Recommendations for the identification and management of fear of cancer recurrence in adult cancer survivors

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A CLINICAL PRACTICE GUIDELINE DEVELOPED BY CANCER AUSTRALIA

This document supplements information contained in the *Clinical practice guidelines for the psychosocial care of adults with cancer*, 2003.[1]

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Purpose

This guideline includes statements and recommendations based on available evidence about the identification of fear of cancer recurrence, and support for adult cancer survivors experiencing it. The guideline provides health professionals with information designed to assist in making management recommendations and providing care for improved patient outcomes. This guideline has been developed for use by all health professionals involved in cancer care, and all members of a patient's healthcare team.

Cancer Australia has also developed a clinical guidance on the *Clinical guidance for responding to suffering in adults with cancer*.

Endorsed by:

The Royal Australian & New Zealand College of Psychiatrists

Australian College of Nursing

APS Australian Psychological Society

Background

Improved methods of cancer detection and treatment have led to an increase in the numbers of people surviving and living with cancer for longer periods of time.[2] While the majority of people adapt well to life after treatment, evidence suggests that some cancer survivors are likely to experience high levels of psychological and social *distress*.[3] For many people who have experienced cancer, the ongoing fear that the cancer will return is a key source of distress and can impact on their physical, psychological, social and spiritual wellness.[4-19] Although fear of cancer recurrence (FCR) is considered to be just one aspect of wellness in the cancer context, it is one of the most commonly reported challenges for people diagnosed with cancer and a major area of unmet need.[20-25] A

recent systematic review[26] reported an average of 72% (range: 39% to 97%) of cancer survivors reporting some degree of FCR, 46% (range: 16% to 87%) reporting a moderate to high degree of FCR, and 7% (range: 2% to 15%) reporting a high degree of FCR.[4-19, 27-39]

Optimal care of people with cancer incorporates the effective management of both physical and psychological wellbeing. The World Health Organization (WHO) defines wellness as "*The optimal state of health of individuals and groups. There are two focal concerns: the realisation of the fullest potential of an individual physically, psychologically, socially, spiritually and economically, and the fulfilment of one's role expectations in the family, community, place of worship, workplace and other settings* ".[40]

Despite an increasing focus on fear of cancer recurrence in the literature, there is no accepted consensus definition. The broad definition commonly adopted by the research on which this guideline is based and therefore the definition used for the purpose of this guideline is "*Fear that cancer could return or progress in the same place or in another part of the body".*[3, 41] Some researchers have noted that a level of fear of recurrence may be considered reasonable, given there is a risk that the cancer will return or metastasise, and propose an alternative definition of "*A perceived risk of cancer recurrence which is disproportionate to the actual risk of recurrence".*[26] Neither definition however, takes full account of the multidimensional nature of FCR: that the fear may relate to a number of aspects of recurrence, such as the possibility of death, further treatment, additional life disruptions, or the impact of a recurrence on the survivor's family or their ability to raise children.[42, 43]

A systematic review of the impact of fear of cancer recurrence on wellness, which explored the prevalence, correlates and interventions for FCR, was undertaken in 2012 and provides the evidence for this guideline.[26] For details about the literature search, including research questions, see the section Evidence from trial or study results.

This guideline has a multidisciplinary focus and is applicable to all professionals providing cancer care in diverse treatment settings, including hospitals and private practices.

A note on the term 'survivor'

It is acknowledged there is a range of definitions for the term 'cancer survivor'. In this guideline the term refers to people who have completed their *primary cancer* treatment; this may include *chemotherapy*, *radiotherapy*, surgery, *targeted therapies*, *biological therapies* or a combination of these. People using ongoing therapies to manage cancer or control symptoms, are also referred to as cancer survivors in this guideline.

The term 'cancer survivor' has been adopted because the recommendations and practice points are primarily focused on the post-treatment needs of people with cancer. The majority of studies in the Systematic Review on which this guideline is based, included participants who had finished primary treatment, however some studies did include a small proportion of participants who were living with cancer, either following their initial diagnosis or due to *metastasis* or recurrence. While this guideline focuses on cancer survivors, it is acknowledged that FCR may also be present at diagnosis and during treatment.

Recommendations And Practice Points

The concept of fear of cancer recurrence (FCR), its identification and interventions to address it are new and emerging areas of research. The recommendations are based on evidence identified in *The impact of fear of cancer recurrence on wellness: a systematic literature review* (the Systematic Review).[26] The practice points are based on expert consensus where the evidence to make a recommendation is insufficient or was outside the scope of the Systematic Review.

Recommendations and practice points should be considered in the context of clinical judgement for each individual. Considerations should also include patient preferences and *quality of life* issues. These factors should be dis-

cussed with the patient and family, and approaches tailored to suit patients' needs for information and decision-making involvement.

Multidisciplinary care is the best practice approach to providing evidence-based cancer care. *Multidisciplinary care* is an integrated team-based approach to cancer care where medical and allied health care professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each patient.[44]

The recommendations for the identification and management of fear of cancer recurrence in adult cancer survivors should be considered within a multidisciplinary team setting.

PRACTICE POINTS - FCR information needs		**REFERENCE**
a	Due to the high prevalence of FCR, all cancer survivors should be provided with information about FCR at the end of primary treatment, including its likelihood, potential impact and strategies to manage it.	Systematic Review[26]
PRACTICE POINTS - Identification of FCR		**REFERENCE**
b	A variety of questions should be incorporated into clinical consultations to assess FCR and its impact on the person's life. (See appendix B)	
c	Due to the high prevalence of FCR, routine psychosocial screening, including for FCR, should be conducted at the completion of primary treatment and during follow-up, so that the patient can be triaged according to need.	Systematic Review[26]
d	The use of validated screening tools to measure FCR should be considered (see appendix A), however, screening using basic questions may be sufficient to triage the patient to further assessment or a psychological intervention. (See appendix B)	
e	Recognising factors and behaviours associated with FCR including younger age, experience of ongoing symptoms, increased psychological issues, decreased levels of physical and emotional functioning or increased contact with health services, is an important role for healthcare professionals.	Systematic Review[26]
f	Qualified interpreters should be engaged in screening, assessment and treatment of FCR when patients are from culturally and linguistically diverse backgrounds.	
RECOMMENDATION - Addressing FCR	**Level of evidence**	**REFERENCE**

PRACTICE POINTS - FCR information needs			REFERENCE
1	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.	**II and III-1**	Heinrichs 2012[45] Herschbach 2010[46] Lengacher 2009[47] Lengacher 2011[48] Shields 2010[49] Cameron 2007[50]
PRACTICE POINTS - Addressing FCR			**REFERENCING**
g	When determining the appropriate care and support for FCR, consideration should be given to establishing the personal resources and support that a patient may have available to them, including family and carers.		Lethborg 2008[51]
h	Psychological interventions that may be considered include cognitive-behaviour therapy, supportive expressive therapy and communication skills-based couples therapy. If access to such therapies is not available, counselling with a practitioner experienced in survivorship issues may also be of benefit.		Heinrichs 2012[45] Herschbach 2010[46] Lengacher 2009[47] Lengacher 2011[48] Shields 2010[49] Cameron 2007[50]

Statements Of Evidence

The statements of evidence are based on evidence identified in the systematic review conducted by Cancer Australia *The impact of fear of cancer recurrence on wellness: A systematic literature review* (the Systematic Review).[26]

In the Systematic Review, FCR was usually measured on a scale of severity rather than as a dichotomous variable. As such, the statements below reflect this method of measurement and refer to 'higher levels of FCR'.

The majority of the studies supporting these statements were cross-sectional in design **(Level IV evidence)**; however there were a number of retrospective longitudinal studies included **(Level III-2 evidence)**. Evidence to support the statement about interventions is supported by *randomised controlled trials* **(Level II evidence)** and one pseudo-randomised controlled trial **(Level III-1 evidence).**

Note that in cross-sectional studies, correlates were reported from which causation cannot be inferred, while in longitudinal studies, predictors were reported which can be more confidently interpreted as suggesting causation.

No.	STATEMENTS OF EVIDENCE	LEVEL OF EVIDENCE	
	Prevalence	**Level III-2 evidence is bolded** Level IV evidence is in plain text	
1.	Fear of cancer recurrence (FCR) was experienced by the majority of cancer survivors in the included studies.	**Cannon 2011[34]** **Humphris 2003[14]** **Liu 2011[31]** **Llewellyn 2008[19]** Baker 2005[5] Befort 2011[7] Cannon 2011[34] Clark 2001[29] Davey 2011[38] Davison 2011[10] Deimling 2006[32] Greenberg 1997[37] Humphris 2003[14] Janz 2011[17] Kelly 2011[33] Leake 2001[27] Liu 2011[31]	Llewellyn 2008[19] Mehnert 2009[39] Mikkelsen 2009[35] Montazeri 2006[4] Mullens 2004[13] Noorda 2007[8] Pandya 2011[6] Parsaie 2000[18] Skaali 2009[11] Steele 2007[16] Stewart 2001[9] Tang 2011[15] van den Beuken-van Everdingen 2008[36] Waljee 2008[30] Waters 2010[12]
2.	In a number of longitudinal studies FCR was found to be prevalent across the cancer trajectory and remained relatively stable post diagnosis.	**Bergman 2009[52]** **Costanzo 2007[53]** **Essers 2006[54]** **Hodges 2009[55]** **Hong 2010[56]** **Humphris 2003[14]** **Humphris 2004[57]** **Kornblith 2007[58]**	**Lebel 2007[59]** **Llewellyn 2008[19]** **Mehta 2003[60]** **Melia 2006[61]** **Moyer 1998[62]** **Poulakis 2003[63]** **Stanton 2002[64]**
	Unmet needs and concerns	**Level III-2 evidence is bolded** Level IV evidence is in plain text	

No.	STATEMENTS OF EVIDENCE	LEVEL OF EVIDENCE	
3.	In assessments of issues that cancer survivors might experience, FCR was consistently identified as a major concern or an unmet need. FCR was the most frequent concern or unmet need in a number of studies.	Unmet needs **Armes 2009[21]** **McDowell 2010[65]** Fitch 1999[66] Fitch 2001[67] Harrison 2011[20] Hodgkinson 2007[68] Katz 2010[25] Lobb 2009[69] Morrison 2012[70] Rogers 2010[24] Schlairet 2011[71] Stafford 2011[22] Uchida 2011[23]	Concern **Lebel 2007[59]** Ashing-Giwa 2011[72] Biglia 2003[73] Fitch 2001[67] Fitch1999[66] Harris 2009[74] Rogers 2009[75] Saleh 2001[76] Schlairet 2011[71] Shanafelt 2009[77] Spencer 1999[78] Wonghongkul 2006[79]
4.	Specific unmet social, emotional, financial, employment, informational, transportation and homecare needs were associated with higher levels of FCR.	**Armes 2009[21]** **Franssen 2009[80]** Davison 2011[10] Matulonis 2008[81]	Mirabeau-Beale 2009[82] Shim 2010[83]
	Demographic characteristics	**Level III-2 evidence is bolded** Level IV evidence is in plain text	
5.	Levels of FCR significantly decreased with age, with younger cancer survivors significantly more likely to report higher levels of FCR than older survivors. The definition younger age however, varied across the studies.	**Costanzo 2007[53]** **Diefenbach 2008[84]** **Essers 2006[54]** **Humphris 2003[14]** **Kornblith 2007[58]** **Liu 2011[31]** **Stanton 2002[64]** Ashing-Giwa 2011[72] Baker 2005[5] Curran 1998[85] Davey 2011[38] Hartl 2003[86]	Janz 2011[17] Leake 2001[27] Mast 1998[87] Mullens 2004[13] Simard 2009[88] Sollner 1998[89] van den Beuken-van Everdingen 2008[36] Vickberg 2003[3] Waljee 2008[30]
6.	Women were significantly more likely to report higher levels of FCR than men.	**Essers 2006[54]** Simard 2009[88]	Baker 2005[5] Gemmill 2010[90]

No.	STATEMENTS OF EVIDENCE	LEVEL OF EVIDENCE	
7.	There is mixed evidence of a relationship between levels of FCR and both educational and marital status.	Education **Bergman 2009[52]** **Costanzo 2007[53]** **Hamrick 2006[91]** **Hodges 2009[55]** **Hong 2010[56]** **Liu 2011[31]** **Llewellyn 2008[19]** **Poulakis 2003[63]** **Roth 2003[92]** **Stanton 2002[64]** Ashing-Giwa 2011[72] Clark 2001[29] Janz 2011[17] Kelly 2011[33] Mehnert 2009[39] Mellon 2007[93] Roth 2006[94] Simard 2009[88] Skaali 2009[11] van den Beuken-van Everdingen 2008[36] Waljee 2008[30]	Marital status **Bergman 2009[52]** **Costanzo 2007[53]** **Diefenbach 2008[84]** **Hodges 2009[55]** **Hong 2010[56]** **Liu 2011[31]** **Llewellyn 2008[19]** **Stanton 2002[64]** Ashing-Giwa, 2011[72] Baker 2005[5] Clark 2001[29] Leake 2001[27] Mehnert 2009[39] Steele 2007[16] van den Beuken-van Everdingen 2008[36]
8.	Lower income and financial problems were both associated with higher levels of FCR.	Ashing-Giwa 2011[72] Avis 2005[95] Franssen 2009[80]	
9.	Cancer survivors with religious or spiritual beliefs reported significantly lower levels of FCR.	**Cannon 2011[34]** **Stanton 2002[64]** Matulonis 2008[81]	Mirabeau-Beale 2009[82] Schreiber 2011[96]
	Cancer stage	**Level III-2 evidence is bolded** Level IV evidence is in plain text	
10.	Survivors who were diagnosed with a poorer prognosis were more likely to experience higher levels of FCR.	**Bergman 2009[52]** **Diefenbach 2008[84]** **Hong 2010[56]** **Latini 2007[97]** **Liu 2011[31]**	Kim 2012[99] Poulakis 2003[63] Roth 2006[94] Shanafelt 2009[77] Waljee 2008[30]

No.	STATEMENTS OF EVIDENCE	LEVEL OF EVIDENCE	
		Rabin 2004[98]	
11.	Survivors who had experienced a recurrence or *metastasis* were more likely to report higher levels of FCR than those who had not.	**Lebel 2007[59]** Rosmolen 2010[100] Shim 2010[83]	Simard 2009[88] Ullrich 2003[101]
	Treatment characteristics	**Level III-2 evidence is bolded** Level IV evidence is in plain text	
12.	Surgery type (extensive vs. conservative) or other treatment types were not significantly associated with levels of FCR in the majority of studies.	**Costanzo 2007[53]** **Essers 2006[54]** **Hamrick 2006[91]** **Liu 2011[31]** **Llewellyn 2008[19]** **Mehta 2003[60]** **Moyer 1998[62]** **Poulakis 2003[63]** **Rabin 2004[98]** **Stanton 2002[64]** Clark 2001[29] Curran 1998[64] de Haes 2003[28] Deimling 2006[32]	Hartl 2003[86] Janz 2011[17] Leake 2001[27] Mehnert 2009[39] Melia 2003[102] Mellon 2007[93] Rogers 2010[24] Rosmolen 2010[100] Skaali 2009[11] Sung 2011[103] Vickberg 2003[3] Walker 1997[104] Yeo 2004[105]
	Physical and psycho-physiological	**Level III-2 evidence is bolded** Level IV evidence is in plain text	
13.	Cancer survivors with a larger number or more severe physical symptoms/side effects experienced higher levels of FCR.	**Liu 2011[31]** Deimling 2006[32] Deimling 2006[106] Mast 1998[87] Matulonis 2008[81]	Mehnert 2009[39] Mellon 2001[107] Mellon 2007[93] Schlairet 2011[71]
14.	Higher levels of FCR were associated with the physical symptoms of fatigue, pain, body image/appearance, sleep difficulties, urinary symptoms and sexual problems.	Fatigue Avis 2005[95] Franssen 2009[80] Janz 2011[17] Matulonis 2008[81] van den Beuken-van Everdingen 2008[36] Body image	Pain Avis 2005[95] Janz 2011[17] Matulonis 2008[81] van den van den Beuken-van Everdingen 2008[36] Sleep difficulties **Roth 2003[92]**

No.	STATEMENTS OF EVIDENCE	LEVEL OF EVIDENCE	
		Kornblith 2007[58] Avis 2005[95] Greenberg 1997[37] Matulonis 2008[81] Mirabeau-Beale 2009[82] Waljee 2008[30] Sexual problems Avis 2005[95]	Matulonis 2008[81] Urinary symptoms Gemmil 2010[90] Ullrich 2003[101]
	Other medical/life-style	**Level III-2 evidence is bolded** Level IV evidence is in plain text	
15.	Having physical co-morbidities was associated with higher levels of FCR.	**Bergman 2009[52]** **Essers 2006[54]** **Poulakis 2003[63]**	Mellon 2007[93] Sollner 1998[89]
16.	No significant association was found in studies that explored FCR and psychiatric history or use of psychotropic medication, family history of cancer, or smoking status.	Psychiatric history **Costanzo 2007[53]** **Rabin 2004[98]** Skaali 2009[11] Smoking status **Humphris 2004[57]** Skaali 2009[11]	Family history **Liu 2011[31]** Janz 2011[17] Kelly 2011[33]
	Psychological	**Level III-2 evidence is bolded** Level IV evidence is in plain text	
17.	A range of psychological correlates were significantly associated with higher levels of FCR. Evidence from a large number of studies found that higher levels of FCR were associated with higher levels of distress, depression, anxiety, cancer-specific anxiety and other post-traumatic stress disorder symptoms (e.g. intrusive thoughts, avoidance and hyper	Distress **Hodges 2009[55]** **Lebel 2009[108]** **Moyer 1998[62]** **Roth 2003[92]** Avis 2005[95] Gotay 2007[109] Greenberg 1997[37] Mast 1998[87] Roth 2006[94] Vickberg 2003[3] Depression **Humphris 2003[14]** **Liu 2011[31]**	Cancer-specific distress **Essers 2006[54]** **Diefenbach 2008[84]** **Lebel 2009[108]** Greenberg 1997[37] Hu 2008[111] Mehnert 2009[39] Simard 2009[88] Skaali 2009[11] Tang 2011[15] Vickberg 2003[3] Anxiety **Humphris 2003[14]** **Liu 2011[31]**

No.	STATEMENTS OF EVIDENCE	LEVEL OF EVIDENCE	
	arousal) were also associated with higher levels of FCR.	**Roth 2003[92]** Deimling 2006[32] Gotay 2007[109] Herschbach 2005[110] Melia 2003[102] Rogers 2010[24] Roth 2006[94] Simard 2009[88] Simard 2010[41] PTSD symptoms Mirabeau-Beale 2009[82] Matulonis 2008[81] Mehnert 2009[39]	**Roth 2003[92]** Deimling 2006[32] Herschbach 2005[110] Melia 2003[102] Rogers 2010[24] Roth 2006[94] Shim 2010[83] Simard 2009[88] Simard 2010[41] Skaali 2009[11] van den Beuken-van Everdingen 2008[36]
18.	Generalised Anxiety Disorder was associated with higher FCR.	Roth 2006[94] Skaali 2009[11]	
19.	Higher perceived risk of recurrence was associated with higher levels of FCR in cancer survivors.	**Essers 2006[54]** **Liu 2011[31]** Waters 2010[12]	Ziner 2012[42] Tzeng 20101[12]
20.	Cancer survivors with adequate levels of social support and a sense of optimism experienced significantly lower levels of FCR.	Optimism Deimling 2006[32] Deimling 2006[106] Llewellyn 2008[19] van den Beuken-van Everdingen 2008[36]	Social support **Liu 2011[31]** Matulonis 2008[81] Mirabeau-Beale 2009[82]
	Quality of Life (QoL)	**Level III-2 evidence is bolded** Level IV evidence is in plain text	
21.	Lower levels of QoL, emotional/mental and physical functioning were associated with higher levels of FCR.	QoL **Roth 2003[92]** Avis 2005[95] Matulonis 2008[81] Mellon 2006[113] Mirabeau-Beale 2009[82] Rogers 2010[24] Roth 2006[94]	Physical functioning **Diefenbach 2008[84]** **Hart 2008[115]** **Mehta 2003[60]** Alfano 2006[114] Franssen 2009[80] Herschbach 2005[110] Matulonis 2008[81] Mehnert 2009[39]

No.	STATEMENTS OF EVIDENCE	LEVEL OF EVIDENCE	
		Simard 2009[88] van den Beuken-van Everdingen 2008[36] Vickberg 2003[3] Emotional functioning Alfano 2006[114] Herschbach 2005[110] Matulonis 2008[81] Mehnert 2009[39] Mikkelsen 2009[35] Noorda 2007[8] Roth 2006[94] Simard 2009[88] van den Beuken-van Everdingen 2008[36] Waters 2010[12]	Melia 2003[102] Mirabeau-Beale 2009[82] Noorda 2007[8] Roth 2006[94] van den Beuken-van Everdingen 2008[36] Zhao 2009[116]
22.	Higher levels of FCR were predictive of poorer emotional functioning in a number of longitudinal studies.	**Diefenbach 2008[84]** **Bellizzi 2008[117]**	**Hart 2008[115]** **Mehta 2003[60]**
	Healthcare	**Level III-2 evidence is bolded** Level IV evidence is in plain text	
23.	Cancer survivors who expressed poor healthcare satisfaction also reported significantly higher levels of FCR than those with higher healthcare satisfaction.	**Hart 2008[115]** **Moyer 1998[62]**	Janz 2011[17] Shim 2010[83]
24.	Higher levels of FCR were significantly associated with more frequent healthcare consultations.	**Cannon 2011[34]** **Mikkelsen 2009[35]**	Herschbach 2005[110]
25.	A significant association between the use of complementary and alternative medicines (CAM) and	**Burstein 1999[118]**	

No.	STATEMENTS OF EVIDENCE	LEVEL OF EVIDENCE	
	higher levels of FCR was reported in one longitudinal study.		
	Positive behaviour change	**Level III-2 evidence is bolded** Level IV evidence is in plain text	
26.	Higher levels of FCR were associated with positive behaviour change, including increase of regular check-ups, healthier diet, using sunscreen, avoiding tobacco use and continuation of treatment.	**Cluze 2012[119]** Burris 2010[120] Hawkins 2010[121]	
	Interventions	**Level II evidence**	**Level III-1 evidence**
27.	Research into psychological interventions to address FCR is limited, however existing evidence suggests a positive benefit for reducing FCR, and there is no evidence of adverse effects.	Cameron 2007[50] Heinrichs 2012[45] Herschbach 2010[46] Lengacher 2009[47] Shields 2010[49]	Lengacher 2011[48]

Evidence From Trial Or Study Results: Overview

The statements and recommendations about the identification of fear of cancer recurrence (FCR) and its management in adult cancer survivors are based on the Systematic Review, which includes available evidence published between 1992 and 2012.[26] The primary research questions examined by the Systematic Review were:

1. What is the prevalence of FCR for cancer patients?
2. What are characteristics associated with having FCR?
3. What is the impact (outcomes) of FCR on patients' wellness?
4. What interventions are effective in dealing with FCR in patients?

The review was undertaken using a systematic method to search and select the appropriate literature. Two existing reviews of the FCR literature for the periods of 1992-1995[122] (a literature review) and 1996-2011[123] (a systematic review, published in 2013) were utilised; these were updated for 2012 using identical search terms and procedures to those utilised in the Simard et al. (2013) systematic review.[123]

All references from this process were pooled. Following the application of the exclusion criteria, a total of 139 citations were identified as eligible for the review. While the majority of included studies were cross-sectional in de-

sign (n=94), 31 longitudinal studies, seven *randomised controlled trials* (RCTs), and seven studies of mixed designs were also included.

The six intervention studies identified by the Systematic Review consisted of four RCTs,[45-47, 49] a quasi-experimental controlled trial[50] and a single group quasi-experimental trial.[48]

While the review included all cancer sites, the majority of the studies were from samples of breast cancer survivors (n=49) and approximately a quarter (n=34) of the studies used a mixed sample. Other included studies focused on prostate (n=15), orofacial (n=5), ovarian (n=5), uveal melanoma (n=3), colorectal (n=3), skin (n=3), oesophageal (n=2), renal (n=2), haematological (n=2), testicular (n=1) and thyroid (n=1) cancers.

Studies included in the review used a wide variety of tools to assess FCR, including longer scales of FCR, brief FCR specific scales; FCR subscales within *quality of life* or needs questionnaires or single item assessments. While analysis of the psychometric properties of the scales was outside the scope of the Cancer Australia Systematic Review, a recent systematic review of FCR self-report measures by Thewes et al. (2012) found 20 multi-item scales and seven single item measures of FCR.[124] Details of the findings can be found in Appendix A. Additionally, single item assessment questions used by studies in the Cancer Australia[26] and the Thewes et al. (2012)[124] systematic reviews are provided in Appendix B.

Quality assessment

Studies relating to interventions for FCR were graded for quality using the QualSyst checklist for quantitative studies.[125] Quality assessment of prevalence and descriptive studies was thought to be less critical, and was beyond the scope of the review. The calculated scores were classified as strong (score of > 80%), good (70–80%), adequate (50–70%) or limited (<50%).[126] The quality of five intervention studies were rated as strong, with only the single group quasi-experimental rated as adequate.

Evidence From Trial Or Study Results: Prevalence

The Systematic Review[26] investigated the prevalence of FCR among adult cancer survivors. The 28 studies relating to prevalence identified by this review reported that most cancer survivors experienced some level of fear that their cancer will reoccur or metastasise.[4-19, 27-39]

Severity of FCR

While the lack of consensus on clinical or pathological cut-offs for FCR makes interpretation of the levels of FCR across studies difficult, the majority of studies used one of the four validated longer scales that measure FCR[3, 88, 110, 127] or measured FCR on a scale of severity allowing for comparison. The included studies reported level of FCR using various measures and cut offs, these results were grouped according to the published results into - some level, moderate to high level and high level of FCR. The Systematic Review[26] averaged the results from each of these studies in the different levels of FCR, with an average of 72% (range: 39% to 97%) of cancer survivors reporting some degree of FCR, 46% (range: 16% to 87%) reporting a moderate to high degree of FCR, and 7% (range: 2% to 15%) reporting a high degree of FCR.[4-19, 27-39]

Stability of FCR over time

Evidence from longitudinal studies suggests that FCR is relatively stable over time,[14, 19, 52-59, 61-64] or relatively stable after an initial post-treatment decrease.[21, 108, 117, 128, 129] Baseline measurements in the included longitudinal studies were taken either pre or post-treatment with a follow-up period of between three and 60 months post-

treatment, with data collected at two to six collection points. Additionally, two studies found that while FCR was stable over time in the sample as a whole, FCR increased over time in particular sub-populations with a poorer prognosis.[56, 63]

Fear of cancer recurrence as a concern or unmet need

A number of studies reported FCR as one of the most frequently endorsed[59, 72, 73, 75, 76, 78] or one of the top five greatest concerns of cancer survivors.[66, 67, 71, 74, 77, 79] FCR was frequently selected above a range of other physical and psychological concerns. For example, Biglia et al. (2003) found that breast cancer survivors rated FCR above concerns about their risk of heart disease, *osteoporosis* and worsening of *quality of life*.[73] Lebel et al. (2007) found that FCR was rated a higher concern than physical limitations, pain, and problems with family or friends due to cancer,[59] and Spencer et al. (1990) found that FCR was rated significantly higher than concern about damage from *adjuvant* therapies, not seeing children grow up and financial worries.[78]

Thirteen studies found that obtaining help to manage FCR was identified by between 20% and 79% of study participants as a *supportive care* need or unmet need.[20-25, 65-71] In five of these studies, it was the most frequently identified need or unmet need.[20-24]

Higher levels of FCR were found to be correlated with a number of unmet emotional, social, financial, employment, medical information, transportation, sexual and homecare-related needs.[10, 21, 80-83, 89] Specifically, higher FCR was associated with a higher need for social and psychosocial support ,[83] higher interest in psychological counselling in moderately to severely distressed cancer survivors ,[89] the opportunity to talk to others with the same diagnosis, and in accessing *support groups* and information about future treatment options.[10] In a longitudinal study of mixed cancer survivors (n=1152), Armes et al. (2009) reported that level of FCR at the end of treatment predicted a number of unmet needs at six month follow-up, particularly in the dimensions of psychosocial (β = 0.027; OR 1.03), information and health system (β = 0.028; OR 1.03) and care (β = 0.026; OR 1.03).[21] The physical and sexual dimensions were not found to be significant.

Evidence From Trial Or Study Results: Characteristics Associated With FCR

There is a large amount of research exploring potential characteristics that are associated with FCR in cancer survivors. The Systematic Review identified a total of 103 studies in this area.[26] Substantial evidence was found for the relationship between FCR and age, religious beliefs/spirituality, treatment side effects, *quality of life* and mental health issues. There was also some evidence to support the relationship between FCR and gender, education, income, disease *stage*, recurrence or *metastasis*, treatment type, anxiety and post-traumatic stress disorder (PTSD) symptoms. While the Systematic Review did consider outcomes of FCR, there is currently limited evidence to support a causal relationship between variables. As such, in this section, evidence for potential outcomes is presented along with evidence for the characteristics associated with FCR.

Demographic characteristics associated with FCR

Gender

Three studies with samples including survivors of various cancer sites[5, 88, 90] and one study of skin cancer patients only[54] reported women experienced higher FCR than men. Simard et al. (2009) found gender to be significantly correlated with FCR when breast, prostate, lung, colorectal were included in the analysis, however, when lung and colorectal cancer (which affect both genders) were analysed separately to the gender- specific cancers (breast and prostate); no significant difference was observed between men and women.[88] These findings suggest the possibility that cancer site may have more influence on FCR than gender. The remaining 12 studies, mainly in

specific cancer sites, found no significant relationship between FCR and gender.[13, 14, 16, 19, 24, 29, 32, 33, 35, 55, 93, 130]

Age

The majority of the studies that examined the association between age and FCR reported that younger cancer survivors experienced greater FCR (r=0.31-0.52).[3, 5, 13, 14, 17, 27, 30, 31, 36, 38, 53, 58, 64, 72, 84-89] While there were consistant findings of a relationship between FCR and younger age, there was significant variation in the definition of younger age in the included studies, with cut offs varying from 45 to 68 years of age. When studies treated both FCR and age as continuous variables, FCR was found to decrease with age.

The majority of these studies were conducted with female-only participants (breast or gynaecological cancers)[3, 17, 27, 30, 31, 36, 38, 53, 54, 58, 64, 72, 85-87] or in people with cancers that affect both genders[5, 13, 14, 54, 88, 89] limiting the generalisability of these findings to men. Only Diefenbach et al. (2008) found a significant association between age and FCR in an all-male sample, with younger men (middle-aged, ≤68 years) experiencing higher levels of FCR than older men (>68 years).[84] Parker et al. (2012) reported contradictory findings, with older (female) breast cancer patients experiencing greater FCR.[131] The remaining 17 studies, eight of which had predominantly male samples, found no significant relationship between FCR and age.[11, 16, 19, 24, 29, 32, 33, 35, 39, 52, 55, 56, 91, 92, 94, 98, 104]

Education

Lower levels of educational attainment was associated with higher levels of FCR in six studies,[11, 31, 53, 63, 72, 92] half of which used multivariate analysis techniques.[11, 31, 53, 72] Only Hamrick et al. (2006), a study of prostate cancer survivors, reported higher FCR in those with higher levels of education.[91] Fifteen studies found no significant relationship between FCR and education, with half using multivariate methods.[17, 19, 29, 30, 33, 36, 39, 52, 55, 56, 64, 88, 93, 94]

Relationship status

While a large number of studies investigated FCR and relationship status, the majority of these studies found no association.[5, 16, 19, 27, 29, 31, 36, 53, 55, 56, 64, 72, 84] Two studies showed an association between FCR and marital status, however these were in opposing directions. Bergman et al. (2009) reported that among men with prostate cancer (n=476), the partnered men experienced lower levels of FCR than un-partnered men (PE=5.79, p=0.03).[52] In a large population- based study of breast cancer survivors (n=1083) Mehnert et al. (2009) found no significant differences in FCR between partnered and un-partnered women, but significant results when married and divorced women were compared with single women, with married and divorced women experiencing higher levels of FCR (η^2=50.02, p>0.001).[39] This study also found that women with children, particularly women under the age of 50 years, experienced higher levels of FCR (*d*=0.42).

Income

Income and FCR were found to be related in a small number of studies, with high levels of FCR significantly associated with financial problems[72, 95] and low income.[80] The remaining seven studies exploring these variables found no significant relationship.[5, 11, 17, 33, 53, 54, 81]

Spiritual beliefs

In four studies the use of religious/spiritual coping was significantly associated with lower FCR[81, 82, 96] or was a predictor of lower FCR over time.[34] Five studies concluded that religious belief/spirituality was unrelated to

FCR[19, 39, 64, 91, 114] including one longitudinal study.[19] Hamrick et al. (2006) found that while religious affiliation and religious/ spritual practice were not independently associated with FCR, when these two variables were combined they were predictive of FCR at 18 months post-diagnosis in survivors of prostate cancer.[91] Similarly, Staton et al. (2002) found no association between FCR and turning to religion but reported an interaction between hope and religious coping.[64]

Cancer and treatment characteristics associated with FCR

Cancer site

Few studies have assessed the relationship between cancer site and FCR in large samples of people diagnosed with different cancers. Of the 10 studies that examined FCR and cancer site, six used mixed samples of three or more cancer sites including samples of people with breast, lung, prostate, colorectal, uterine, bladder, and head and neck cancers.[24, 32, 41, 88, 93, 95] Of these, two studies reported that prostate cancer survivors expressed lower FCR than breast, colorectal and lung cancer survivors.[41, 88] Kornblith et al. (2007) compared only breast and uterine cancers, finding that women who had been diagnosed with breast cancer experience significantly higher levels of FCR than those diagnosed with uterine cancer (F=17.48).[58] Other studies examined differences in FCR among people diagnosed with different cancer types in a particular organ system, for example different gynaecological, gastrointestinal or orofacial cancers. Significant differences were reported for the various gynaecological cancers[27] and gastrointestinal cancers[33] but not for different orofacial cancers.[55] In particular, women with invasive *ovarian cancer* had higher FCR than women with other gynaecological cancers,[27] while people with colorectal cancers had lower FCR than those with other gastrointestinal cancers that have a higher mortality rate, such as liver and pancreatic cancers.[33]

Disease prognosis, metastasis and recurrence

While a number of studies reported that indicators of cancer prognosis were associated with higher levels of FCR, [30, 31, 52, 56, 63, 77, 84, 94, 97-99] none of these studies used multivariate methods to explore this association, and further research is needed to explore the possibility of confounding variables. Cancer prognosis was measured using a variety of indices including TNM *stage*, T stage, PSA level, Gleason score and the presence of positive margins. Sixteen studies that explored these variables found no significant association or reported no significant association in multivariate analyses.[3, 14, 17, 19, 24, 32, 33, 39, 53, 55, 60, 64, 82, 86, 92, 93]

In four studies, metastatic diagnosis[83, 88] or recurrence[59, 100] was significantly associated with higher levels of FCR. Ullrich et al. (2003), however, found that recurrence was not independently associated with higher FCR; prostate cancer survivors who had both a cancer recurrence and urinary symptoms reported a higher level of FCR than for each variable alone.[101] Four other studies found no association between FCR and either *metastasis* or recurrence.[39, 54, 102, 103]

Surgery type

The majority of studies reported no association between extensive or conservative surgery with FCR.[3, 17, 28, 29, 39, 53, 54, 62-64, 85, 103, 105] These studies included samples of patients with breast cancer, renal cancer, thyroid cancer and basal cell *carcinoma* of the skin . While a small number of studies found significant results, these findings were inconsistent. Lui et al. (2011) reported that women who underwent breast-conserving surgery were more likely to experience higher levels of FCR six-months and two years post diagnosis in a longitudinal study using multivariate techniques.[31] Hartl et al. (2003) found similar results in a cross-sectional study but this study used only univariate techniques (breast-conserving therapy=63.9 vs. mastectomy=55.3).[86] Rabin et al. (2004) reported contradictory findings, with breast cancer patients experiencing higher FCR with more extensive surgery (mastec-

tomy compared to lumpectomy) in a longitudinal study.[98] Additionally, Lasry et al. (1992) reported that breast cancer patients who had undergone multiple surgeries (e.g. breast-conserving surgery followed by radical mastectomy) experienced higher levels of FCR.[132]

Other treatment types

Nineteen studies of survivors of various cancer types have explored the association between treatment type, or number of treatments, and FCR. These studies examined treatments including surgery, *radiotherapy* and *chemotherapy* as well as surveillance, with the majority of studies finding no association.[3, 11, 14, 19, 24, 27, 30 , 31, 32, 39, 53, 60, 64, 91, 93, 98, 102-104] A small number of studies, however, found an effect in one or more treatment types. Simard et al. (2009) reported that higher FCR scores were associated with chemotherapy (r = 0.26), radiotherapy (r = 0.12) and surgery (r = 0.10).[88] Janz et al. (2011) found both chemotherapy and radiotherapy treatment were related to higher FCR using a multivariate regression model in a sample of patients with breast cancer.[17] Additionally, two studies of patients with prostate cancer reported that *adjuvant* therapy (radiotherapy/ brachytherapy) was associated with greater FCR using multivariate analysis.[52, 56]

Physical and psycho-physiological symptoms

A large number of studies (n=28) explored the relationship between the presence or severity of physical symptoms and FCR. Although different measures were used to assess FCR, and several symptoms were explored, evidence emerged suggesting that cancer survivors with a higher number or more severe physical symptoms experienced greater FCR than those with fewer or less severe symptoms. A number of studies reported an association between higher levels of FCR and global side effects (somatic concerns),[31, 32, 39, 71, 81, 87, 93, 106, 107] fatigue,[17, 36, 80, 81, 95] pain,[17, 36, 80, 81, 95] and body image/appearance complaints.[30, 37, 81, 82, 95]

Other medical information or lifestyle characteristics

Five studies reported that having a concurrent illness was related to higher levels of FCR.[52, 54, 63, 89, 93] In the two studies that used longitudinal methods, Essers et al. (2006) found a significant interaction between having comorbidities and FCR, however the predictive effect of comorbidities was only significant in people under 65 years,[54] while Bergman et al. (2009) reported that comorbidities were not a significant predictor of change in FCR at 12 months amongst prostate cancer patients.[52] Five mainly cross-sectional studies reported no association between these variables.[11, 17, 29, 31, 87]

A small number of studies investigated other medical or lifestyle characteristics but found no association between FCR and psychiatric history or use of psychotropic medication,[11, 53, 98] family history of cancer,[17, 31, 33] life events/ circumstances[43, 81] or smoking status.[11, 57] Mellon et al. (2007) found that family stressors were related to higher FCR in both patients and carers.[93] Three cross-sectional studies also reported that menopausal breast cancer survivors experienced lower FCR than premenopausal survivors, but none of these studies explored the confounding effect of age.[7, 73, 85]

Complementary and alternative medicine

A small number of studies have explored the relationship between FCR and the use of complementary and alternative medicines (CAM). A few studies indicated a relationship between high levels of FCR and CAM use[118] or *spiritual interventions*.[4] Burstein et al. (1999) reported a high level of CAM use among breast cancer survivors (38.8%), with a high proportion of CAM use newly occurring after breast surgery (28.1%).[118] The study (n=480) also found a consistent relationship between higher levels of FCR and starting CAM at three and 12 months post-

treatment. Using multivariate analysis researchers determined that higher scores for FCR, depression and a greater number of symptoms were associated with the use of mind-body type CAM therapies, which included *relaxation* therapies (used by 57.3%), self-help groups (58.3%), imagery (37.9%) and spiritual healing (27.2%). Some women used more than one type of therapy. Montazeri et al. (2006) also found high levels of CAM use in mixed sample of Iranian survivors (35.0%).[4] However, the predominant CAM therapy used by this sample was prayer and spiritual healing (75.7%), with other CAM therapies used by less than 10% of the sample, limiting the generalisability of this study to an Australian context.

Psychological characteristics

A range of psychological characteristics were found to be associated with higher FCR. The importance of treating these psychological issues is acknowledged with further information on appropriate care available in the *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer*.[1]

Distress

Eight cross-sectional studies showed that *distress* was significantly associated with higher levels of FCR (r = 0.26 to 0.56),[3, 37, 62, 87, 92, 94, 95, 109] and two longitudinal studies reported that higher levels of distress predicted higher FCR over time, however these studies did not find a significant predictive effect of FCR on distress.[55, 108]

Additionally, a number of studies reported a significant positive association between cancer-specific distress and higher levels of FCR.[3, 11, 37, 39, 84, 88, 108] Using multivariate techniques, higher FCR was found to be associated with higher death anxiety in a mixed sample of Taiwanese cancer survivors (ß = 0.29),[15] and with decision regret in a sample of American prostate cancer patients (OR= 0.19).[111] In a study of survivors with facial basal cell *carcinoma* (BCC), higher FCR was significantly associated in both predictive and explanation models with worry about facial health (ß = 0.24 to 0.26) and susceptibility for BCC (ß = 0.21 to 0.51).[54] Lebel et al. (2009),[108] however, showed that a change in FCR did not lead to changes in distress and cancer-specific distress over time.

Depression

The relationship between higher levels of depression and higher levels of FCR was observed in a number of cross sectional studies[24, 32, 41, 88, 94, 102, 109, 110] and at baseline in three longitudinal studies[14, 31, 92] Additionally, Rogers et al. (2010) found that cancer survivors who reported FCR as a concern were more likely to experience depressed mood.[24] One study reported no significant relationship[19] and another reported that depression was unrelated to FCR in multivariate analyses.[11]

Anxiety

A number of studies reported that anxiety was significantly associated with FCR (r=0.34 to 0.69)[11, 32, 36, 41, 83, 88, 92, 94, 102, 110] or that patients with FCR experienced higher anxiety than those with no FCR.[14, 24, 31] Llewellyn et al. (2008), however, reported that anxiety was unrelated to FCR when optimism was included in the multivariate model.[19]

Additionally, a small number of studies explored the relationship between specific, General Anxiety Disorders and FCR.[11, 94] Roth et al. (2006) reported that General Anxiety Disorder (GAD) symptoms were significantly associated with FCR.[94] Additionally, in semi-structured psychiatric interviews of cancer survivors that screened for anxiety or depression, Skaali et al. (2009) reported that among the mental disorders observed, only the presence of an anxiety disorder showed a significant association with FCR.[11] Three studies reported that other post-traumatic stress disorder symptoms were associated with higher levels of FCR.[39, 81, 82] Although these studies found asso-

ciations between FCR and anxiety disorders, the design, diversity of the assessment methods, and the numbers of disorders explored, limits the strength of conclusions that can be reached.

Risk perception

The five studies investigating risk perception reported that higher perceived risk of cancer recurrence was significantly associated with higher levels of FCR.[12, 31, 42, 54, 112] To overcome the confounding effect of actual risk of recurrence, Lui et al. (2011) evaluated cancer survivors' risk perception compared to their actual risk of recurrence using standardised measures of risk based on participants' disease profile.[31] In this longitudinal study of breast cancer survivors (n=506), using multivariate models, survivors who overestimated their risk at two-year follow-up had significantly higher levels of FCR; similarly survivors who underestimated their risk of recurrence had significantly lower levels of FCR than survivors who accurately estimated FCR (ß=-0.13 and 0.14, Adjusted R^2 =0.32). This relationship was not significant in models using baseline or six month data.

Social support

Two cross-sectional studies reported that cancer survivors who perceived that they had an adequate level of social support expressed lower FCR (r=-0.32 and -0.34).[81, 82] Additionally, in a longitudinal study, Lui et al. (2011) found a moderate correlation between higher FCR and lower social support at baseline (r=-0.08) and in multivariate analysis showed that lower social support at baseline and six months was consistently associated with higher FCR at two-year follow-up (ß=-0.11 and -0.13, Adjusted R^2 =0.25 and 0.27).[31]

Optimism

Optimism was also correlated with lower FCR (r = -0.27 to -0.40).[19, 36, 106] Additionally, Deimling et al. (2006) identified optimism as a significant predictor of lower FCR in a longitudinal study of survivors of head and neck cancer.[32]

Coping strategies

Coping stategies found to be related to higher FCR include avoidance/denial coping,[106] reassurance seeking,[39] active problem-oriented coping[39] and depressive coping.[39] One study also found that more desire to undertake cognitive tasks, such as problem-solving or effortful thinking (known as need for cognition), was related to lower worry about cancer recurrence.[33]

Quality of life (QoL)

Global Quality of Life

All studies that investigated *quality of life* and FCR found that cancer survivors who reported lower levels of global quality of life(QoL) or wellbeing expressed higher FCR (r = -0.26 to -0.63).[3, 24, 36, 81, 82, 88, 92, 94, 95, 113] One longitudinal study reported that physical and mental functioning were the main predictors of FCR,[60] however another reported that QoL was not significant in multivariate analysis.[11]

Emotional functioning

FCR was associated with lower emotional/mental functioning, the awareness, expression, and regulation of emotions, in a number of studies (r = -0.23 to -0.66).[8, 12, 35, 36, 39, 60, 80-82, 84, 94, 102, 110, 114-116] Additionallly, using multivariate techniques, a number of longitudinal studies found that FCR was predictive of poorer emotional functioning.[84, 115, 117] Bloom et al. (2004), however, reported that a change in the level of FCR did not lead to a change in mental functioning.[128]

Physical functioning

Lower physical functioning was also reported to be associated with higher FCR in a number of studies (r = -0.10 to 0.40).[36, 39, 60, 81, 84, 88, 94, 110, 114, 115] Hart et al. (2008) found that physical functioning was predictive of FCR at 12 to 18 months post-treatment (ß=-0.08).[115] This study also reported an interaction between FCR and QoL satisfaction, with survivors who reported high FCR also reporting significantly lower physical QoL satisfaction (ß=-1.11). Another study showed that FCR impacted negatively on physical functioning but only in younger cancer survivors (≤68 years).[84] Six studies found that FCR was not significantly associated with physical functioning.[8, 12, 35, 84, 117, 128]

Social and role functioning

Poor social functioning, a person's ability to manage to undertake social activities, or a greater impact of the disease on social functioning were found to be related to higher levels of FCR in all studies that explored these variables (r = -0.21 to -0.41).[36, 81, 82, 84, 88, 94, 95, 114] Similarly poor role functioning, a person's ability to fulfill one's social roles such as worker and parent, or a greater impact of the disease on role functioning were found to be related to higher levels of FCR in the majoritiy of studies (r = -0.11 to -0.57).[36, 81, 84, 88, 94, 114] Only one study found no relationship between role functioning and FCR.[82]

Healthcare factors

Healthcare satisfaction

While only a small number of studies have examined the relationship between FCR and healthcare satisfaction, all studies showed that cancer survivors who expressed poor healthcare satisfaction also reported higher levels of FCR.[62, 83, 115] Janz et al. (2011) reported that lower satisfaction with understanding information, symptom management and care coordination were significantly associated with greater FCR in multivariate models.[17]

Frequency of healthcare consultation

Higher levels of FCR were associated with cancer survivors having more frequent contact with their GP in two studies.[34, 35] Additionally, one longitudinal study found that high level of FCR at baseline was associated with increase in follow up visits as well as increased phone calls at six and 12 month follow ups, suggesting FCR may be predictive of increased health care consultation.[34] Three studies showed no association between health care consultation and health behaviour with FCR.[11, 62, 129]

Positive behaviour change

A small number of studies reported a relationship between higher levels of FCR and positive behaviour change and reassurance seeking behaviour.[34, 35, 119, 121] In a cross-sectional study that controlled for demographic and illness variables, Hawkins et al. (2010) reported that higher levels of FCR were associated with positive behaviour

change (for example, increase of regular check-ups, healthy diet and use of sunscreen) in a mixed sample of long-term survivors.[121] Cluze et al. (2012) found amongst breast cancer survivors, those with higher FCR were more likely to continue *tamoxifen* use.[119] Two cross-sectional studies reported that higher levels of FCR were associated with more frequent reassurance-seeking behaviour (for example, contact with a GP, phone calls to health professionals and follow-up visits).[34, 35] Additionally, one study reported that a higher level of FCR was associated with intentions to make positive health behavior changes and using open ended questioning, reported that the most common motivator for behaviour change was 'general health' followed by 'to prevent recurrence'.[13]

Evidence From Trial Or Study Results: Interventions

General care for FCR and other psychosocial issues

While interventions that specifically address FCR have been shown to be effective in reducing levels of FCR, especially in the short term, it is important that health professionals provide holistic psychosocial care for cancer survivors. Details on best practice psychosocial care of people with cancer can be found in the *Clinical practice guidelines for the psychosocial care of adults with cancer*.[1]

Interventions for dealing with FCR

Research into psychological interventions to address FCR is limited, with only six interventions that specifically targeted FCR identified by the Systematic Review.[45-50] The majority of these studies however reported reductions in FCR with no adverse effects identified.[45-48, 50] Short term reductions in FCR were reported for couples-based skills training[45] , mindfulness-based stress reduction[47, 48] and emotional regulation.[50] Only Herschbach et al. (2010) reported long-term reductions (12 months) using two short psychotherapeutic group interventions based on *cognitive behavioural therapy* group and supportive expressive therapy.[46]

The quality of five of the interventions studies was rated as strong using the QualSyst checklist[125]; one study by the Lengacher et al. (2011) a quasi-experimental pilot feasibility study on Mindfulness-Based Stress Reduction was rated as adequate.[48]

Short psychotherapeutic group interventions

Herschbach et al. (2010) found short psychotherapeutic group interventions to be effective in reducing FCR.[46] Patients attending a rehabilitation clinic were screened for FCR using a standardised measure in order to identify those with higher levels of FCR who might gain most from the intervention. Those who screened positive for higher levels of FCR were recruited into either a *cognitive behavioural therapy* (CBT) group (n=91), a supportive expressive therapy (SET) group (n=83) or the *control group* which received care as usual (n=91). Both interventions were short, consisting of four-90 minute sessions led by a *psychiatrist*. This longitudinal RCT assessed patients prior to the intervention, at intervention completion, and at three and 12 months post-intervention. The CBT intervention specifically focused on FCR; topics were pre-defined and the therapy was directive. Patients initially learned how to identify their specific fears then learned cognitive behavioural strategies to cope with their fears. By contrast, the SET group intervention was non-directive and client-centred; topics were chosen by the patients and discussed on the basis of their personal experiences, with a focus on emotional experiences and social support.

While all groups, including the control group, showed significant improvement after treatment completion, long-term improvements were only significant in the *intervention groups* (12 month CBT mean difference=0.97, $p \leq 0.01$; SET mean difference=0.58, $p \leq 0.01$). Additionally, significant improvements over time were found in the secondary measures of anxiety, depression and health-related QoL in both intervention groups. The therapy spe-

cifically targeting FCR (CBT) was not significantly more effective than the non-directive *support group* (SET). These findings suggest that even short interventions can have significant improvements in FCR in patients over time, particularly when patients screen positive for higher levels of FCR.

Couple-skills interventions

Couples-based skills training was found to have significant short-term improvements in breast and gynaecological cancer survivors, but long-term decreases in FCR were not found.[45] In this RCT couples were recruited from three regional hospitals and randomly allocated to the intervention or *control group*. The intervention (n=38) consisted of four two-hour face-to-face sessions delivered by a therapist in the couple's home. The program focused on teaching relationship skills but also taught individual skills and was based on empirically supported cognitive behavioural techniques. The control (n=34) consisted of one two-hour session where the couples received written educational information about breast or gynaecological cancers and the therapist responded to individual concerns but did not give information on relationship skills. This active control was used to determine the benefits of relationship training over a control where both partners are present but are not given specific relationship skills. Improvements in couples' FCR for the *intervention group* were seen pre- to post-intervention (ß=-5.06, SE=1.9, p=0.007), but when gender was controlled for, only women showed significant decreases in FCR (ß=4.29, SE=1.2, p=0.04). After the initial improvements in levels of FCR in women post-intervention, levels of FCR plateaued, while the level of FCR in the control group continued to decline post intervention, with no significant difference found in long-term follow up (six and 12 months post-intervention). Male partners in both the intervention and control groups had similar patterns of decline of FCR over time.

Mindfulness-based and emotional regulation interventions

Mindfulness-Based Stress Reduction (MBSR) is a form of therapeutic intervention that combines techniques of *meditation*, body scans (visualisation) and *yoga* in order to reduce perceived stress by self-regulating one's arousal to stressful circumstances or symptoms.[47, 48] Two studies investigated FCR as a secondary outcome of MBSR.[47, 48] Both studies were based on the original eight-week MBSR program developed by Kabat-Zinn, which was modified to take into consideration the needs of women with breast cancer.[47, 48]

The MBSR intervention involved six two-hour group sessions delivered by a *psychologist* trained in MBSR along with daily homework exercises of formal and informal meditation practices to be undertaken for 15-45 minutes per day, six days a week. Lengacher et al. (2009) conducted an RCT with a *control group* (n=42) that received standard post-treatment care but were asked to avoid meditation or yoga during the intervention period.[47] The *intervention group* (n=40) showed significant reductions in FCR immediately following the six sessions (mean difference=2.3, p=0.007) and showed improvements in other areas, including anxiety, depression and QoL. In a subsequent single group, quasi-experimental pilot feasibility study, Lengacher et al. (2011) found similar results (mean difference=2.7, p=0.01) for the same program in a group of women with *early breast cancer* (n=19).[48] Long-term data was not collected in either of these studies.

Cameron et al. (2007) also reported significant reductions in FCR immediately following a 12-week Emotion Regulation Group for breast cancer patients which included training in *guided imagery*, meditation, emotional expression, and exercises promoting control of beliefs and benefit-finding.[50] This quasi-experimental controlled trial randomised participants by alternating the availability of the intervention with care as usual. This design allowed the recruitment of an intervention group (n=56), comparison group (who were offered the intervention but declined) (n=56), and a standard care group who were not offered the intervention (n=44). The intervention group reported decreased levels of FCR at the end of the intervention period relative to the control and decline comparison groups ($F=3.28$, $p<0.05$), however these reductions were not sustained at two and eight months post-intervention.

Telephone coaching intervention

Shields et al. (2010) compared a nurse-delivered telephone coaching intervention (n= 22) to usual care (n=22) in a randomised controlled pilot trial of breast cancer survivors.[49] In the *intervention group*, participants were sent a question prompt sheet and were coached by an *oncology nurse* over the phone prior to a scheduled visit with an oncologist, with the aim of improving doctor-patient communication about survivorship concerns. FCR was assessed as a secondary outcome, with the primary focus of the intervention being enhanced self-efficacy. No significant differences between the intervention and *control group* in terms of FCR levels were reported, but significant improvements in self-efficacy were demonstrated and found to mediate the effects of the intervention on FCR.

Strengths And Weaknesses Of The Evidence

As fear of cancer recurrence (FCR) is an emerging area of research there is limited high-quality evidence available for the four primary research questions. While there was a large amount of evidence from cross-sectional studies, causation was difficult to determine due to limited evidence from prospective longitudinal studies.

Additionally, due to the lack of consensus on the definition of FCR, there are a large number of tools used for assessing FCR. Included studies used various measures, from single dichotomous variables to specific validated tools, which limited the interpretation of results.

While the Systematic Review[26] included all cancer types, more than a third of the 139 studies were of breast (n=49) and ovarian (n=5) cancer survivors. Since a large number of the studies were of breast cancer survivors, the generalisability of these findings to other cancer sites and to men are limited. However, nearly a quarter (n=34) of the studies used a mixed sample of participants (e.g. breast, prostate, colorectal, lung) which may enable the results to be generalised to both men and women.

Few interventions to reduce FCR were identified (n=6). Most had small sample sizes and reported FCR as a secondary outcome to other primary study outcomes such as self-efficacy.[49] Only one study examined FCR as the primary outcome and used screening procedures to identify and include only those with high levels of FCR.[46] These studies, therefore, form the initial evidence base and show the potential for interventions to decrease FCR, particularly in the short term. It is suggested that future large-scale trials be undertaken, with FCR as the primary outcome, to further strengthen the validity and reliability of the evidence.

Each of the six intervention studies were quality assessed against a series of 15 QualSyst questions designed to measure the strength of the study design. The quality rating of five of the six intervention studies was strong, with just one study considered to be of adequate quality. This allows greater confidence in the positive results reported for these studies.

Due to the large number of studies identified for the prevalence and characteristics sections, the quality of these studies was not assessed.

Unanswered Questions

Important unanswered questions about the identification and management of fear of cancer recurrence in adult cancer survivors may be addressed through research investigating the following questions.

- What is the international consensus on the definition of FCR?
- Which measures are most effective to screen for FCR in a clinical setting?

- What are the cut offs for clinically significant or problematic levels of FCR?
- Is screening effective in the identification of FCR?
- Does screening and detection of FCR improve health outcomes?
- What are the predictors and outcomes of FCR?
- Which interventions are effective in addressing FCR?
- What are the long term outcomes of interventions to address FCR?

International Guidelines

The following international guidelines were identified that relate to the identification and management of fear of cancer recurrence in adults with cancer.

National Comprehensive Cancer Network (NCCN)

NCCN Guidelines (Version 2.2013) for Distress Management (2013). These guideline recommendations are based on statements of evidence from multiple evidence reviews.

National Comprehensive Cancer Network (NCCN)

NCCN Guidelines for survivorship (2013).

Comprehensive Cancer Centre of the Netherlands (IKNL)

Screening for psychosocial distress (June 2010). These guideline recommendations were based on multiple evidence reviews.

National Institute for Health and Clinical Excellence (NICE)

Improving supportive and palliative care for adults with cancer (CSGSP) (2004). These guideline recommendations were based on multiple evidence reviews.

Ongoing And Additional Trials Or Studies

Two pilot *randomised controlled trials* (RCTs) investigating interventions to reduce FCR in breast cancer survivors are ongoing and/or awaiting results:

- a mindfulness and values-based living intervention(NCT01354041),[133] and
- an attention and interpretation modification intervention (NCT01517945).[134]

Six RCTs investigating interventions to improve general *quality of life* or address psychological issues, which include FCR as an outcome measure, are ongoing and/or awaiting results:

- a comprehensive counselling by a nurse specialist intervention in patients with head and neck cancer (ISRCTN06768231)[135]
- a mindfulness-based stress reduction program in breast cancer survivors (NCT01177124)[136]
- a multimedia educational program to assist newly diagnosed prostate and breast cancer patients prepare for their cancer (NCT00830635)[137]

- an Inquiry Based Stress Reduction (IBSR) program in a mixed sample of breast, colorectal and prostate cancer survivors (NCT01795404)[138]
- a "Change Cycle Workshop" coping class in breast cancer survivors (NCT01734499)[139]
- a Mindful Movement Program in older female breast cancer survivors (NCT00903474),[140] and
- a randomised controlled trial of a psychological intervention to reduce fear of cancer recurrence.[141]

Four RCTs investigating interventions to address various other health related factors, which measure FCR as an outcome or secondary outcome measure, are ongoing and/or awaiting results:

- a side effect prevention training (SEPT) intervention that optimizes patients' response expectations before the start of *adjuvant* endocrine treatment (AET) to prevent nocebo side effects and enhance quality of life(NCT01741883)[142]
- a group exercise intervention, combining aerobic and strength training to reduce lean mass and body fat tissue in breast cancer survivors (NCT01843608)[143]
- a comparison of hospital-based follow-up examinations and instruction in self-referral in *stage* I endometrial cancer patients(NCT01853865),[144] and
- a comparison of Mindfulness-Based Stress Reduction (MBSR) to an attention control psycho-educational *support group* in treating cancer-related fatigue (CRF) in early-stage (0-III) post-treatment cancer survivors with clinically-significant CRF (NCT01919853)[145]

Seven cross-sectional or longitudinal studies which include FCR as an outcome measure are ongoing and/or awaiting results. These investigate:

- the needs in operable lung cancer patients receiving surgery (NCT01362842)[146]
- the aspects of the bladder cancer (BlCa) survivorship experience that differ by clinical risk at diagnosis (NCT01090388)[147]
- the long-term health status of adult survivors of childhood retinoblastoma (NCT00639301)[148]
- physical function and quality of life before and after non-radical surgical therapy in patients with stage I cervical cancer(NCT01649089)[149]
- patterns and identify predictors of post-treatment physical activity and dietary changes made by colorectal cancer survivors (NCT00966667)[150]
- behavioural and psychosocial issues in melanoma survivors (NCT00518050),[151] and
- quality of life of women who were diagnosed with *ovarian cancer* 5 years to 10 years ago (NCT00596349).[152]

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Additional Information

Topic-specific guideline development process

Priority topic areas for Cancer Australia guideline development are determined in consultation with key stakeholders including experts in relevant disciplines and consumer representatives. A specific multidisciplinary Working Group, including consumers, is established for each topic identified and is involved in all aspects of guideline development. A systematic evidence review is undertaken for each guideline. All members are asked to declare any conflicts of interest and these declarations are recorded. The content of the guideline is not influenced by any external funding body. The guideline is reviewed externally by key stakeholders and the wider community and endorsement is sought from relevant professional colleges and groups in Australia.

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Glossary

Active treatment – The period of treatment after a cancer diagnosis, usually including surgery, chemotherapy or radiotherapy, or a combination, to actively treat the cancer.

Adjuvant – Treatment given in addition to primary (initial) treatment. For breast cancer, the primary treatment is surgery and adjuvant treatments include *chemotherapy, radiotherapy, hormonal therapies* and *targeted therapies*.

Anxiety- The apprehensive anticipation of future danger or misfortune accompanied by a feeling of dysphoria or somatic symptoms of tension. The focus of anticipated danger may be internal or external.

Association – Any relationship between two variables that makes them statistically dependent.

Cancer-specific anxiety – Anxiety related to any aspect of having cancer, such as diagnosis, treatment, side effects or prognosis.

Causation – An indication that one event is the result of the occurrence of another event. This is also referred to as cause and effect.

Chemotherapy – Treatment for cancer using drugs.

Cognitive Behaviour Therapy (CBT) – A form of psychotherapy that helps patients change their behaviour by altering the way they think about certain things. It is used to treat mental, emotional, personality, and behavioural disorders.

Comorbidity – The presence of one or more disorders in addition to cancer.

Complementary and alternative medicines (CAM) – An umbrella term for therapies used as well as (complementary), or instead of (alternative), conventional medical treatment.

Correlation – a statistical measure expressed as a number describing the size and direction of the relationship between two or more variables.

Cross-sectional – A study that involves observation of participants or collection of data at a point in time.

Depression - A pervasive and sustained lowering of mood or the loss of interest or pleasure in nearly all activities. When used clinically, it is a cluster of symptoms, or syndrome, whose other features may include: changes in appetite or weight, sleep and psychomotor activity; decreased energy; feelings of worthlessness or guilt; difficulty thinking, concentrating or making decisions; or recurrent throughs of death or suicidial ideation, plans or attempts.

Distress – Emotional, mental, social or spiritual suffering. *Distress* may range from feelings of vulnerability and sadness to stronger feelings of depression, anxiety, panic and isolation.

Emotional regulation – A type of therapy that aims to improve one's ability to respond to emotions and experiences in a manner that is appropriate to the situation.

Fear of cancer recurrence – Fear that cancer could return or progress in the same place or in another part of the body.

Generalised Anxiety Disorder (GAD) – A diagnosed condition that can interfere with day-to-day living that causes people to feel anxious and worried most of the time, even about minor, everyday activities.

Imagery – A *cognitive behavioural therapy* technique which encourages imagining a scene or series of experiences in order to promote mindfulness and relaxation.

Intervention – A treatment or therapy designed to improve the condition of a patient.

Rating scale- A set of fixed-response choices that are anchored to a particular concept, for example satisfaction (very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied) or evaluation (poor, fair, good, excellent).

Longitudinal – An observational study that incorporates repeated observations of the same variables over a period of time, often months or years.

Metastasis – The secondary or distant spread of cancer, away from its initial site in the body

Mindfulness-based stress reduction - Promotes the concept of being "mindful," and heightened awareness of the present. Employs practices to relax the body and mind to counteract stress.

Multivariate analyses – Statistical analysis that examines more than one variable in relation to a particular factor.

Predictor – An independent variable that can be changed to observe its effect on the dependent variable, for example, age or gender.

Prognosis – The likely course of a medical condition, including the prediction of recovery or survival from a disease.

Psychological intervention – A type of therapy designed to bring about positive change when people are experiencing psychological difficulties.

Psychometric properties – Properties of a psychological test, which determines its accuracy for measuring the issue under investigation.

Quality of life – An individual's overall appraisal of their situation and subjective sense of wellbeing. *Quality of life* encompasses symptoms of disease and side effects of treatment, functional capacity, social interactions and relationships, and occupational functioning.

Radiotherapy - Treatment for cancer in a particular area of the body using *X-rays*.

QualSyst checklist – A tool to evaluate the quality of qualitative and quantitative research using a checklist of standards such as appropriate study design, sample size, and descriptions of various aspects of the study.

Quasi-experimental controlled trial – A trial that lacks random assignment to a treatment and *control group*. The researcher controls which arm of a trial a participant is assigned to, usually based on another criterion that is not random, such as a clinical cut-off or participant choice.

Randomised controlled trial – Research in which participants are allocated randomly to receive either an experimental treatment or therapy or standard care (the control).

Reassurance-seeking behaviour – When someone excessively and persistently seeks reassurance about an issue of concern, for example, having more health check-ups than is necessary.

Relaxation - A form of therapy where emphasis is put on teaching the patient how to relax both mentally and physically, and to control breathing, with the aim of reducing emotional distress, and improving control of symptoms such as anxiety or pain.

Screening tool – An instrument used to identify the possible presence of a problem and to indicate whether further assessment is required.

Significant – In statistics, a result that is likely to be attributable to a specific cause, that is, not likely to have occurred randomly.

Single group quasi-experimental – A study where all participants receive the same treatment and there is no control or comparison group.

Spiritual healing – The use of spiritual practices, such as prayer, for the purpose of effecting a cure of or an improvement in an illness.

Stage – A way of describing how advanced a cancer is.

Supportive care - Improving quality of life for people with cancer from different perspectives, including physical, social, emotional, financial and spiritual.

Supportive expressive therapy – A type of psychological therapy that aims to enhance people's sense of control over their physical, emotional and relational problems and improve their ability to resolve interpersonal and mental conflict.

Survivor – People diagnosed with cancer that have completed *primary cancer* treatment.

Systematic review – A literature review that attempts to identify and synthesise all the high-quality research evidence available, which relates to a particular research question.

Tamoxifen - A drug that blocks the effects of *oestrogen* in cancer cells; a treatment for oestrogen-receptive and progesterone-receptive cancers.

Univariate analyses – Statistical analysis that examines a single variable in relation to another factor.

Unmet need – Identified treatment or supportive care needs that are not being adequately met

Validated tool – A tool that has been demonstrated to satisfy certain psychometric standards so that it will reliably assess patients.

Appendix A: Summary Of Validated Tools To Assess FCR

While the use of validated screening tools to measure FCR should be considered, as yet there is no consensus on which tool is most appropriate to use to measure FCR in a clinical context. The appropriateness of any measure is dependent on a range of considerations including the context in which it is to be used, its psychometric properties in this context, respondent burden, and the desired mode of administration. Assessment in a clinical setting is ideally supplemented by open-ended questions and by being alert to non-verbal and verbal cues from the patient and the results of the screening tool should be communicated with the patient. Where FCR is detected, with the permission of the patient, this information should be shared with the healthcare team. For more information on general communication skills see page 38 of the *Clinical practice guidelines for the psychosocial care of adults with cancer*, 2003.[1]

A recent review *Fear of cancer recurrence: a systematic literature review of self-report measures* by Thewes et al. (2012), identified 20 assessment tools to measure FCR.[124] These tools included four longer scales (10+ items), ten brief scales (2-10 items) and six subscales of larger *quality of life* or psychosocial assessment tools.

Clinicians and researchers seeking to assess FCR as a part of a larger evaluation may prefer to use brief measures of FCR. Of the brief questionnaires (2–10 items), the Fear of Relapse/Recurrence Scale (FRRS)[37] had the largest number of studies evaluating its psychometric properties, and the Assessment of Survivor Concerns Scale (ASCS)[109] has undergone extensive validation work with mixed cancer survivor populations.

Longer multidimensional scales may be useful where FCR is the primary outcome of interest. Of the four longer scales evaluated (10+ items), the Fear of Cancer Recurrence Inventory (FCRI)[88] and Fear of Progression Questionnaire (FoP-Q)[110] seem to be suitable for heterogeneous cancer populations and appear to have the strong psychometric qualities. The Concerns About Recurrence Scale (CARS) had the best psychometric qualities, however the measure is breast cancer specific.[3] The FoP-Q and FCRI also offer validated short form versions of the larger scales that may be useful for brief assessment.

While there are a variety of measures available to measure FCR and some of the longer instruments have demonstrated good preliminary psychometric qualities, the authors concluded that further refinement and validation of the scales is required before any scales be recommended as a gold-standard measure for FCR.[124] As such, the details of the tools identified in the review are provided below for information.

Longer scales (10+ items)	No of items	Reference
Concerns About Recurrence Scale (CARS)	30	Vickberg 200[33]
Fear of Progression Questionnaire (FoP-Q)*	43	Herschbach 2005[110]
Fear of Cancer Recurrence Inventory (FCRI)^	42	Simard 2009 [88]
Fear of Recurrence Questionnaire (FRQ)#	22	Northouse 1981[153]

* 12 item short form available[154]

^ 9 item short form available

6 item short form available[64]

Brief scales (2-10 items)	No of items	Reference
Assessment of Survivor Concerns Scale (ASCS)	5	Gotay 2007[109]
Fear of Relapse/Recurrence Scale (FRRS)	5	Greenberg 1997 [37]
Brief measures Cancer Worry Scale-A (CWS-A)	3	Easterling 1989[155]
Lasry and Margolese Fear of Recurrence Index (LMFRI)	2	Lasry 1992[132]
Fear of Recurrence Scale (A) (FRSa)	4	Rabin 2004[98]
Cancer-related Worries Scale (CRWS)	4	Deimling 2006[106]
Worry About Prostate Cancer Scale (WPCS)	2	Diefenbach 2008 [84]
Worry of Cancer Scale —Revised (WOC-R)	2	Hodges 2009[55]
Cancer Worry Scale (B) (CWS-B)	2	Cameron 2007[50]
Fear of Recurrence Scale (B) (FRSb)	3	Franssen 2009[80]

Appendix B: Questions To Assess FCR

Informal assessment based on single questions may be sufficient to prompt further conversation about FCR. These questions may be used at the completion of primary treatment and during follow up tests and reviews so the patient can be triaged according to need. Such questioning can also allow healthcare professionals to respond to elements of FCR and increase patients' coping ability by listening, providing input and acknowledging the importance of the issues raised. Where FCR is detected, with the permission of the patient, this information should be shared with the healthcare team. For more information on general communication skills see page 38 of the *Clinical practice guidelines for the psychosocial care of adults with cancer*, 2003.[1]

The questions presented below are based on the items to assess FCR that were identified by the Systematic Review[26] and in the Thewes et al. (2012) review[124] and provide a summary of those used to measure FCR in a research context. In the research setting, questions commonly used a rating scale response format, where participants are asked to choose from a set of related responses. While these questions have been used in a research setting and may form the basis of questions suitable for clinical use, they have not been validated in either setting.

Presence of FCR

- Do you worry that your condition will get worse?[72]
- During the last week, have you been afraid of relapse of your disease?[11]
- Are you bothered by thoughts about the recurrence of cancer?[156, 157]
- Are you fearful that your disease will come back?[90]
- Do you worry your cancer may come back?[16]
- Have you experienced fear of reoccurrence?[35]

Frequency of worry

- How often do you think about recurrence?[9]
- How often are you worried about cancer recurrence[158] (or disease recurrence/progression)?[34]
- Over the past month, how often have you worried about the cancer coming back?[19]

Level of worry

- How stressful, if at all, have fear and uncertainty about the future been for you in the past month?[108]
- What is your level of anxiety about recurrence?[9]
- How much are you concerned/worried/ fearful about the cancer coming back?[78, 159]
- To what extent do you feel fearful that your illness will return?[99, 160]
- How would you rate your fear of the cancer coming back?[27]
- How much does you uncertainty about whether your disease will progress effect your quality of life?[77]

Level of need of help in relation to the worry

- Do you need help to manage your concerns about the cancer coming back?[20]
- In the last month, what was your level of need for help with fear about the cancer spreading?[23]