

Evidence Check

Self-management of psychological distress in people with cancer

An **Evidence Check** rapid review brokered by the Sax Institute for Cancer Institute NSW.
June 2015

This report was prepared by:

Anna Ugalde, Kerry Haynes, Vicki White, Meinir Krishnasamy, Anna Boltong, Penelope Schofield, Trish Livingston

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1 Executive summary

Approximately one-third of all cancer patients will experience psychological distress, but not all receive support to manage their distress. Self-management programs and resources focus on promoting an individual's ability to manage their own health and wellbeing, and a large body of literature has evaluated self-management programs in chronic disease groups such as in those with heart disease, arthritis or diabetes. While many of these programs have been beneficial, they require substantial costs in facilitation, and there is opportunity to develop resources that are patient-driven and self-delivered, to allow people with cancer to manage psychological distress.

The purpose of the review was to assess the evidence for the effectiveness of self-management resources to address psychological distress in adult patients with cancer. Additional questions were:

- What patient outcomes showed benefit associated with self-management resources?
- What systems-based factors relating to patient experience areas were associated with optimal effectiveness?
- Was there evidence for effectiveness for population subgroups, in particular, people from culturally and linguistically diverse communities, Indigenous Australians, rural and remote communities and people living on low incomes?
- To what degree do effectiveness outcomes depend on the stage of treatment and/or the point of service contact?

Academic literature and grey literature were reviewed. Fifteen key papers were found. There were no self-management resources identified in the grey literature that had an evidence base. There were several relevant areas explored which did not meet inclusion criteria and these are covered within the appendices of this report. Specifically, appendices are presented for: self-management programs that require facilitation; an overview of the Stanford model of self-management; similar literature reviews (none covered this topic); recent protocol papers and relevant resources available in the grey literature.

Of the fifteen identified papers, self-management resources were categorised into interactive materials, online resources and brief resources. The papers were diverse in the content, delivery, population and settings. This evidence check review indicated that there was insufficient evidence for the implementation of self-management resources for cancer patients to address psychological distress. Patient outcomes have largely focused on patient-reported outcomes, specifically in relation to measures of anxiety and depression. Evidence was sparse for systems-based factors that promote optimal effectiveness, and no studies focused specifically on under-served groups. Some studies suggested that self-management resources were preferable when they were delivered early in the disease and treatment trajectory, specifically targeting distressed groups.

Key recommendations are:

- The field is developing and it is premature to recommend implementation of a self-management resource
- There is a need to generate evidence to understand the impact of self-management resources, for: a) the ideal entry point in the disease trajectory, b) key patient groups, c) settings, d) content and e) mode of delivery (online, interactive resource)
- Optimal outcomes associated with self-management resources require consideration; potentially this should extend beyond patient-reported outcomes
- The role of the facilitator in self-management is currently unclear. All self-management resources are accompanied with some requirements for facilitation, introduction or encouraging patient adherence. There is a need to explore how this can be optimised
- Effective programs may already be used in practice, but are not well documented and there is no body of evidence for these. Investing in understanding the evidence base for existing resources is likely to contribute to the knowledge of what is most suitable
- A translational framework for progressing this body of work is necessary; adopting research designs that facilitate implementation and identifying synergies with existing policies and guidelines.

This review found that self-management resources are diverse and there is insufficient evidence to recommend implementation. The term 'self-management' may not be appropriate given this terminology traditionally describes the Stanford model of self-management, which is a facilitated program. Identifying optimal outcomes, and exploring the role of a facilitator, needs addressing. This is a developing field, and with several encouraging protocols by Australian authors recently published, the evidence base is improving. Additionally, there may be opportunities to adapt and evaluate promising self-management resources from other fields.

2 Background

Psychological impact of cancer

A diagnosis of cancer is a stressful event, and psychological distress in people diagnosed with cancer is common. Approximately one-third of all cancer patients will experience psychological distress.^{1,2} This can vary with clinical characteristics such as disease type or stage and demographic variables such as gender or age.^{2,3} Furthermore, cancer survivors can experience high levels of psychological distress up to 12 months post-diagnosis.⁴ Psychological distress refers to anxiety or depression,^{2,5} and is now internationally recognised as the “*sixth vital sign*” in cancer care along with body temperature, heart rate, blood pressure, respiratory rate and pain.⁶ Clinical practice guidelines have been developed in Australia for the psychosocial care of people affected by cancer, recommending that patients have access to psychology services as needed.⁷ In addition, addressing psychological distress is important as it is associated with increased costs of cancer care⁸ and non-compliance to treatment.⁹

However, people with cancer who have high levels of psychological distress do not always engage with support services aimed at reducing distress.¹ A UK study found that only one-third of distressed patients with emotional or psychological difficulties were willing to be referred for help.¹⁰ Similarly, an Australian study found that 70% of distressed cancer patients did not want help with their distress, and of those, the majority (59%) of patients with a distress score of 10/10 indicated they did not want help with distress.¹¹ In a large Canadian study of over 3000 cancer patients, more than half of those found to have psychological distress had not sought assistance, and had no intention of doing so in the future.¹ Furthermore, many patients did not feel comfortable raising emotional issues with their oncologists.¹² Even when patients report psychological distress and could benefit from professional intervention, engagement does not always occur, meaning that psychological distress can go untreated.

There are a variety of reasons why people do not seek or engage in psychological services when they are experiencing psychological distress. Although one reason is poor identification of psychological distress,¹³ other common reasons that patients decline help for psychological distress are because they are either receiving help elsewhere, or they prefer to manage their emotional and psychological difficulties on their own.^{1,10} However, there are few services that may support or aid this large group of patients in their endeavour to manage their psychological distress.

Self-management

Self-management has been defined as *“The individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses the ability to monitor one’s condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established.”*¹⁴

Self-management interventions have been explored in a range of diagnostic groups. The Stanford model of self-management was one of the early programs and consisted of a course that delivered topics on exercise, cognitive symptom management techniques, nutrition, fatigue and sleep management, use of community

resources, use of medications, dealing with the emotions of fear, anger and depression, communication with others including health professionals, problem solving and decision making.¹⁵ This self-management course was run for groups of between 10-15 participants, who had chronic lung disease, heart disease, stroke or chronic arthritis. Cancer patients were specifically excluded from this study.¹⁵ This intervention was successful at increasing health behaviours, improving health status and decreasing hospitalisation.¹⁵ Since this landmark program, self-management has been well explored in a variety of patient groups.^{16, 17}

Specifically in oncology, an influential paper evaluated the effectiveness of a self-administered intervention to manage stress.¹⁸ This randomised controlled trial (RCT) allocated people commencing chemotherapy to receive professionally managed stress management training or self-administered stress management training or usual care. Findings indicated that better quality of life was achieved in the group that received the self-administered intervention compared to both the control group and the group in which the intervention was professionally administered, supporting patient-driven self-management as a strategy to reduce psychological distress. A 2011 literature review of self-management programs in cancer identified 16 papers, finding there was evidence for self-management during treatment, post-treatment and at the end of life.¹⁹ These interventions could positively affect symptom distress, uncertainty, problem solving, communication, general quality of life domains and potentially survival. However, this review focused on self-management of symptoms and information, without specifically focusing on self-management of psychological distress. Additionally, the focus was on professionally facilitated self-management programs.

While these programs have been beneficial, they require substantial costs in facilitation. There may be capacity for patients to engage in self-management independently. This may also be more suitable for those who do not enjoy group work or those who are from rural or regional areas. The purpose of this report is to explore the evidence base for the effectiveness of self-management resources which aim to address psychological distress in adults diagnosed with cancer. The literature will be reviewed to:

1. Summarise and assess the evidence for self-management resources
2. Make recommendations about potential self-management resources that could be implemented to improve patient psychological distress.

3 Review questions and scope

The scope of this review was defined by Cancer Institute NSW (CINSW).

The purpose of the review was to assess the evidence for the effectiveness of self-management resources to address psychological distress in adult patients with cancer. Further questions are:

- What patient outcomes showed benefit associated with self-management resources?
- What systems-based factors relating to patient experience areas were associated with optimal effectiveness?
- Was there evidence for effectiveness for population subgroups, in particular, people from culturally and linguistically diverse communities, Indigenous Australians, rural and remote communities, and people living on low incomes?
- To what degree do effectiveness outcomes depend on the stage of treatment and/or the point of service contact?

These review questions generated recommendations for a best model of supportive care in cancer which includes self-management resources for patients.

Definitions

For the purpose of this review, a self-management resource is defined as an intervention that is patient-driven and self-delivered to improve psychological functioning (specifically anxiety, depression or psychological distress). The focus is not on interventions that require a facilitated component by peers or health professionals.

This review excluded interventions that focus on self-care in response to specific symptoms, counselling programs, interventions that focus on clinical decision making or shared care, interventions that target lifestyle behaviours rather than psychological functioning, and passive interventions such as fact sheets or booklets. Specifically, peer support, support groups, decision aids, question prompt lists, patient diaries, and strategies to respond to specific symptoms (e.g. wigs to improve body image), were all excluded.

The focus of this review was on self-management resources that could be widely adopted and easily implemented for the majority of adult cancer patients.

4 Search methods

Two searches were employed: a review of academic literature and a grey literature review.

Academic literature review

Searches were undertaken in PsycInfo, Medline and CINAHL during April 2015.

Following consultation with staff from CINSW, the following search terms were agreed:

- ((cancer) AND
- ((patient OR person OR self) N3 (manag* OR care OR driv* OR asses* OR direc* OR help)) AND
- ((helpline OR phone OR hotline OR telephone) OR (internet OR computer OR web OR online) OR (app OR smartphone OR device) OR (program OR "care program" OR service OR intervention OR support))
- AND (anxiety OR depression OR distress).

The Cochrane database was also searched, for terms: self-management OR self-guided OR self-care AND cancer.

The Near Function (N3) was used to identify keywords that are within three words of each other, allowing a range of search terms including self-management, self-assessed, person centred care, self-help, patient directed. Papers were limited to publication in or after 2005. Only English papers were identified.

Abstracts and titles were screened and refined to a list of potential titles for inclusion. Reasons for exclusion were applied and noted. Full texts were read by two reviewers. Agreement was reached for all included and excluded full text articles. Areas of discrepancy were resolved through discussion. Records of articles identified through the search strategy were managed with Endnote. Extensive hand searching was also conducted.

At the stage when full texts were identified, the scope was refined. Specifically, the definition of self-management was changed to exclude programs that have a facilitated or delivered component, on request of CINSW. This resulted in the exclusion of programs and helplines, which require delivery to the patient. The search was not re-run, rather, abstracts were screened based on these new criteria. Papers that were identified within this search, then excluded, are presented in Appendix 1. The refined scope of the literature search is presented in Table 1.

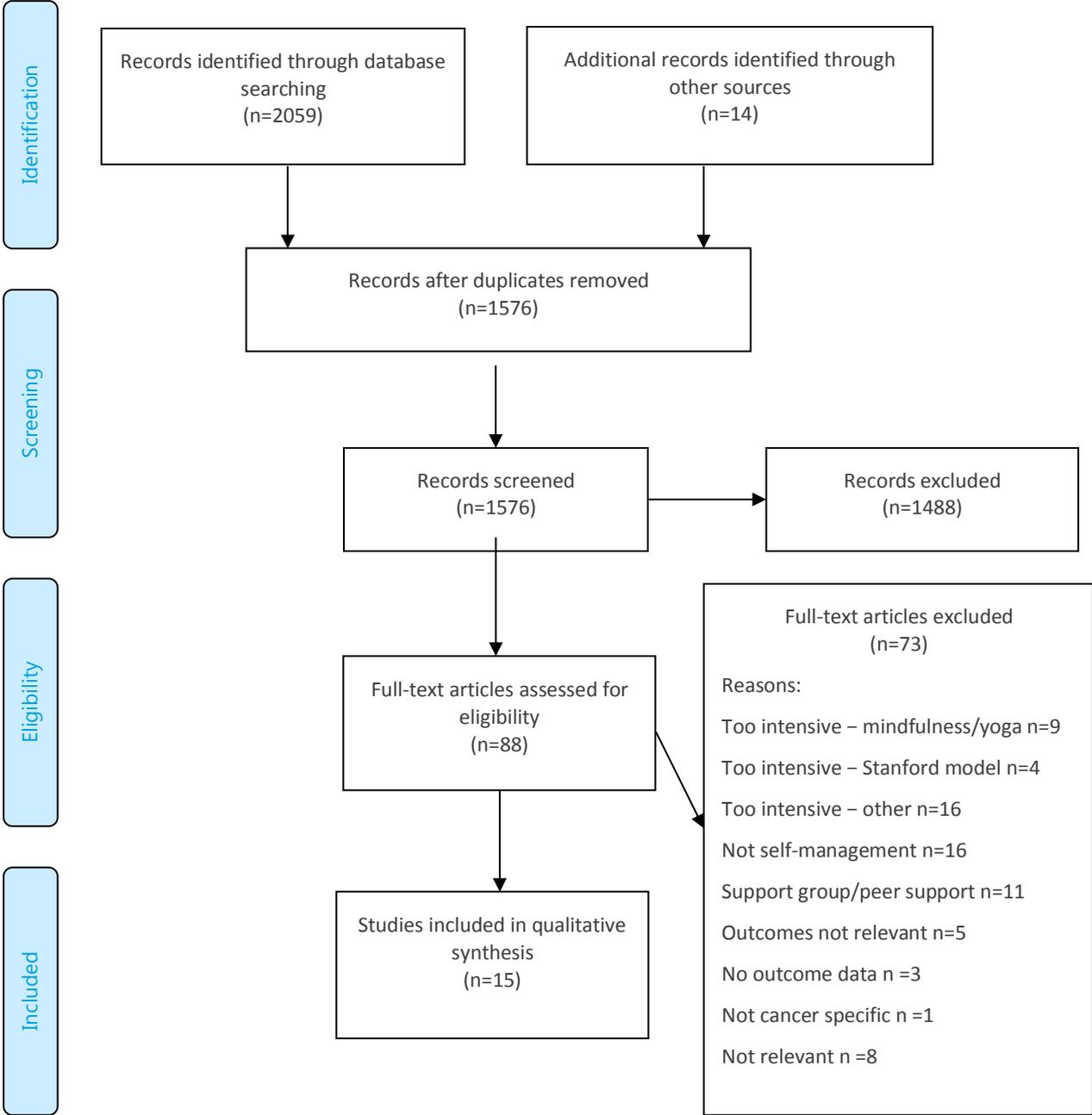
Table 1: Scope of literature search

	Included	Excluded
Facilitation	Minimal, e.g. brief telephone calls, introductions, orientations or brief monitoring	Intensive facilitation, e.g. delivery of a group session, facilitation of a program
Mode of delivery	Broad: provision of a online, physical, or technological resource	Face-to-face peer or support programs (due to the facilitation component)
Content	Management of anxiety, depression or psychological distress being a significant part of the intervention	Self-management for physical symptoms
Medical variables	Any cancer type and stage	End of life
Setting	Broad: any community, outpatient setting	Inpatients
Outcomes	Patient-reported or systems factors	Papers which did not report outcomes

Further, papers were excluded if they were published before 2005, they were not in English and they did not present evidence for self-management resources (i.e. a development or protocol paper). Papers that were deemed highly relevant to understanding the evidence base for self-management resources in cancer, but were not eligible, are presented in Appendices.

An overview of abstracts identified and reviewed is presented in Figure 1.

Figure 1: PRISMA diagram



Grey literature review

A review of the grey literature was conducted, which comprised non peer-reviewed resources and documents from websites of relevant national and international groups. The following were reviewed:

International:

- American Cancer Society
- Memorial Sloan Kettering Cancer Centre
- Macmillan Cancer Support UK
- MD Anderson
- Mayo Clinic
- Cancer Research UK

Australian:

- Cancer Councils across states
- Breast Cancer Network Australia
- *beyondblue*

5 Results

Identified literature

Fifteen studies met the search criteria. These are summarised in Table 2.

All studies had adopted a quantitative design; with 13 randomised controlled trials, one quasi-randomised design (allocating to study arm based on date of informed consent) and one pre-post design. Four studies were Australian, three of which were from the School of Psychology at Flinders University, South Australia. Eight studies were conducted in the USA, one each from the UK, Germany and Korea. Sample sizes were diverse: Six studies had small sample sizes (less than 50 participants), whereas four had relatively large samples (over 250 participants). Some studies adopted qualitative phases to assess satisfaction or uptake.

Papers that were marked for inclusion in the original search (i.e. facilitated programs and mindfulness programs) are not included in this results section. Examples of these are summarised in Appendix 1A and 1B. The Stanford program of self-management was influential with several programs and adaptations in the literature, albeit primarily in disease groups other than cancer. This program is summarised in Appendix 2.

There were two types of papers that were deemed relevant but excluded from this review. Firstly, literature reviews were reviewed separately. There was no literature review that covered this topic specifically; however, there were some similarities between this review and others. Relevant literature reviews have been summarised in Appendix 3. Additionally, several relevant protocol papers were identified. They were excluded from this review as there was no evidence of the effectiveness for the described self-management resources. Relevant protocol papers are described in Appendix 4.

Table 2: Included papers

First author, year, country	Participants	Research design	Self-directed component	Facilitated component	Outcome measures	Results
Aguado Loi 2012 ²⁴ USA	220 adults recently diagnosed with cancer and scheduled to undergo chemotherapy	RCT. Groups: 1. Usual care 2. Stress management kit	Stress management training kit for self-administration, comprising a DVD and booklet about relaxation techniques, plus patient testimonials	5 minute introduction	Measured at baseline, before cycles two and three of chemotherapy and before cycle four: QOL, depression, anxiety. Use and usefulness of stress management techniques was collected at endpoint	No improvement in QOL, depression or anxiety in intervention group, compared with control. However intervention group had improved emotional adjustment scores, demonstrated a stabilising effect on the functional adjustment scores and reported greater use of relaxation techniques throughout treatment
Beatty 2010a (randomised pilot) ²⁶ Australia	40 women who had completed treatment for breast cancer in the past three months	RCT. Groups: 1. Treatment as usual 2. Workbook intervention	A workbook/journal with education on medical and psychosocial issues, suggestions and worksheets to address the issues. Chapters addressed maintaining the medical partnership, physical wellbeing, feeling alone, family and friends, emotional recovery, spirituality, seeking closure, moving forward, living the life you want and resources. It also included a relaxation and meditation tape	Treatment compliance was assessed by phone at one and two months	Measured at baseline, three and six months. Primary outcome: coping (planning, restraint coping, seeking social support, turning to religion, venting emotions). Secondary outcomes: traumatic stress and QOL	No significant group/time interactions. However workbook participants experienced a positive effect in venting coping, and a benefit compared to controls in cognitive functioning. Trend toward a protective effect across all coping measures for participants. Feedback from participants suggested they would prefer to receive the workbook during treatment

Beatty 2010b (RCT) ²⁵ Australia	49 women diagnosed with breast cancer in the previous month	RCT. Groups: 1. Controls received booklets but no suggestions, worksheets or relaxation and meditation CDs 2. Workbook intervention	Self-help workbook, with information on medical and psychosocial issues; suggestions and worksheets to address the issues and survivors' quotes. Chapters dealt with relaxation and meditation (including a CD); coping with side effects; emotional adjustment; body image and identity; social support; and survivorship	None	Measured at baseline, three and six months. Primary outcome: distress (depression, anxiety, traumatic stress). Secondary outcome: QOL, body image and coping (cognitive avoidance, helplessness/hopelessness and anxious preoccupation)	At three months, the intervention group had lower levels of traumatic stress, helplessness/hopelessness, cognitive avoidance than control group. Intervention was more effective for women with higher levels of distress. However intervention group had poorer body image than control which was still significant at six months
Beatty 2011 ²⁷ Australia	12 adults receiving or recently completed curative treatment for breast, gynaecological, lymphoma or bowel cancer	Pre-test/post-test	Six-module online workbook. Included personal blog for online journal writing and resources section (adapted from Beatty 2010b)	None	Measured at baseline and seven weeks. Primary outcome: distress (negative affect, traumatic stress). Secondary outcome coping (helplessness/hopelessness, anxious preoccupation, cognitive avoidance, fatalism and fighting spirit)	Reductions in negative affect, helplessness/hopelessness and anxious preoccupation
Carpenter 2014 ²⁹ USA	135 women within 18 months of diagnosis of breast cancer and reporting at least moderate distress	RCT. Waiting list controls. Participants paid for phone calls and assessments	10 chapter online workbook, comprising cognitive and behavioural coping strategies, relaxation training, guided expressive writing exercises and weekly homework activities. Video was used to guide users through the workbook and provide survivor stories	Biweekly phone calls for 10 weeks to monitor participants' distress (using the Distress Thermometer) and keep them engaged. Weekly emails of encouragement. Workbook included a discussion board	Measured at baseline, week 10 and week 20. Primary outcomes: self-efficacy for coping with cancer, self-efficacy for coping with negative mood, and finding benefit in the cancer experience. Secondary outcomes: cancer-related post-traumatic symptoms, social wellbeing, functional wellbeing, and positive affect	At 10 weeks, the intervention participants showed improved self-efficacy for coping with their cancer and for regulating negative mood and lower levels of cancer-related post-traumatic symptoms, compared to controls

				moderated by health professionals		
David 2013 ³⁰ Germany	186 adults with haematological cancer	RCT. Groups: 1. Waiting list control 2. Online program	Four week online cognitive behavioural program. The modules comprised: Information on stress and behavioural assessment, techniques for coping with acute stress and upcoming stressful situations, and an expressive writing module	Psychologists sent an introductory email and provided support on request	Measured at baseline and four weeks. Primary outcome: mental adjustment to cancer. Secondary outcomes: psychological distress and patient satisfaction	Intervention group scored higher on fighting spirit than control at four weeks. No other effects were observed. Most patients were satisfied with the program
Duffecy 2013 ³¹ USA	31 adults who had completed cancer treatment and were in remission	Randomised into two groups: 1. Website alone 2. Website plus internet support group (Onward) Participants paid for assessments	Website was eight-week treatment. Lessons covered basic cognitive behavioural concepts. It included self-monitoring features	Short introductory phone call. Onward intervention included a discussion board which was monitored by staff	Measured at baseline, four and eight weeks. Depressive symptoms and psychiatric diagnosis	For participants with depressive symptoms at baseline, both the website alone and website combined with support group showed pre-post reductions in depression
Phillips 2012 ²¹ USA	391 adults receiving chemotherapy	RCT. Groups: 1. Usual care 2. Stress management 3. Home-based exercise 4. Stress management and exercise	Stress management group given video and audio recordings, and booklet with information and instructions for relaxation techniques for use during chemotherapy. The exercise group received a video, booklet and pedometer. The booklet included information and instructions on engaging in exercise while undergoing chemotherapy. The combined self-management and exercise group received both types of	Introductory phone call. Intervention group participants given materials prior to first chemotherapy session	Measured at baseline and 12 weeks. Ability to enact several self-management skills, which included relaxation, awareness of tension, getting needs met and coping confidence	Compared with participants receiving usual care, those in the stress management group reported an increase in the ability to relax, those in both the exercise group and combined stress management/exercise group maintained awareness of tension, and those in the combined group also reported an increase in ability to get their needs met

			information and materials			
Jacobsen 2013 ²⁰ USA	286 adults receiving chemotherapy	RCT. Groups: 1. Usual care 2. Stress management 3. Home-based exercise 4. Stress management and exercise	See Phillips (2012) for study materials	Short phone call at week one. Intervention group given materials prior to first chemotherapy session	Measured at six and 12 weeks. Primary outcome: QOL. Secondary outcomes: depression, anxiety, exercise and stress reduction activity	Compared to control, the combined stress management and exercise intervention improved depression, anxiety and stress management activity. The stress management intervention alone also improved stress management activity. There was no effect on depression or anxiety for the stress management or exercise components alone. None of the interventions impacted QOL
Jacobsen 2014 ²² USA	711 adults with haematopoietic cell transplant (HCT) planned within six weeks	RCT. Groups: 1. Usual care 2. Stress management 3. Home-based exercise 4. Stress management and exercise	See Phillips (2012) for study materials	20-minute introduction to program prior to HCT. Patients contacted at 30 and 60 days post HCT to review training goals and provide encouragement	Measured at baseline, 30, 60, 100 and 180 days after HCT. QOL, cancer and treatment distress, sleep quality and nausea	No differences in QOL, treatment related distress, sleep quality, pain or nausea at day +100 among the groups
Krischer 2007 ²³ USA	310 adults undergoing radiotherapy	RCT. Groups: 1. Usual care 2. Self-administered stress management training	Instructional materials comprised a videotape and booklet on stress management, relaxation techniques, and positive thinking. A relaxation audiotape was also provided.	Intervention group each met briefly with a clinician for an explanation of the program and provision of study materials	Measured at baseline, one, two and three weeks after initiation of radiotherapy. Measures: QOL, depressive symptoms and anxiety	Overall, no difference in psychological distress between groups. However patients with higher levels of distress after their first radiotherapy treatment reported improvements

Lee 2014 ³³ Korea	36 adults receiving chemotherapy who had significant levels of distress	Quasi-RCT. Groups: 1. Control group received tablet PC with 20-minute video of , scenic images and relaxing music 2. Intervention group received tablet PC with 20 minutes of psycho-educational material	The psycho-educational material consisted of four parts: distress education, cancer survivor interview, coping strategies and stress management, and psychosocial resources.	Both groups were given PC tablets at the start of chemotherapy infusion. When the researchers retrieved the tablet PCs, they informed participants about how to access psychosocial services	Measured at baseline and three weeks. Primary outcomes: anxiety, depression and QOL. Secondary outcomes: symptom inventory, sleep disturbance, post-traumatic stress and patient satisfaction. At six months, use of psychosocial services was also assessed	Compared with controls, the intervention group showed improved depression, QOL, insomnia and avoidant tendency following cancer related traumatic events at three weeks. There was no difference in use of psychosocial services
Owen 2005 ³² USA	62 women with breast cancer	RCT. Groups: 1. Waiting list control 2. Internet based discussion group	Website included a bulletin board for group discussion, a dictionary of medical terms, breast cancer resources, information and coping advice for management of common physical symptoms, a forum for sharing artwork and poetry, and six structured coping skills training exercises. 39 automated email prompts were sent at regular intervals over the 12-week course, providing information and encouragement to post messages to the group	The investigators monitored online discussions	Measured at baseline and 12 weeks. Health-related QOL, distress, physical well-being, satisfaction with the website and quality of participation	No effects for treatment were observed at 12 weeks. However women with baseline poorer self-perceived health status in the intervention group showed greater improvement in perceived health over time
Ramachandra 2009 ³⁴ UK	46 adults with stable metastatic breast or prostate cancer	RCT. Groups: 1. Waiting list control 2. Self-administered psychosocial intervention	The intervention had three components: Patients were requested to keep a diary, plan pleasurable activities and practice mindfulness using the CD provided.	Intervention group were briefed on the intervention and given study materials. Both groups received	Measured at baseline, 6, 12 and 18 weeks. QOL, anxiety, depression, optimism/pessimism and personality	Compared to controls, there was an improvement in QOL in the intervention group. Feedback from participants was generally positive

				brief phone calls at one, two and four weeks to answer any questions and encourage participation		
Wooten 2014 ²⁸ Australia	142 men with localised prostate cancer	RCT. Groups: 1. My Road Ahead (MRA) alone 2. MRA plus access to online forum 3. Online forum alone	MRA was a 10-week self-guided online intervention that consisted of six modules designed to facilitate improved emotional well-being. It provides psycho-education (through text, video, audio and graphics), interactive exercises and regular automated feedback	The online forum component was moderated. Weekly email reminders	Psychological distress measured at baseline, weeks five, 10, 12 and 20	Mean content completed was 59%. Participants who had access to MRA plus online forum had greater improvements in psychological distress, compared with other groups. There was no change for those who had access to MRA alone or the online forum alone

Evidence for self-management resources

The interventions were varied in content, delivery, population and settings. For the purpose of this review, they have been summarised into three main types: interactive materials (seven papers), online programs (six papers) and brief resources (two papers).

Interactive materials

Interactive materials were defined as tangible products that included education and activities. These resources typically consisted of chapters or components, involving a variety of medical and psychosocial issues. Participants were required to engage in modules in their own time, and follow programs or exercises. The activity component meant that they were more interactive than fact sheets.

There were two main programs of interactive materials: those that focussed on stress management and/or exercise training, examined in the USA²⁰⁻²⁴ and those that had psycho-educational content.^{25, 26}

Two interactive resources were tested in Australia that included psycho-educational content, referred to as workbooks. One was delivered to 40 breast cancer survivors in a randomised controlled trial, which was intended to be completed at the patient's own pace over a three-month period post-treatment.²⁵ There were 10 chapters, with a chapter on emotional recovery. Each chapter consisted of education, suggestions or worksheets to complete, and stories from survivors. Receiving the workbook had no effect on coping, post-traumatic stress, or physical, emotional, cognitive, or social functioning, six months post-intervention. Qualitative results indicated that women found the workbook supportive and affirming, however their preference was to have it delivered earlier in the disease trajectory. Engagement in the workbook was briefly reported; with the authors stating that 88% had read all the information and 81% had completed at least a quarter of the exercises. In addition, 88% spent between 1-15 minutes per week using the book. Participant engagement can therefore be described as relatively brief, with the majority using it for less than 15 minutes weekly. The number of participants who completed 100% of the exercises was not reported. Given the small sample size and lack of reported data around use, conclusions about the efficacy of the workbook cannot be made confidently.

The same group of researchers trialled a similar workbook in women recently diagnosed with breast cancer in another randomised controlled trial, including 49 women commencing treatment.²⁶ The workbook was similar in that it had various chapters consisting of education, suggestions or worksheets and stories from survivors, and participants could work through it at their pace, recommended to be used over a three-month period. There were six chapters, with several of which were relevant to psychological distress: relaxation (included meditation tracks on a compact disc); emotional adjustment; body image and identity; and social support. Similar to the study in survivors, women were followed up at three and six months, for distress (defined as anxiety, depression and posttraumatic stress), quality of life and coping. Results were more promising: women in the intervention arm had reduced post-traumatic stress at three months, and those with high distress had more benefit. However by six months post-traumatic stress scores did not differ between study groups. There was also one negative finding: people in the intervention group had poorer body image and this was sustained at six months, with the authors suggesting addressing body image through self-help may not be appropriate. Qualitative data indicated the workbook was comprehensive, reassuring and relevant. There was little data provided about use. Compared to Beatty's previous trial, these

findings suggested this workbook might be superior, and more appropriate to be delivered at the start of treatment.

Four other interactive materials were trialled in the USA, with results reported over five papers. All focused on stress management and exercise. In the largest study workbooks were trialled in patients preparing to undergo a haematopoietic cell transplantation.²² The sample consisted of 711 patients randomised to one of four groups: exercise training, stress management training, exercise plus stress management or usual care. The intervention had a more intensive facilitated component, consisting of a 20-minute introduction to clarify the goals of the program and proper exercise technique, and contact at 30 and 60 days. The program was self-directed, consisting of a DVD and a diary to monitor involvement in exercise and/or stress management. Specific targets were set, based on guidelines, for the amount of exercise or stress management for the patient. At 100 days post-transplant, there was no benefit shown for patient quality of life for any of the groups.

A similar study, consisting of a four-arm randomised controlled trial (stress management, exercise, stress management plus exercise or usual care) was trialled in patients commencing chemotherapy for a variety of diagnoses (primarily breast or lung cancers).²⁰ Stress management patients were allocated to receive a brief facilitated component of 10 minutes with an interventionist, a 15-minute video, 12-page booklet and 30-minute audio recording, with encouragement to follow directions. Exercise participants were allocated to receive 10 minutes with an interventionist, a 12-minute video and a 14-page booklet. Participants in the stress management and exercise program combined content from both arms. Compared to control, the combined stress management and exercise intervention improved depression, anxiety and stress management activity. There was no effect on depression or anxiety for the stress management or exercise components alone. None of the interventions impacted on broader measures of quality of life. The authors concluded the combination of stress management and exercise was most successful. A further paper analysing this trial found that those in the stress management group reported an increased ability to relax compared to control patients, and those in both the exercise group and combined stress management/exercise group maintained awareness of tension, while those in the combined group were able to get their needs met; though this was not measured with a validated needs questionnaire.²¹ This second report from this trial suggested that self-management interventions were likely to provide other benefits in terms of patients' ability to relax, rather than measuring psychological functioning or quality of life.

Another study evaluated a stress-management training kit in 220 people recently diagnosed with cancer.²⁴ A RCT design allocated participants to receive the kit, consisting of a DVD and booklet, with participants instructed to watch the DVD, then follow the booklet for directions as to further training, practice and use of stress management techniques. At the final follow up (before cycle four of chemotherapy), those that received the self-management kit used more relaxation techniques, but there were no changes to quality of life and psychological distress.

A final interactive resource evaluated the benefits of a stress management program for patients undergoing radiotherapy.²³ The intervention tested in this study was similar to that in the previous stress management studies, but did not include an exercise component. This was a two-arm RCT, with the intervention consisting of various instructional materials: a videotape, and audiotape and a booklet focusing on stress management, relaxation and positive thinking. While there was no difference between intervention and control groups for the primary outcome of distress, exploratory analyses suggested that a reduction of distress was more pronounced for intervention patients who had higher levels of baseline psychological

distress. However, this was an exploratory analysis and the study was not adequately powered to assess this further.

There was insufficient evidence to support the use of interactive materials to address psychological distress for people with cancer, although some studies have shown short-term benefits. Recommendations for components of workbooks are limited by poor descriptions of the interventions. Additionally, data collected on use of the resources is limited, consequently recommendations cannot be made regarding which components are preferred and used broadly. Overall, study sample sizes were small, with the only study that appeared to be sufficiently powered conducted in a specific group of cancer patients (those undergoing hematopoietic cell transplantation).

Online Programs

Two online programs were developed and tested in Australia. One was run by Flinders University and was adapted from the Australian Workbooks described above. The program, *Cancer Coping Online*,²⁷ is a six-week program, covering a range of topics such as coping with physical symptoms, coping with emotional distress, and your family and friends. It was pilot-tested on 12 cancer patients (eight had breast cancer) in a pre-test and post-test design. Conclusions about the effect on distress or coping are limited due to the small sample size, however, 10 of the 12 participants logged in weekly. Positive feedback for the program was provided by 11 participants.

Another Australian online program was the recently published *My Road Ahead* (MRA) website (www.myroadahead.org), developed for and tested on men with prostate cancer.²⁸ The 142 participants were randomised to one of three groups: The MRA website, an online moderated forum, or MRA plus the forum. MRA consisted of online cognitive behavioural therapy, providing psycho-education, exercises and feedback. The forum consisted of online discussions. It was hypothesised that participants who used MRA (with or without the forum) would have greater reductions in psychological distress compared to the online forum group. However it was found that the MRA plus forum group improved compared to the MRA website only, and the forum only groups. The sample was diverse; diagnosed with prostate cancer in the past five years, and distress levels were comparable to the general population. The authors conclude that there might be more benefit when men participated in the website together with a forum, but it was noted that further follow-up data was currently being collected and would be published at a later date.²⁸

A USA study adapted a stress management workbook to an online format.²⁹ All participants (n=135) were distressed at study entry, and were randomised to the intervention or a wait list. The online program comprised cognitive and behavioural coping strategies, relaxation training, guided expressive writing exercises and weekly homework activities. Video was used to guide users through the workbook and provide survivor stories. Participants were given access to the whole workbook, but encouraged to use one chapter per week. The content of the resource was well described. The authors reported an increase of self-efficacy among the intervention group. However the study did not achieve the target sample size. Satisfaction with the online program was high, and 29% of participants completed all 10 chapters, and 82% of the content was viewed. However it is noted that participants received financial incentives to complete the research components and this may have influenced these results.

An online cognitive behavioural program for people with haematological malignancies in Germany adopted a similar structure: over four modules, patients were taught cognitive behavioural therapy techniques.³⁰

There was an option for participants to also communicate with psychologists via email. Of the 186 participants, 20% completed all four modules. Patients were satisfied, and those in the intervention group had improvements in fatalism and fighting spirit four weeks later compared to the control group however there was no difference between groups for several outcomes: distress, avoidance, anxious preoccupation and helplessness/hopelessness.

Another cognitive behavioural intervention was administered online over eight weeks to 17 people with cancer.³¹ Participants were randomised to the website alone or the website plus a support group. The website had weekly content which took up to 15 minutes to complete, with the intent of participants reviewing and using the website every few days. Feedback was positive, and there were reductions in depressive symptoms for both the website group and the website plus support group. Given the small sample size, short follow up of four weeks and lack of a control group, the evidence for this intervention was relatively weak.

Finally, Owen et al.³² adopted a group approach; running self-guided internet coping groups in women with breast cancer in the USA. In group sizes of 5 to 13 women, participants were given access to a website with a bulletin board for group discussion, a dictionary of medical terms, breast cancer resources, information and coping advice for management of common physical symptoms, a forum for sharing artwork and poetry, and six structured coping skills training exercises. Thirty-nine automated email prompts were sent at regular intervals over the 12-week course, providing information and encouragement to post messages to the group. The authors state that the groups were self-guided rather than facilitated, however, there was insufficient detail regarding the facilitated component. Participants were 62 women with early stage breast cancer. No effects from the intervention were observed at 12 weeks, however women with baseline poorer self-perceived health status in the intervention group showed greater improvement in perceived health over time, although this analysis was exploratory.

Of these online resources, no study found evidence of an effective intervention, with studies failing to show improvements across patient-reported outcomes. The most promising study was the trial by Carpenter²⁹, which specifically targeted depressed cancer patients and found only a significant improvement for self-efficacy for coping.

Brief resources with limited interaction

Two brief self-management resources were trialled; a psycho-educational intervention presented on a tablet,³³ and a brief well-being and mindfulness intervention.³⁴ These self-management resources have been categorised separately due to their brevity and the limited patient interaction.

The least interactive resource was a psycho-educational movie clip presented on a tablet.³³ This was presented to people with a variety of cancer diagnoses and stages (lung the most common; 28% of the sample), who watched a 20-minute video as they received chemotherapy. As per previous studies,²⁹ patients were screened for distress prior to enrolment, and only distressed participants were included. The content largely focused on psychological functioning, consisting of four parts: distress education, cancer survivor interviews, coping strategies, and psychosocial services. Despite being a very brief intervention, with a relatively small sample size of 36, the intervention group showed improved depression, quality of life, insomnia, and avoidant tendency, compared to controls at three weeks. There was no difference in use of psychosocial services six months later. While the authors argued that this study was evidence for a brief

psycho-educational intervention on a tablet, this was a Korean study, with a small sample size, therefore conclusions may have limited relevance in the Australian setting.

In a setting with more similarities to Australia, Rumachandra et al.³⁴ tested a simple wellbeing intervention for people with metastatic breast or prostate cancer in the UK. Forty-six participants were randomised to the intervention or a deferred entry group. The intervention consisted of keeping a wellbeing diary, using a mindfulness CD and planning a pleasurable activity. It was designed to be used at home without specialised help, although brief phone calls were made at weeks one, two and four, to encourage participation. Compliance was relatively low, with 46% completing the six weeks of the intervention, and only 10 patients completing the 18-week follow up. Feedback was generally positive, and there were improvements in psychological distress and quality of life after six weeks of the intervention. Conclusions are limited by the small sample size and low compliance.

These two studies are diverse in their content and format. However they both showed potential, suggesting that even brief interventions can be successful at improving patient outcomes in the short term.

Grey literature

The review identified websites, fact sheets, resources such as compact discs and online educational programs. No evidence to support the efficacy of these resources could be identified, however many of them had content which was evidence based (e.g. there is evidence for the benefits for exercise in cancer, but these particular programs have not been evaluated). Internal intervention may have been conducted. Given the lack of available evidence, these have not been included in this main report, but are summarised in Appendix 5.

6 Discussion

We reviewed the academic and grey literature to establish evidence for the effectiveness of self-management resources for treating psychological distress in adult cancer populations. Findings are summarised below:

What is the evidence for effectiveness of self-management resources?

Overall there is limited evidence to support the implementation of self-management resources. No study was adequately powered or showed high compliance to and engagement with the intervention, and significant improvements across measures. There are some promising pilot interventions, however, evidence is currently insufficient to recommend implementation of any self-management resources. The papers identified are diverse, and the majority of self-management resources are complex interventions,³⁵ and the effectiveness of each components is not known. Evidence was generated through quantitative approaches; with very few studies understanding patients' perceptions of using the self-management resources.

The most promising area for the self-management resources is the workbooks developed by Beatty and colleagues from Flinders University in Australia.²⁵⁻²⁷ These studies demonstrated improvements in posttraumatic stress, cognitive avoidance and depressive symptoms. However sample sizes were small. A search of current trial registry numbers indicated the lead author is progressing this program of work with a larger study currently underway.³⁶ These programs show potential as they are brief, require minimal facilitation, had generally quite good compliance and have been tested in the Australian setting.

Identifying studies which met the criteria for inclusion within this study was challenging; reflecting the variety of approaches to self-management, different types of contact at different points, and at times, poor reporting, meaning it was difficult to establish which studies had minimal facilitation. The definition of self-management traditionally refers to the Stanford program, adopted broadly as a program for chronic illness.¹⁷ The language used to describe self-management programs is inconsistent in the literature.¹⁹ Self-management typically consists of disease management which is delivered by a clinician, as opposed to self-care or self-guided interventions, which are focused on the actions an individual takes to maintain a level of health.³⁷ It is not surprising, therefore, that several identified self-management resources for anxiety and depression were presented within a broader self-management program, with components focused on physical wellbeing, symptoms, managing family and friends, spirituality, seeking closure, exercise, communication with health professionals, and resources. There was a paucity of studies that focused only on self-management for anxiety and/or depression.

Of our 15 included papers, 7 were published in the past two years. Furthermore, we identified 12 relevant protocol papers (Appendix 4) indicating that more research is currently underway in this area. Of the protocol papers, seven were Australian; indicating an emerging contribution to this research question. The *My Road Ahead* website²⁸ showed promise for men with prostate cancer with an online forum, and it is noted that longer term evaluation is underway.

Of note, despite including 'smartphone apps' in the search terms, none were identified within this search. This is consistent with a recent literature review, which found that of nearly 300 smartphone apps specifically for people with cancer, there was a lack of apps with scientifically-backed outcomes.³⁸

What patient outcomes show benefit associated with self-management resources?

The majority of articles reviewed focused on psychological functioning or quality of life (encompassing psychological functioning) as a primary endpoint. All studies focused on patient self-reported measures. Given that self-management for psychological distress in cancer patients is in its infancy, with a lack of evidence for patient reported outcomes, it is not surprising that there was no evidence for self-management resources having any impact on measures of adherence, indices of health or survival, comorbidity, and care journey (i.e. hospital admissions).

No studies explored factors that may mediate patient outcomes or engagement with self-management resources. A review of self-management and education in cancer pain also noted this gap in the literature.³⁹ A further review on online self-management for chronic disease noted the importance of considering socio-demographic factors.⁴⁰

Which systems-based factors relating to patient experience are associated with optimal effectiveness?

Successful management of chronic illnesses, including cancer, are highly dependent on individual patients who have to take extensive responsibility themselves as they spend the majority of time outside the healthcare system.⁴¹ In these studies, patients' adherence to self-management resources is often difficult to ascertain. In a trial design, the usability of an intervention may not be reflected in a real-world setting. For example, Carpenter²⁹ paid participants to complete follow-up questionnaires, which may have increased participation in the resource. Across the studies, there were several examples of poor or reduced adherence, e.g. 46% completed the requirements in Rumachandra's study.³⁴ Adherence also varied across different components of the intervention; e.g. engagement was low for the modules in Beatty 2010a²⁶ but many read the workbook. Poor reporting of compliance to different sections of an intervention and a lack of qualitative research means it is difficult to ascertain preferred aspects of programs, or what was considered helpful. Because of poor evidence, the effects of systems-based factors such as clinician endorsement are not known. The briefest intervention, consisting of a movie by Lee et al.,³³ had very promising results but in a very different health care context to Australia.

Several programs had a facilitated component. Only two studies, both Australian and by Beatty^{25, 26}, had no facilitated component. Given insufficient evidence, it is not possible to conclude the effects of a facilitated component on adherence or engagement with self-management resources. As this work was evaluated in a research context, there was no evidence about optimal models of routine integration or endorsement factors that supported effectiveness.

Is there evidence for effectiveness for population subgroups?

No studies focused specifically on culturally and linguistically diverse populations, Indigenous Australians, rural and regional groups or groups with financial limitations. Beatty 2010b²⁵ recruited participants from two Australian hospitals, one of which served a large geographical region and the other had a high proportion

of culturally and linguistically diverse (CALD) groups. However, the geographic spread of participants, or ethnicity, was not described.

There was insufficient evidence for recommendations in regards to population subgroups. However, several studies noted that distressed participants had better responses.^{23, 25, 29, 32} Two studies also noted that their samples were well functioning with distress scores comparable to the general population.^{24, 28} Two studies specifically enrolled people with distress,^{29, 33} and one other had attempted to do this but was limited by poor recruitment rates.³¹ In the broader psycho-oncology literature, interventions are being trialled that triage cancer patients in supports based on levels of distress. It is possible that this approach is also most suitable for self-management resources.

To what degree do effectiveness outcomes depend on the stage of treatment and/or the point of service contact?

Given the limited evidence, recommendations cannot be made for a specific stage of treatment. However, in a study by Beatty 2010a²⁶ in which a workbook was offered to women who had completed treatment, participants reported that the workbook would have been more relevant and beneficial towards the start of treatment. Studies often had diverse samples, e.g. Carpenter²⁹ recruited early stage breast cancer survivors, eligible if they had been diagnosed in the past 18 months, 49% having being treated previously with chemotherapy, 49% having previously been treated with radiation, and 20% were currently having chemotherapy or radiation, which may have diluted the effect for a particular subgroup.

All studies were conducted within the outpatient setting, post diagnosis. There were no studies that were targeting populations that were undergoing tests that could potentially diagnose cancer. There were no studies that reported on the cost-effectiveness of self-management resources, however this research question may be better addressed once efficacy is established.

7 Recommendations

Six key recommendations are presented:

1. Implementation of self-management resources

There is insufficient evidence to recommend implementation of self-management resources, and no one type of resource has demonstrated benefit over others. Several research protocols investigating the efficacy of self-management resources in managing or reducing distress among cancer patients have been published recently. Monitoring the outcomes of these research projects will further inform the understanding on the potential benefits of self-management resources among cancer populations.

Use of self-management resources to manage psychological distress in cancer is a developing field and it is premature to recommend implementation of a self-management resource for cancer because more evidence is required.

2. Generation of evidence-based outcomes

It is recommended that CINSW invest in a research program to address the gaps in the evidence. Currently, optimal a) ideal entry point in the disease trajectory, b) key patient groups, c) settings (e.g. health services or community settings), d) content and e) mode of delivery (e.g. online, interactive resource), are unknown. This review suggested that self-management resources to manage or reduce distress may be most effective for patients with some level of distress. However as evidence for this effect was limited, further investigation is needed.

Attention to subgroups is needed (culturally and linguistically diverse, Indigenous Australians, people from rural and remote communities, and people with low incomes) to ensure self-management resources can impact on a wide range of minority groups. Consideration of the needs of differing target groups, and how this relates to mode of delivery is recommended, e.g. older Australians, people from rural and remote communities.

Given the substantial gaps in the literature, engagement with national experts may be useful in progressing this program of research. Specifically, the group from Australian National University, led by Professor Kathy Griffiths, who have developed self-management resources for people with anxiety and depression, could be engaged to examine whether there is capacity to adapt and evaluate these existing resources from a general population to a cancer population. Partnership with CINSW to explore adaptation of these programs to cancer settings is recommended. Additionally, Dr Lisa Beatty from Flinders University, South Australia has focused on a program of work specific to self-management resources for psychological distress in cancer. In New South Wales, Professor Phyllis Butow has recently been awarded funding for a Translational Program Grant for Clinical Pathway for Managing Anxiety and Depression, which may be highly relevant to this topic. Establishment of an expert steering committee to promote a coordinated approach to this body of work may be beneficial.

There were no identified research studies which reported on patient preferences for self-management in cancer care. A further recommendation is to undertake or commission further investigation on patient preferences for self-management of psychological distress. One study collected data on why participants chose to participate, finding that the primary reason was because of altruism and gratitude, rather than personal benefit.³⁴ Other studies reported issues with recruitment or retention. Development of resources that patients view as relevant is vital in progressing the evidence for self-management resources that will be used by participants.

Refining the terminology and applying definitions may assist in consolidating this research program. Self-management may not be the most suitable description of this research program³⁷ given the links to the Stanford program (Appendix 2), which traditionally teaches a variety of self-management skills in a prescribed program. Describing these as self-guided interventions may be more appropriate.

It is recommended that the generation of the required evidence occurs with consideration of a translational framework (see below).

3. Identify optimal outcomes

Identification of optimal outcomes is important for demonstrating effectiveness. In this literature review, most of the outcome measures did not extend beyond patient-reported outcomes. There is a need to examine whether self-management resources impact on other outcomes. Given the debate about commonly used patient-reported outcomes for anxiety and depression,⁴² reliance on these outcome measures is not advisable. The issue of measurement in self-management has been documented previously, noting that the outcomes are typically patient reported outcomes, which can be associated with measurement error and response shift.⁴³ The efficacy of self-management programs in other disease groups can be more readily assessed with objective and reproducible physiologic outcomes, such as blood pressure, blood glucose control, or asthma attacks,⁴⁴ however in psychological distress for cancer patients, studies have relied on patient-reported measures.

It is recommended that optimal outcomes for self-management be explored, considering both patient and system factors. For example, the Health Education Impact Questionnaire (HeiQ) was developed specifically in Australia for self-management programs^{45, 46} and covers a broad range of dimensions including health-directed activity, self-monitoring and insight, and social integration and support. It may be a preferred instrument than those that focus specifically on anxiety and depression. There is an opportunity to broaden the way these programs are assessed. Consequently, it is also recommended that more objective or systems data be considered as part of the evaluation such as patient adherence to self-management resources, missed appointments or emergency department presentations. Examining more robust and diverse outcome measures, and extending beyond the previously identified psychological and physical outcomes is important in progressing an understanding of the role of self-management resources.

An evaluation involving the cost-effectiveness of self-management resources is necessary. This would enable practical judgements regarding the value-for-money credentials of these resources.

4. Explore the role of the facilitator

Papers were included that involved minimal facilitation. Within the cancer literature, there was a lack of evidence as to whether any facilitated component was beneficial, and the optimal model of facilitation. There was diversity across studies, with brief facilitation including introductions or orientations,^{22, 23} email communication³⁰ or follow-up phone calls.^{20, 31} Optimal strategies to facilitate self-management programs were also unclear within the broader self-management literature.⁴⁷ Facilitators can be clinicians or peers; and their engagement, endorsement or ongoing support may be helpful in reinforcing the content of self-management resources, promoting adherence or use of the resources. Understanding preferred facilitators and the amount of facilitation to best promote self-management is an important avenue for research. A small facilitated component, such as enquiring about compliance with two phone calls,²⁶ an introductory email³⁰ or a 20-minute introduction to the program²⁰ may be helpful in encouraging engagement.

While interventions that do not have a facilitated component are likely to be viewed as more cost-effective, any self-management resource is likely to require resources to promote use to the patient. Interactive materials require costs to print whereas websites have costs for establishment, troubleshooting, ongoing monitoring to ensure relevance and maintenance. Although these are minimal compared to clinician-delivered psychological support, no self-management resource is entirely free of cost to deliver.

Given that the focus of this body of work is on self-management of psychological distress, monitoring may be particularly relevant. It is important to develop protocols for responding to high levels of distress or self-harm. Training of staff, triaging according to risk, and having oversight of self-management may be vital in ensuring patient safety.⁴⁸ Furthermore, self-management resources may cause harm; one self-management resource showed deterioration of body image in the intervention group.²⁵ Self-management should be delivered with options for more support, contact details for help, and monitoring.

5. Consider existing programs

Although the grey literature was searched, we were not able to identify any evidence-based self-management resources specifically for managing psychological distress in people with cancer. However, given that the target intervention is brief, and is largely delivered by the patient, there may be small programs that currently exist in community or support groups that could not be identified. As there may be little clinical resourcing required to supply this intervention, it cannot be concluded that self-management resources to manage psychological distress in people with cancer are not in practice.

Existing online resources for the general population aimed at preventing and treating mental illness are established and have been shown to be effective (Appendix 5). Testing these in people with cancer, or adapting if necessary, is a promising avenue for future work.

6. Adopt a translational framework

While randomised controlled trials are viewed as the gold standard for internal validity, creation of trial environments may limit real-world settings in which self-management resources would be delivered if implemented.^{49, 50} Furthermore, despite a known need for programs to treat psychological distress in cancer patients, recruitment issues were an issue in several of the studies reviewed within this report.

It is recommended that any future research program incorporate a translational framework to promote implementation of self-management resources across services. Stepped wedge randomised trial designs, which allow sequential roll-out of an intervention, may be most appropriate to evaluate the efficacy of these interventions and allow them to be continued in practice.

Additionally, qualitative research designs may assist in detailed understanding of the strengths of particular interventions.⁵¹ In the current review, studies were poor at reporting which aspects of the self-management programs were satisfactory and utilised by patients. Interviews with patients to understand how they use self-management resources are likely to be vital in understanding how they can best be applied in practice.

Future work should develop robust evidence for self-management resources to inform development of recommendations in clinical practice guidelines such as clinical practice guidelines for the psychosocial care of adults with cancer. There is also opportunity to link dissemination of self-management resources with existing strategies to identify distress,⁵² once the evidence base develops.

8 Conclusions

Self-management resources for managing psychological distress in people with cancer are diverse in their content, delivery, population and settings. There was insufficient evidence for recommendation of implementation of a self-management resource, and there were several gaps in the literature. Identifying optimal outcomes, and exploring the role a facilitator both need addressing. Terminology needs consideration, as self-management frequently refers to the Stanford programs that have been trialed extensively in chronic disease. This is a developing field, and with several encouraging protocols by Australian authors recently published, the evidence base is improving. There may be opportunity to adapt a self-management resource from another disease group to be applicable to cancer populations. Additionally, programs specifically for psychological distress that are aimed at the general population are worthy of further investigation.

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10 Appendices

Appendix 1A: Examples of facilitated programs from preliminary search findings

First author and year	Country	Participants	Design	Intervention	Results	Reason for exclusion from main review
Abernethy 2010 ⁵³	USA	50 people with a range of cancer diagnoses and stages	Single arm, phase II study	Patients met with a trained social worker (a Pathfinder); services provided included cognitive restructuring, mind/body technique, self-care, end of life planning, according to a standard manual. The pathfinder met with the patient at least monthly for up to six months	Several improvements across measures and subscales at three months including distress, despair and QOL	Intensive facilitation required
Antoni 2006 ⁵⁴	USA	199 women newly treated for non-metastatic breast cancer	RCT	10-week group cognitive-behavioural stress management intervention	Reduced reports of thought intrusion, interviewer ratings of anxiety, and emotional distress across one year significantly more than controls	Group intervention too intensive
Børøsdund 2014 ⁵⁵	Norway	167 women recently diagnosed and treated for breast cancer	RCT. Groups: 1. Usual care 2. Internet based patient-provider communication (IPPC) alone 3. IPPC plus WebChoice	WebChoice comprised: an assessment component where patients could monitor their symptoms and problems; an advice component which provided tailored symptom self-management support; access to other online resources; an online forum and the ability to ask questions of health professionals	The IPPC plus WebChoice group reported lower symptom distress, anxiety and depression, compared with usual care. The IPPC group alone reported lower depression scores, compared with usual care	Intervention too intensive. Health professionals monitored the online forum and checked emailed questions daily
Capozzo 2010 ⁵⁶	Italy	29 women with early stage breast cancer	Pre-post surveys	6 week psychoeducational group intervention	Reduction in anxious preoccupation	Facilitated six-week course

Chambers 2014 ⁵⁷	Australia	354 adults with cancer and 336 caregivers	RCT	A single session of nurse-led self-management intervention was compared to a five-session psychologist cognitive behavioural intervention delivered by phone	For low-education patients, only the psychologist intervention was associated with a significant drop in distress. For all other participants, distress decreased over time in both arms. Post-traumatic growth increased over time for all participants	Involved a facilitated nurse-led session for each patient
Garssen 2013 ⁵⁸	Netherlands	70 women who were scheduled to undergo surgery for breast cancer	RCT	Stress management training which comprised four sessions pre- and post-surgery, conducted by a psychologist	Reduced depression and fatigue in the intervention group	Facilitated four week course
León - Pizarro 2007 ⁵⁹	Spain	66 women with gynaecological cancer or breast cancer undergoing brachytherapy as inpatients	RCT	45-minute psychological intervention delivered to all participants. Experimental group then received training in relaxation and guided imagery for ten minutes and provided with a cassette	Significant improvement of anxiety and depression at three weeks post intervention	Delivered as an inpatient in brachytherapy patients only
Loh 2011 ⁶⁰	Kuala Lumpur	51 questionnaires returned from women with breast cancer who had participated in a self-management program two years ago	Follow up study of a RCT	The intervention consisted of a four week self-management program (described in another study)	The experimental group reported higher confidence to live with breast cancer, and improved anxiety scores, compared to control	Intervention too intensive
Loprinzi 2011 ⁶¹	USA	25 women with breast cancer	RCT	Two 90-minute group training sessions, an individual session, three telephone calls, focused on Stress Management and Resiliency Training	The intervention group had a statistically significant improvement in several outcomes: resilience, perceived stress, anxiety and overall quality of life at 12 weeks, compared with the baseline arm	Intensive facilitation required
Oh 2010 ⁶²	Korea	71 cancer patients undergoing adjuvant therapy	Participants were assigned to intervention or control groups	Two week psychosocial intervention involving 20 minutes of health education, a CD-ROM, booklet and 15 minutes of telephone counselling	The intervention group had higher scores than the control for fighting spirit and self-care behaviours. There was no	Intervention requires facilitation

					differences in helplessness or hopelessness, anxiety or depression	
Ruland 2013 ⁶³	Norway	325 men and women undergoing treatment for breast or prostate cancer	RCT. Controls given information about publicly available websites	WebChoice intervention comprised: an assessment component where patients could monitor their symptoms and problems; an advice component which provided tailored symptom self-management support; access to other online resources; an online forum and the ability to ask questions of health professionals	Compared to controls, decreased symptom distress in intervention group using one global measure of distress only. Within group improvements in depression in the intervention group only	Intervention too intensive. Health professionals monitored the online forum and checked emailed questions daily
Salvatore 2015 ⁶⁴	USA	1170 participants; 116 had cancer	Cohort study, reporting on cancer participants to non-cancer participants	Chronic disease self-management program, consisting of the standard Stanford six week program	Improvements in cancer patients up to 12 months post sessions, including: reduced pain, fewer days in poor physical/mental health Cancer survivors reported fewer improvements than non-cancer survivors	Stanford model: intensive facilitation
Smith 2011 ⁶⁵	USA	44 women with breast cancer	Single arm pilot	Patients met with a trained social worker (a Pathfinder), who focused on teaching coping skills, identifying inner strengths, and developing a self-care plan	Improvements were evident for active coping skills, self-efficacy, spiritual meaning/peace	Intensive facilitation required
Song 2013 ⁶⁶	China	100 women with breast cancer	RCT	50 intervention arm participants received relaxation training taught during chemotherapy. Participants were taught abdominal breathing and progressive muscle relaxation. There is no information about the duration of the intervention delivery or the person who delivered it	Mental and physical health was improved in the experimental group arm	Facilitation is required

Appendix 1B: Examples of facilitated mindfulness programs from preliminary search findings

First author and year	Country	Participants	Design	Intervention	Results	Reason for exclusion from main review
Eyles 2015 ⁶⁷	UK	19 women with metastatic breast cancer, 100 women approached	Mixed methods, feasibility study. Interviews and pre- and post-surveys	Eight-week mindfulness-based stress reduction (MBSR) program	During interviews most participants reported the course was acceptable and beneficial. There was a reduction in anxiety and QOL at 24 weeks	Facilitated eight-week course
Garland 2013 ⁶⁸	Canada	268 adults with cancer who attended five of the eight sessions	Pre- and post-surveys	Eight-week MBSR program	Reduction in mood disturbance and symptoms of stress	Facilitated eight-week course
Henderson 2012 ⁶⁹	USA	172 women with early stage breast cancer	RCT compared MBSR to nutritional education program (NEP) and usual care	Eight-week MBSR program	Increased QOL and coping and anxiety for MBSR intervention group at 4 months, compared with NEP and usual care	Facilitated eight-week course
Kieviet-Stijnen 2008 ⁷⁰	Netherlands	47 adults with cancer	Pre-post surveys	Eight-week MBSR program	Participants were highly satisfied. Improved QOL, more joy in life and less tension at eight weeks. A decrease in depression, anger and mood disturbance was measured a year later	Facilitated eight-week course
Lengacher 2009 ⁷¹	USA	84 breast cancer survivors	RCT	Six-week MBSR program	Intervention group had lower levels of depression, anxiety, fear of recurrence and QOL at six weeks, compared with controls	Facilitated six-week course
Matousek 2010 ⁷²	Canada	59 women who had completed treatment for breast cancer	Pre- and post-surveys	Eight-week MBSR program	91% program adherence. Reduction in stress, depression and coping with illness	Facilitated eight week course
Zernicke 2014 ⁷³	Canada	62 adults within three years of cancer treatment, with moderate to high distress	RCT, wait list control	Eight-week online mindfulness-based cancer recovery program	Participants were satisfied with the program and had improved mood disturbance and stress symptoms	Online program was in real time and facilitated over eight weeks

Appendix 2: Stanford chronic disease self-management courses

The Stanford chronic disease self-management program (CDSMP) was developed at Stanford University more than 20 years ago, and is probably the most extensively evaluated approach to self-management⁷⁴. It is conducted in small group workshops either in community settings or online, and is designed for people with chronic conditions, such as arthritis, diabetes or heart disease.

The CDSMP is led by two facilitators who have completed a 4.5 day training course. One or both of the facilitators may be lay people with a chronic condition. Trained leaders follow a scripted manual⁷⁵.

The program is delivered as six, weekly 2.5 hour sessions. Subjects covered include:

- 1) Techniques to deal with problems such as frustration, fatigue, pain and isolation
- 2) Appropriate exercise for maintaining and improving strength, flexibility, and endurance
- 3) Appropriate use of medications
- 4) Communicating effectively with family, friends, and healthcare professionals
- 5) Nutrition
- 6) How to evaluate new treatments.

The program content is based on social learning theory and incorporates skills mastery, through weekly action planning and feedback of progress; modelling of self-management behaviours and problem solving strategies; and social persuasion, through group support and guidance for individual self-management effort. The program emphasises the critical role of the patient in managing their health in partnership with health professionals.

Before an organisation can offer programs it must have a licence from Stanford University. The program operates in a number of countries, including Australia and Australian organisations licensed to run the program are shown in the following table.

A randomised control trial of a self-management program, based on the Stanford model, for people from Vietnamese, Chinese, Italian and Greek backgrounds was conducted in Victoria⁷⁴. This study found that program participants had better outcomes on the following measures: energy, exercise, symptom management, self-efficacy, general health, pain, fatigue, and health distress. Chinese and Vietnamese speaking participants gained greater benefits. There were no significant effects on service utilisation.

Early Stanford CDSMPs specifically excluded people with cancer. However a recent examination of the program's applicability for cancer survivors found that they experienced improvements in general health, depression, and sleep from baseline to 6 months and these improvements were still present at 12 months⁶⁴.

Recently a six-week online workshop, *Surviving and Thriving with Cancer*, was adapted from the CDSMP specifically for cancer survivors⁷⁶. Results showed that the program reduced insomnia and increased strenuous and stretching exercises in cancer survivors, but did not affect depression or fruit and vegetable consumption. The authors note that the majority of the sample met or exceeded national recommendations for health behaviours and were not suffering from depression or fatigue at baseline. Thus, their ability to make substantial changes health behaviours as a result of the program may have been limited.

A further study of the *Surviving and Thriving with Cancer* program analysed online posts made by participants during the program⁷⁷, and found that participants who wrote the most posts showed greater

improvements in role function (illness intrusiveness) and exercise over six months, compared to other participants. It was noted that this group had greater stress and depression and poorer role function at baseline than the population as a whole.

Table 3: Australian organisations licensed to offer Stanford Chronic Disease Self-Management program

<p>New South Wales</p> <ul style="list-style-type: none"> • Central Coast Local Health District • Central Coast NSW Medicare Local • The Bobby Goldsmith Foundation • Western Sydney Local Health District <p>ACT</p> <ul style="list-style-type: none"> • Community Care Program, ACT Health Directorate <p>Victoria</p> <ul style="list-style-type: none"> • Arthritis Foundation of Victoria • Campaspe Primary Care Partnership • Casterton Memorial Hospital • Central West Gippsland Primary Care Partnership • Heywood Rural Health • Southern Mallee Primary Care Partnership • South West Healthcare - Community Health • Terang & Mortlake Health Service • Yarram and District Health Service <p>Western Australia</p> <ul style="list-style-type: none"> • Canning Division of General Practice Ltd. • Child and Adolescent Health Services, Princess Margaret Hospital • Community West Inc. • Fremantle Medicare Local Ltd • Kimberley Aboriginal Medical Services Council, Inc • Marr Mooditj Training, Inc. • Perth North Metro Medicare Local Ltd. • Silver Chain Nursing Association • South West Aboriginal Medical Service 	<p>Queensland</p> <ul style="list-style-type: none"> • Australian Pain Management Association Inc. • BlueCare • Burdekin Community Association Inc. • Carers Queensland Inc. • Metro South Medicare Local • Queensland Health • Ozcare • R.S.L. (QLD) War Veteran's Homes • The Corporation of the Synod of the Diocese of Brisbane • The Queensland AIDS Council, Inc. • Toowoomba Health Service District <p>Tasmania</p> <ul style="list-style-type: none"> • Dept Health and Human Services - Population Health <p>South Australia</p> <ul style="list-style-type: none"> • ECH, Inc. • In our Hands Health Information & Resource Centre, Inc. • LEAP SA • University of South Australia <p>Northern Territory</p> <ul style="list-style-type: none"> • Arthritis Foundation of Northern Territory, Inc.
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Source: Stanford University School of Medicine website

Despite numerous program evaluations, there is still some controversy in the literature about the effectiveness of CDSMP. Much of the discussion focuses on the suitability of the measures used to measure outcomes. Most outcomes are self-reported, although some have reported improvements in clinical outcomes, such as blood pressure⁴⁴. A systematic review of outcomes from chronic disease self-management programs concluded that across most of the outcomes studied (pain, disability, depression, self-efficacy, physician visits, general health, fatigue, communication with physician, anxiety and physical functioning) effect sizes were small. However effects on participant knowledge were large across the studies⁷⁸.

Appendix 3: Summary of relevant literature reviews

Author and year	Title and review question	Type of review	Differences to this self-management resources review	Papers reviewed	Key findings relevant to self-management resources	Implications for this review
Beatty 2013 ⁴⁷	<p><i>A systematic review of internet based self-help therapeutic interventions to improve distress and disease-control among adults with chronic health conditions</i></p> <p>Aimed to review the application of the internet to the psychological treatment of distress among adult patients with chronic diseases</p>	Systematic review of randomised controlled trials	Closely aligned with this self-management resources review. The focus was on self-facilitated interventions that were delivered online, with a focus on anxiety and depression. However the focus was on chronic disease, and only on internet interventions	<p>24 papers were included, published 1980–2011</p> <p>One paper for cancer was identified (Owen 2005; included in this self-management review)</p>	<p>There was no support for internet self-help interventions for cancer pain, however only one study was identified. There was mixed evidence for improving distress across different disease types</p> <p>There was stronger evidence that internet self-help interventions could improve physical symptoms, and most studies had symptom control as the primary outcome</p> <p>Cost-effectiveness was supported in three studies (none of which were the cancer study)</p> <p>Only one paper identified within this review investigated the impact of therapist involvement (an intervention for people with headaches, published in 2003). It found no differences for a facilitated vs not facilitated component. Authors note more research is required</p>	<p>Internet self-help may be promising especially for physical symptoms rather than psychological</p> <p>The reviewers also note that attrition and compliance were problematic, as was consistent with the findings in this self-management review</p> <p>Also consistent with this self-management review, it notes the developments in this field are relatively recent</p>

					regarding the impact of facilitation supporting self-management	
Charova 2015 ⁵⁰	<p><i>Web-based interventions for comorbid depression and chronic illness: a systematic review</i></p> <p>Examined targeted web-based interventions for depression among chronic illness groups, focusing on methodological quality, short- and longer-term biopsychosocial effects, and treatment factors that impact on consumer acceptability and satisfaction</p>	Systematic review	Included a range of chronic conditions, only one cancer paper (Duffecy, 2013). The interventions examined were web-based only	1990–2014. 11 studies were examined	Web-based interventions resulted in short term improvements in depression and broader psychosocial outcomes. Longer term treatment effects could not be established	The authors note that the relationship between depression outcomes and degree of therapist involvement requires further evaluation. The broader web-based intervention literature favours supported intervention over self-guided help, although there are some exceptions to this. The authors also note the need to consider alternative research designs, with randomised controlled trials and double blinding difficult within a psychotherapeutic setting
Griffiths 2010 ⁷⁹	<p><i>The efficacy of internet interventions for depression and anxiety disorders: a review of randomised controlled trials</i></p> <p>Aim was to review the outcomes, nature and quality of RCTs of interventions to treat or prevent depression and anxiety disorders</p>	Narrative review including a risk of bias rating and effect size analysis but no data on number of identified studies or reasons for exclusion	The focus was on impact of interventions delivered over the internet for mental health. No included studies focused specifically on cancer and all interventions required therapist time (minimum 90 minutes)	26 trials were included, published from 2001 – June 2009	The majority of trials (23 of 26) had some evidence demonstrated for their effectiveness. Effectiveness appears to be comparable to face-to-face psychological treatment	The authors note that the variation in the methodologies of studies makes it difficult to make recommendations as to whether those without therapist input are just as effective
Kaltenthaler 2002 ⁸⁰	<i>A systematic review and economic evaluation of computerised cognitive</i>		The focus was specifically on the effectiveness of online delivered CBT	16 studies were included, 11 of which were RCTs	In depressed or anxious populations, CCBT may be just as effective as	A lack of high quality studies is noted, consequently results are to be interpreted with caution

	<p><i>behaviour therapy (CCBT) for depression and anxiety</i></p> <p>The aim was to assess the clinical effectiveness of CCBT for treating anxiety, depression and phobias, and to compare the cost-effectiveness of CCBT and CBT delivered by conventional methods</p>			Papers were included if they were published 1966–2001	therapist led CBT	<p>The authors note the variety of CCBT interventions, as was found in this self-management review</p> <p>The review included older papers; those that were published up until 2001</p>
Kroon 2014 ⁸¹	<p><i>Self-management education programs for osteoarthritis</i></p> <p>To assess the effectiveness of self-management education programs for people with osteoarthritis</p>	Cochrane review	Focus was on facilitated programs, as opposed to self-management resources, and the participant group was people with osteoarthritis rather than people with cancer	29 studies identified prior to January 2013	<p>Self-management programs may not have sustained benefits at 12 months</p> <p>Benefits are likely to be small, for outcomes including self-management skills, pain, function and symptoms. These are not likely to be clinically significant</p>	<p>Included reviews were heterogeneous and some studies provided inadequate description of interventions</p> <p>Other models of self-management, rather than focusing on the Stanford model, should be investigated</p>
Matcham 2014 ⁸²	<p><i>Self-help interventions for symptoms of depression, anxiety and psychological distress in patients with physical illnesses: A systematic review</i></p> <p>This review aimed to assess and summarise the impact of written self-help interventions on symptoms of</p>	Systematic review of randomised controlled trials and meta-analysis	The focus was on written materials, and these papers may have been excluded in this self-management review for being passive. Computer and multimedia interventions were excluded. The focus was on self-management materials, with papers excluded if interventions had more than 60 minutes with a health professional	25 papers published up until November 2012. Eight were in cancer populations, of these, two are also included in this self-management review (Krischer 2007; Beatty 2010)	Meta-analyses indicated that self-help interventions improved depression but not anxiety or psychological distress	<p>Similar content to the interactive materials that we reviewed; finding some support for them in improving depression</p> <p>They note the heterogeneity in included interventions</p> <p>They also note the lack of high-quality evidence across studies</p>

	depression, anxiety and psychological distress					
McCorkle 2011 ¹⁹	<p><i>Self-management: enabling and empowering patients living with cancer as a chronic illness</i></p> <p>Randomized controlled trials of self-management interventions with cancer patients and families in the treatment, survivorship, and end-of-life phases of the cancer care continuum were reviewed</p>	Narrative review	The focus was on self-management throughout the disease trajectory rather than focusing on self-management to address psychological concerns. Many of the studies were conducted prior to 2005	16 papers included from 1992–2007	Self-management is critical across all phases of the cancer care continuum. However, the demands patients experience within a particular phase may influence their level of participation. For example, patients may become more passive during active, aggressive treatment	The authors note the lack of a common language for self-management programs
Murray 2005 ⁸³	<p><i>Interactive health communication applications for people with chronic disease (Review)</i></p> <p>To assess the effects of interactive health communication applications (IHCA; defined as computer-based, usually web-based, information packages for patients, that combine health information with at least one of social support, decision support, or behaviour change</p>	Cochrane review including a meta-analysis and including only randomised controlled trials	<p>The focus was on health information, rather than psychological distress. The level of facilitation required was not explored. The focus was on all of chronic disease not cancer</p> <p>Interventions included were computer networks linking to information, interactive computer games for children with cancer and multimedia education programs</p>	<p>24 randomised controlled trials were included, with 3739 participants in the meta analysis</p> <p>Studies were published 1990–2003</p> <p>Three studies were on cancer patients. None of these were included in the self-management review</p>	<p>There is evidence that IHCAs improve knowledge, social support and clinical outcomes</p> <p>Similarly to the evidence for self-management resources, there was insufficient information on the effect of IHCAs on economic outcomes</p> <p>The reviewers were unable to ascertain whether IHCAs promote equity between advantaged and disadvantaged patient groups, but they may benefit underserved</p>	Participants can improve their knowledge, social support and clinical outcomes from using interactive health communication, but there is little evidence for this specifically in cancer

	support)				populations	
Pal 2013 ⁸⁴	<p><i>Computer-based diabetes self-management interventions for adults with type 2 diabetes mellitus</i></p> <p>Aim was to assess the effects on health status and health-related quality of life of computer-based self-management interventions for adults with type 2 diabetes mellitus</p>	Cochrane review including only randomised controlled trials	Interventions were not relevant: either clinic-based, too intensive, included peer support or focused on diabetes specific outcomes	16 studies were included, published prior to November 2011	Computer-based diabetes self-management interventions appear to have a small beneficial effect on blood glucose control and the effect was larger in the mobile phone subgroup. There is no evidence to show benefits in other biological outcomes or any cognitive, behavioural or emotional outcomes	Computer based interventions can have an effect on the health of those with a chronic disease, however the interventions used were not relevant to this review
Paul 2013 ⁴⁰	<p><i>The impact of web-based approaches on psychosocial health in chronic physical and mental health conditions</i></p> <p>Aimed to examine the effectiveness of web-based psychosocial support for chronic conditions, as well as the association between effectiveness, reach and adoption and socio-demographic and condition-related characteristics</p>	Systematic review	Included a range of chronic conditions. The interventions examined were web-based only	2001-2011. 36 studies were included. Seven focused on cancer. One (Owen 2005) was included in the current review	20 studies showed a positive effect of web-based interventions, no effect in 11 and mixed effects in five studies. Effects were not consistent across conditions. The role of socio-demographic characteristics in relation to outcomes, reach and adoption was explored in very few studies	There is insufficient evidence to conclude that a web-based approach is generally suitable for all patient groups and all types of social support. Socio-demographic factors need to be considered in relation to intervention effectiveness, reach and adoption. However there is little evidence available to support decision making for specific population subgroups
Ventura	<i>An integrative review of</i>	Integrative review	Focused specifically on online	28 papers	There was evidence that	People at different stages of

<p>2013⁸⁵</p>	<p><i>supportive e-health programs in cancer care</i></p> <p>Aimed to understand more about the design of supportive e-health interventions for patients diagnosed with cancer</p>	<p>(inclusive of various methodologies)</p>	<p>health interventions, rather than self-management interventions. Facilitated vs not-facilitated was not explored. Additionally, the reviewed papers did not specifically address patient psychological distress, consequently, the interventions included education and decision-making programs</p>	<p>published from 2000-2012</p>	<p>e-health interventions can be successful</p> <p>Usage of e-health could be predicted by socio-demographic factors and disease factors, e.g. those in a post-chemotherapy phase used information services more, whereas those in a post-radiation phase used expert communication services less</p> <p>No interventions focused only on emotional support; always included information, social support, decision making and/or self-care components. Many had an information component</p> <p>There is a lack of a common structure for e-health interventions</p>	<p>cancer treatment will have different preferences for an online program</p> <p>Consistent with the findings of our self-management review, the Ventura (2013) review found interventions mainly use self-report instruments as outcome measures, often with measures that are not well validated</p>
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Note: Chronic Disease Self-Management Course reviews are covered in Appendix 2

Appendix 4: Summary of relevant protocol papers

Author and year	Title	Country
Protocols		
Beatty 2015 ³⁶	Finding my way: protocol of a randomised controlled trial evaluating an internet self-help program for cancer-related distress	Australia
Boele 2014 ⁸⁶	Internet-based guided self-help for glioma patients with depressive symptoms: design of a randomized controlled trial	Netherlands
Bryant 2015 ⁸⁷	Protocol of a multi-centre randomised controlled trial of a web-based information intervention with nurse-delivered telephone support for haematological cancer patients and their support persons	Australia
Chambers 2009 ⁸⁸	Beating the blues after cancer: randomised controlled trial of a tele-based psychological intervention for high distress patients and carers	Australia
Eakin 2014 ⁸⁹	Translating research into practice: the health living after cancer partnership project	Australia
Lambert 2012 ⁹⁰	A pilot randomised controlled trial of the feasibility of a self-directed coping skills intervention for couples facing prostate cancer: rationale and design	Australia
Lambert 2013 ⁹¹	A parallel-group, randomised controlled trial of a multimedia, self-directed, coping skills training intervention for patients with cancer and their partners: design and rationale	Australia
Lee 2012 ⁹²	Efficacy of walking exercise in promoting cognitive-psychosocial functions in men with prostate cancer receiving androgen deprivation therapy	Canada
Mattson 2013 ⁹³	U-CARE: Internet-based stepped care with interactive support and cognitive behavioral therapy for reduction of anxiety and depressive symptoms in cancer – a clinical trial protocol	Sweden
van den Berg 2012 ⁹⁴	Rationale of the BREast cancer e-healTH [BREATH] multicentre randomised controlled trial: an internet-based self-management intervention to foster adjustment after curative breast cancer by decreasing distress and increasing empowerment	Netherlands
Known programs underway		
Solberg 2015 (accessed)	A research program focusing on stress management for cancer. This project is underway at the Oslo University Hospital (2014-2017) and aims to develop and test an interactive computer-assisted, cognitive behavioral stress management intervention for cancer patients www.communicaretools.org/research-projects/stress-management-in-cancer/?language=nb	Netherlands

Protocols identified from literature search, hand searching and knowledge of the literature

Appendix 5: Summary of Grey Literature

Grey literature was sourced from websites. This is not an exhaustive list of all self-management programs. Those that have intensive facilitation are not included as per the criteria for this review (e.g. Living with Cancer Education Programs which are run across Cancer Councils in Australia are not included because of the facilitation requirements). As stated in the main report, evidence for the identified programs was not clear, however, many of them have content which is evidence-based (e.g. there is evidence for the benefits for exercise in cancer, but these particular programs have not been evaluated).

International organisations

The American Cancer Society has an online education program called the *I Can Cope Online* program, which contains information about common emotional responses to cancer but does not provide any self-management techniques.

MD Anderson has an Integrative Medicine Centre which offers services such as free meditation and art therapy classes. The website contains a short written guide to meditation as well as meditation audiofiles. These can be accessed from the following websites:

- www.mdanderson.org/patient-and-cancer-information/cancer-information/cancer-topics/prevention-and-screening/health/stressrelief.html
- www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/specialty-and-treatment-centers/integrative-medicine-center/meditation.html

Cancer Research UK provides detailed written information about a range of stress management techniques, such as meditation and visualisation, and provides links to complementary therapy organisations that offer these services.

Australian organisations

Australian cancer-specific organisations have resources available, but these are often passive and have not been evaluated in a research design (to our best knowledge).

Cancer Australia provides links to a range of organisations, including a link to the beyondblue resources about mental health and cancer:

www.cancerlearning.gov.au/find/suppcare_rsrc.php#patient_support_resources

Cancer Council Australia websites had no specific resources on mental health.

Cancer Council Queensland featured a 'Learn to relax CD', accessible from:

www.cancerqld.org.au/page/information_resources/podcasts/

Cancer Council NSW offers a free CD on mindfulness meditation.

Cancer Council SA has a mindfulness video

www.cancersa.org.au/information/a-z-index/counselling

Cancer Council WA Offers free yoga, art, exercise and mindfulness courses, and mindfulness CDs.

www.cancerwa.asn.au/patients/support-and-services/life-now/

www.cancerwa.asn.au/resources/publications/patients/tracks/

The **Breast Cancer Network Australia** provides written information about anxiety and depression, but resources to self-manage psychological health are not provided.

An online resource is being trialled for people with cancer, but the focus is on psychosexual concerns rather than psychological distress: www.rekindleonline.org.au. Acceptability, feasibility, uptake and reach of *Rekindle* was presented at the Clinical Oncology Society of Australia 2014.

beyondblue provides written information about mental health and cancer. It also gives a link to *mindhealthconnect* (see below), which provides a directory of online mental health programs developed by a range of Australian health organisations.

mindhealthconnect is a national initiative operated by Healthdirect Australia, on behalf of the Australian Federal Government.

www.mindhealthconnect.org.au/online-self-help-programs

One example is MindSpot which offers assessment and online treatment courses for Australians suffering from anxiety and depression (not necessarily in relation to cancer or other diseases):

mindspot.org.au/treatment-courses

In summary, a number of Australian online self-help programs are available for people with psychological distress, but none that specifically target people with cancer or other chronic diseases could be identified. A review of internet interventions for anxiety and depression showed that the internet was an effective medium to deliver programs of this type⁷⁹. At the Australian National University, the e-hub group at the National Institute for Mental Health Research, develop, evaluate and deliver online mental health programs and have developed programs that are widely available, such as MoodGYM and e-couch⁴⁸. These programs are evidence-based and automated so that users receive automated feedback and advice based on their answers to symptoms and other self-report measures. However there is still a need to monitor the programs as users are able to email questions to the e-hub group. The programs are evaluated using routinely recorded demographic and repeated symptoms measures. As the e-hub group has extensive experience in the development and evaluation of online programs for anxiety and depression, they would be well placed to provide input into the development of a program targeted specifically to the needs of cancer patients.