitude). Each underlying dimension must be measured separately, sometimes using different tests, and scores can be combined (possibly in a weighted manner) to create an overall value.

**Multi-item measurement scale:** designed to measure respondent's attitude towards more than one attribute related to the construct of interest. It is a rating scale made of multiple items, where each item is a single question/statement that needs to be evaluated.

**Psychometric(s):** branch of clinical or applied psychology that deals with the design, administration, and interpretation of mental measurements.

**Regression Analysis:** statistical method of data analysis that allows you examine the relationship between two or more variables of interest, specifically, the influence of one or more independent (changeable) variables on a dependent (fixed) variable.

**Rumination:** repetitively going over a thought or a problem without completion. Focused attention on the symptoms of one's distress, and on its possible causes and consequences, as opposed to its solutions.

**Single-item measurement scale:** uses a single item/question to measure a certain construct (i.e. loyalty, satisfaction, ease of use). For example, 'how satisfied are you with your job?' measured using a 5 point scale. Useful when the construct is unambiguous, or when a holistic impression is informative.

**Unidimensional measurement scale:** measuring a single ability, attribute, construct or skill. Has only one dimension, so it can be represented by a single number line (i.e. height, weight, IQ, volume of liquid).

# LYMPHOMA COALITION

Worldwide Network of  
Lymphoma Patient Groups

A graphic consisting of a grid of teal circles and ovals that tapers to the right, forming a semi-circular shape. The circles are arranged in four rows, with the number of circles decreasing from left to right and from top to bottom.

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