

Australian Cancer Survivorship Centre

A Richard Pratt Legacy



Needs Assessment for Cancer Survivors: Toolkit



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Needs Assessment for Cancer
Survivors: Toolkit
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Contents

Contents	ii
Acknowledgements	1
Disclaimer	2
Part I: The importance of needs assessment	1
Introduction	1
Background to the development of the toolkit	1
Intended audience	1
Aim and intended purpose of needs assessments	1
Benefits of needs assessment tools	2
Part II: Delivery and implementation	4
Introduction	4
How do you develop a successful model of delivery?	6
How should the needs assessment be carried out?	7
Intended audience	8
When to assess need	9
How often should the needs assessment be carried out?	9
Who should carry out the needs assessment?	9
What is required after needs assessment?	10
Other considerations	11
Needs assessment of cancer survivors: the Victorian experience	12
Part III: Which tool to use?	13
Introduction	13
Use of needs assessment tools in research versus clinical settings	13
Needs assessment tools for adult cancer survivors	13
Needs assessment tools for young adult survivors	14
Needs assessment tools for survivors of childhood cancer	15
Other assessment tools	15
Specific needs assessment tools	17
Appendix A: Needs assessment of cancer survivors - the Victorian experience	19
Glossary	20
References	21
List of tables and figures	
Table 1: Recommendations about needs assessment	5
Table 2: Questions to consider during model development	7
Table 3: What needs assessment tool to use?	8
Table 4: Considerations for referral process	10
Table 5: Needs assessment tools for cancer survivors.....	16
Figure 1: Four stages of needs assessment.....	4



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The Victorian Department of Health and Human Services funds the ACSC to support the Victorian Cancer Survivorship Program (VCSP). The VCSP was established to develop innovative models of survivorship care to address the needs of survivors post-treatment.

The ACSC facilitates the VCSP Community of Practice, develops and distributes key survivorship resources, and provides survivorship education and training. The publication of a needs assessment literature review and toolkit is considered an important resource for the VCSP and national services with an interest in caring for cancer survivors. More information on the literature review can be found [here](#).

This toolkit has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise. The purpose of this independent review is to provide candid and critical comments that assist in making this toolkit as relevant and sound as possible. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this toolkit:

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It should be noted that although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft before its release. Therefore, responsibility for the final content of this toolkit rests entirely with the ACSC.

Further information regarding the toolkit can be obtained by contacting the Manager, Australian Cancer Survivorship Centre on phone +61 3 9656 5207 or email contactacsc@petermac.org.

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Disclaimer

This work is the result of a collaborative effort between the Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre and the Department of Health and Human Services Victoria. Work has comprised analysis, interpretation and comparison of published research literature. It also incorporates data and information obtained from grey literature sources and opinions of clinical experts. It is not intended to reflect all of the available evidence and is not intended to be exhaustive. The authors acknowledge that it is possible that other relevant scientific findings may have been published since the completion of this report.

Part I: The importance of needs assessment

Introduction

In many parts of the world, particularly in developed countries, the number of people surviving cancer is increasing. This is a consequence of early diagnosis and improved cancer treatments and follow-up care. As a consequence, the focus of cancer care delivery has been extended well beyond treatment.

Current literature demonstrates that cancer survivors deal with a myriad of acute, chronic and late effects of cancer treatment. They face a host of physical, psychological, emotional, social, spiritual and economic effects (24). Although some cancer-related concerns, such as cognitive difficulties and social concerns, tend to decrease with time, some symptoms such as fatigue, aches and pain and sleep difficulty persist, with some cancer survivors experiencing physical or psychological symptoms more than 10 years after treatment completion⁽²⁾.

Identifying and reporting problems is a key skill for effective disease self-management. Needs assessments provide structured opportunities for survivors to voice their needs and can be used to normalise and legitimise reporting of ongoing challenges following treatment. As found in the accompanying literature review, survivors are often under-prepared for what to expect post-treatment, and under-report problems. In this context, needs assessment tools can provide critical health literacy support.

This toolkit is designed to support healthcare professionals working in cancer services to implement needs assessment tools in the post-treatment phase.

Background to the development of the toolkit

The VCSP Phase I (see Acknowledgements) highlighted the need for toolkits to assist in the conceptualisation, development and implementation of future models of survivorship care as well as summaries of the evidence surrounding various topics. The ACSC will develop a suite of resources to support the field. The first two resources have been developed and focus on survivorship care plans and needs assessment tools.

The basis for this toolkit comes from the recommendations from the accompanying ACSC publication Needs Assessment Tools for Post-treatment Cancer Survivors: Literature Review. The review can be found [here](#).

This document can be used to provide practical guidance to assess cancer survivors' needs. The authors acknowledge the complexities and differences between healthcare settings. The toolkit has been developed to provide a practical and relevant guide that can be applied to a variety of settings.

Intended audience

This document is intended to be used by healthcare professionals to develop and deliver needs assessment within a clinical setting.

Aim and intended purpose of needs assessments

Needs assessment tools are designed to systematise the identification of patient needs to allow relevant and appropriate care to be delivered to patients in a timely manner.

A tool can:

- enable healthcare professionals to understand the needs patients would like to be met through professional care at defined points during and after treatment⁽³⁾
- improve communication and the relationship between the patient and provider. This is especially relevant as patients move into the post-treatment survivorship phase and transition from acute care

back to community healthcare settings. Needs assessment is important to ensure that there is a clear pathway in place to address patients' needs during this phase.

Needs assessment tools should be utilised to provide efficient and targeted survivorship care planning for survivors and are an important aspect of the development and delivery of survivorship care plans.

If used systematically, needs assessments can also provide data that can drive service and system level quality improvement initiatives.

Benefits of needs assessment tools

While there is limited research available on the use of needs assessment tools in the clinical setting, information suggests that there is benefit to the patient when these tools are used. A formalised assessment is beneficial as patients may be reluctant to talk about various issues with their doctor, resulting in these issues not being addressed. As reported in the ACSC [*Needs Assessment Tools for Post-treatment Cancer Survivors: Literature Review*](#), randomised clinical trial results demonstrate that a needs assessment tool delivered to cancer patients starting treatment significantly reduced symptom distress and need for symptom management support over time⁽⁴⁾. This provides evidence that the effective implementation of needs assessment can result in positive patient outcomes.

A survivor's experience

My name is Meg Rynderman, I am 65 years old, a wife, mother and grandmother and a volunteer with the Australian Cancer Survivorship Centre and with Cancer Council Victoria's Cancer Connect.

For the past 21 years I have travelled the cancer journey—originating with a diagnosis of Hodgkin's lymphoma, followed by two recurrences.

I have experienced radiotherapy, chemotherapy, stem cell transplant, hormone therapy and surgery; I've been hospitalised and treated for a myriad of related side effects.

The companions of my journey have been a formidable array of chemical compounds with intimidating names, usually accompanied by gloved, gowned and bespectacled attendants.

At the end of 2010 I found a lump in my right breast and rapidly experienced a whole new set of tests and diagnoses confirming hormone-positive breast cancer. A new random cancer occurrence or one related to previous mantle radiotherapy? It doesn't really matter which. My earlier cancers made treatment decisions complicated—radiotherapy was contra-indicated and chemotherapy non-preferred. My doctors and I came up with a treatment plan: bilateral mastectomy and reconstruction followed by hormone therapy. And my luck continued to run — pathology results showed evidence of cancer in both breasts, previous radiotherapy rendered my tissues less elastic than they might have been and promoted the production of fibrotic tissue. The reconstruction process and beyond has proved challenging and I have needed to advocate for myself to find answers and alternatives.

Slowly, I am reclaiming my life. The goal posts have shifted once more—I am changed physically and psychologically, and again I survive.

It is my hope that medical and nursing educators will come to recognise that cancer diagnosis and treatments have far-reaching implications, requiring sensitivity, empathy and understanding often extending well beyond the treatment oncologist and surgeon and will incorporate that recognition into their training of all health professionals. That health professionals will come to accept and acknowledge the differing needs and requirements of each individual patient, focusing on their holistic needs, not just their medical requirements. They will listen to their patients, hearing their concerns, focusing on each person rather than their own professionally accepted idea of practice and outcomes. That GPs will be educated and informed as to the most effective way of dealing with the survivors returned to their care. And most importantly, that cancer will finally be treated as a whole-of-life health issue with survivors supported, not just through the critical stages of diagnosis and treatment, but for the remainder of their lives.

My survivorship is informed by my own survival and my experiences. I am indeed lucky to have been given the opportunity to find my voice as a survivor—and hopefully to use that voice to assist other survivors find theirs and help to change the system to make their ride on the roller coaster a smoother one than mine has been.

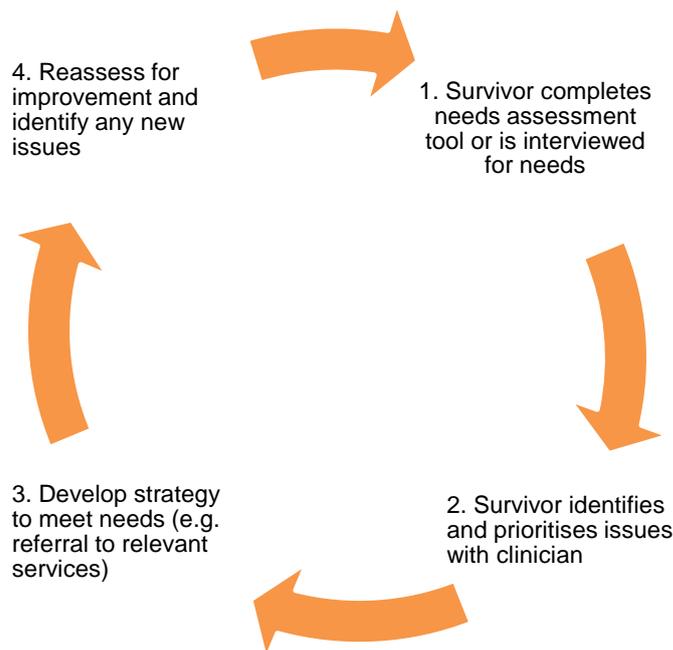
Part II: Delivery and implementation

Introduction

Successful implementation of needs assessment tools into the clinical setting involves developing a sustainable model. Consider resources and infrastructure (including staff time) as well as the anticipated volume of assessment when developing a delivery model to suit your facility.

Figure 1 identifies the four stages of needs assessment screening. It recognises that survivors' needs may change over time. Therefore rescreening is recommended, to both measure improvement and identify new needs.

Figure 1: Four stages of needs assessment screening



A number of international oncology groups have published guidelines on survivorship care. Some of these provide useful background information and recommendations on the implementation of needs assessment and survivorship care programs (see the ACSC [Needs Assessment Tools for Post-treatment Cancer Survivors: Literature Review](#) for more information). Table 1 provides a summary of recommendations about needs assessments drawn from international guidelines. These should form the basis of the implementation process.

Table 1: Recommendations about needs assessment

Consideration	Recommendation	Addition
<p>Preparation prior to needs assessment implementation</p>	<ul style="list-style-type: none"> • Refer to published data to consider common unmet needs of the patient population. Consider starting with a broad measure to ascertain the needs of the population. • Allocate a clinical leader to facilitate implementation of needs assessment implementation. • Allocate the staff responsible for needs assessment (e.g. cancer nurse) and plan for adequate staff training (in needs assessment and communication skills). • Ensure resources and services for referral are available prior to implementation. • Create local procedures and guidelines for needs assessment and how this process fits in with follow-up care. 	
<p>Which needs assessment tool to use</p>	<ul style="list-style-type: none"> • Consider patient demographics and select a needs assessment tool that is suitable. For a mixed cancer survivorship clinic, a general needs assessment tool may be chosen. • Clinic review is required post-assessment to discuss findings and allow the patient to voice any other concerns. 	<ul style="list-style-type: none"> ○ An additional open question may be added to elicit other patient concerns. ○ Supplement with additional needs assessment tool for specific patient groups or needs.
<p>When to assess needs</p>	<ul style="list-style-type: none"> • Assess soon after treatment completion as part of survivorship care planning. • Periodic follow-up may be required during early survivorship (<5 years post-diagnosis) as clinically indicated. • Reassess at times of significant need (e.g. health or social changes). 	
<p>Who should assess needs</p>	<ul style="list-style-type: none"> • When possible encourage patients to self-complete the tool. • All staff implementing needs assessment must be adequately trained in needs assessment. 	

Choosing assessment format	<ul style="list-style-type: none"> • Assess whether paper or electronic assessments is most practical. 	<ul style="list-style-type: none"> ○ Electronic versions of needs assessment tools have additional benefits such as reducing documentation time, electronic data storage, ease of information distribution, rapid assessment and collation of data. ○ Not all tools are available in electronic form, implementation is time consuming and there is limited experience regarding successful implementation.
Use of needs assessment results	<ul style="list-style-type: none"> • Be guided by published evidence and guidelines. • Use the needs assessment to identify when a survivorship care plan is needed. • Communicate survivorship care plans to the patient and relevant team members including the patient's general practitioner. • Aggregated data from needs assessment should be used for service planning. Ideally this should result in survivors reporting fewer unmet needs and/or appropriate allocation of resources. 	
Other	<ul style="list-style-type: none"> • Monitor needs assessment implementation and service usage. • Identify people who may require help or further consideration to complete the tool. 	<ul style="list-style-type: none"> ○ People from CALD backgrounds, with poor literacy and with intellectual and other disabilities may require alternative modes of delivery or assistance.

How do you develop a successful model of delivery?

Developing a successful model to deliver and implement needs assessment tools involves a collaborative effort between various stakeholders. These stakeholders should include relevant organisational heads of departments as well as those who will be responsible for distributing and coordinating needs assessments and follow-up. Consider available resources and infrastructure (including staff time) as well as the volume of needs assessment tools being delivered prior to determining a delivery model which will suit your facility.

The timing of the needs assessment screening is also an important consideration to make. Use the box below as a guide for the implementation process.

When considering the best way to implement a needs assessment model, suggestions include:

- Identify a clinical leader to facilitate the implementation of needs assessment processes.
- Allocate the staff responsible for needs assessment (e.g. cancer nurse) and plan for adequate staff training (in needs assessment and communication skills).
- Ensure resources and services for referral are available prior to implementation.
- Create local guidelines for needs assessment including how this process fits in with follow-up care

Table 2 provides a series of questions that will help inform your model.

Table 2: Questions to consider during model development

Questions
What organisational support is there for needs assessment implementation?
Which key stakeholders need to be considered in the development stage?
Who is the target survivorship group?
What format will the tools be developed in?
How will the plan be stored?
How will the information be communicated?
How will you ensure follow-up of the care plan contents?
Is there awareness of the community support services available to refer patients to, based on the outcomes of the needs assessment?

How should the needs assessment be carried out?

Resources

The most important factor to consider before implementing needs assessment tools in the clinical setting is access to adequate resources. This includes appropriate staff with adequate time to undertake the assessments as well as the additional time required during consultations to follow up on identified needs. Potential resource constraints may impact the type of tool chosen.

Another consideration in the planning stage is ensuring that you have adequate resources to direct and refer survivors to, based on needs identified in the assessment. A review of community supports, services and programs should be included in the planning process.

All relevant parties should be involved in the initial planning stages (including referral services) to ensure that they have adequate resources to manage a potential increase in demand for their services.

Electronic versus paper based

Is paper or electronic assessments more practical for your clinical setting? Electronic needs assessment tools have additional benefits such as reducing documentation time, electronic data storage, ease of information distribution, rapid assessment and collation of data. Paper-based tools may be easier to distribute depending on the patient population.

As further described in the literature review, not all tools are available in electronic format, implementation is time consuming and there is limited experience regarding successful implementation.

Standardisation of tools in the hospital setting

Clinical leaders in a facility should facilitate the process of standardising the document for use in the clinical setting. This process should include a standardised/consistent approach within the organisation/service with clear allocated roles and responsibilities and referral pathways.

Other considerations

During the planning stages, ensure members of your demographic who may require additional assistance or considerations in completing the tool are identified. People from CALD backgrounds, with poor literacy and with intellectual and other incapacities may require alternative modes of delivery or additional assistance in completing needs assessment tools.

Intended audience

Which needs assessment tool to use?

Part III of this document provides more detail on the needs assessment tools validated for use in survivorship care. In the case of a specialised clinic, a more targeted assessment tool may be chosen, whereas for a mixed clinical area, a more generalised assessment form may be chosen. Table 3 outlines a number of considerations regarding which needs assessment tool to use.

Table 3: What needs assessment tool to use?

Consideration	Rationale
What are the demographics of your target audience?	The demographic of your population may require a specific tool (such as Cancer Needs Questionnaire - Young People (CNQ-YP)) to ensure that specific needs are addressed.
Is there a need to supplement with an additional needs assessment tool to address specific patient groups and their needs?	In some cases one tool may not address the unique needs of your patient group. For example, the needs of survivors of bowel cancer may include bowel, urinary and sexual functions. For survivors of cancers of the head and neck region, needs may relate to speech, swallowing, body image, etc. In this case, the use of two tools may be appropriate.
How will clinical review be undertaken post-assessment to discuss findings and allow the patient to voice any other concerns?	The initial planning stages should include a plan/process for how the needs identified through the tools will be addressed.

Consideration	Rationale
Is the tool validated for use with cancer survivors?	A number of needs assessment tools are used in the treatment period but may not have been validated for cancer survivors. Additional tools may be used but the use of at least one tool validated for cancer survivors is recommended.
Is the tool available and validated in other languages? If not, how will this be addressed?	Identification of needs of the CALD population should be taken into consideration. Where possible, the use validated tools in the survivor's native language should be used.

When to assess need

Patients should be given ample time to complete the assessment. In current practice, most needs assessment tools are filled out by the patient in paper format prior to clinic visits. The tool may be posted out to the patient to be completed prior to appointments or completed in clinic.

The timing of needs assessment of your cohort of survivors is also an important factor in the initial planning stages. This may be at their last treatment appointment, first follow-up appointment or even prior to completing treatment.

How often should the needs assessment be carried out?

As stated in the ACSC [Needs Assessment Tools for Post-treatment Cancer Survivors: Literature Review](#), there is a lack of consensus on the frequency of needs assessment. This may be due to a lack of evidence on when it is most useful and relevant to conduct needs assessment. Guidelines recommend assessing unmet need at points of high stress and change in a patient's circumstances. Periodic follow-up may be required during short term survivorship (<5 years post-diagnosis) as clinically indicated. Decisions should take into consideration the set-up of your healthcare service and how follow-up will occur. Low-risk patients are often discharged without plans for follow-up. It is therefore important to develop local protocols.

A schedule should be in place to determine the planned frequency for rescreening. This should include a process for a reminder/recall to ensure that the patient is being followed up as appropriate.

- One way to ensure that rescreening is being undertaken is to link these with scheduled follow-up appointments.
- It is important to rescreen if there is concern or evidence of recurrence/metastatic disease.
- If relevant, rescreening should be linked to and inform the survivorship care planning process.

Who should carry out the needs assessment?

When possible the patient should complete the needs assessment themselves. Considerations should be taken regarding patients from non-English speaking backgrounds (e.g. use of interpreters), with low literacy levels or experiencing other barriers which may prevent them from being able to fill out the tool independently.

Completed tools can be delivered and reviewed by any member of the multidisciplinary team (medical, allied health or nursing staff). In some cases it may be appropriate for the same tool to be delivered by different members of the treating team at different intervals to ensure that the patient is being assessed regularly. A systematic and coordinated approach to assessment should be considered to avoid unnecessary duplication.

All staff undertaking needs assessment must be adequately trained to undertake assessment and make appropriate referrals. Remember the importance of communication: conversation and clarification is key.

Initial training should acknowledge that each individual will have different needs following completion of the tool. A conversation regarding the needs identified, self-management support interventions/information resource or recommended referrals is necessary.

Needs assessment training should include (but is not limited to):

- communication skills
- advanced assessment skills
- effective triage.

What is required after needs assessment?

As identified in the literature review, there is a lack of clarity about who may have responsibility for follow-up of identified needs. While follow-up may occur in either the hospital or community setting (or both) it is important to identify who will be initially responsible for addressing the needs identified and referring on to appropriate services. As identified in the literature, local health providers may not be familiar with or adequately trained in survivorship care. Steps should be taken to identify and overcome these barriers.

Referring

Information gathered from the needs assessment tools should be used to make appropriate referrals to services. Referral pathways will depend on the most appropriate service available for the identified need and the survivor’s preference. As the survivor moves into the post-treatment phase, it is important to recognise that the most appropriate services may be outside of the acute care setting such as community based allied health or primary care services. Consideration should be made regarding what the process is for making these referrals and how to promote take-up of services (see Table 4).

The Institute of Medicine recommends coordination between specialists and primary care practitioners to ensure that all of the survivor’s health needs are met⁽⁵⁾.

Further information about community supports and services that are available can be found in the [Survivorship Care Plans: Toolkit](#).

Table 4: Considerations for referral process

Considerations for referral processes
Who will you be referring to: other staff members at your facility or to outside services such as general practitioners and community based services?
Cost of services
Will records of the referrals be stored in the patient’s file? What will be the process for storing and ensuring referrals are actioned?
If your facility also uses survivorship care plans, will the referrals be separate or included in this plan?
Is there opportunity for the survivor to self-refer to services or for this process to be undertaken by their GP?

Other considerations

Authorising and documentation

Consider how the tools will be filed and how to notify the responsible parties about when/if another assessment will be needed. Also consider the use of medical record numbers and electronic storage.

Identify healthcare providers responsible for authorising the process of follow-up and referrals of the identified needs. There may be scope to develop guidelines and procedures around this. This process may depend upon your organisational structure.

Auditing

Consider regular audit of a sample of all completed needs assessment tools to assess quality assurance, compliance with referral pathways and documentation of patient outcomes.

Analysis of audit data may also identify patterns of need. This may lead to the development of targeted interventions for specific groups or cancer streams and assist in prioritising allocation of resources. This should be considered during the initial planning stages.

Cost-effectiveness

At the time of publication, no cost analysis studies on needs assessment tools in adult cancer survivors had been found. While evidence is limited, the needs assessment tool should ideally be quick to implement and may support early intervention and reduce the need for more resource intensive interventions at a later stage. . It is anticipated that the majority of costs incurred will come from staffing the clinical consultation to follow up the needs identified in the screening process.. The ACSC recommends that your organisation aims to integrate assessment into existing clinical visits to minimise additional cost.

Survivorship care plans

As survivorship care plans should be developed in conjunction with the survivor, needs assessment tools should inform the development of the plan. If the clinical setting currently uses survivorship care plans, the ACSC strongly recommends these plans be informed by the findings of the needs assessment tools.

For more information see the ACSC [*Survivorship Care Plans: Literature Review and Survivorship Care Plans: Toolkit*](#).

Needs assessment of cancer survivors: the Victorian experience

The Victorian Department of Health and Human Services initiated the Victorian Cancer Survivorship Program (VCSP) in 2011 to pilot new models of survivorship care within the health system. The VCSP was established to develop innovative models of follow-up care to address the needs of survivors post-treatment. The program initially funded six pilot projects to test new models of care within the health system. Three of these projects were funded to implement the new model of care in other Victorian cancer services and support sustainability.

Four of the six projects conducted needs assessments to inform care coordination and survivorship care plan development. Screening tools were commonly used to identify supportive care needs and the impact of symptoms, while some projects used needs assessment findings to inform risk stratification⁽¹⁾. Most of the projects acknowledged that needs changed over time and repeat assessment may be required.

Survivorship Program for Patients Completing Definitive Breast Cancer Treatment

This pilot used the Distress Thermometer and Problem List to identify areas of need. The pilot also translated a version of the Distress Thermometer and Problem List into six languages to reflect the demographics of their patient population (non-validated). They also incorporated the Menopause Rating Scale (MRS) and the Functional Assessment of Cancer Therapy – Breast, (FACT-B) to assess specific needs of breast cancer survivors. Psychosocial issues were more commonly reported than physical symptoms. The most common referrals were to peer support, menopause and psychology/mindfulness services.

Barwon South West Survivorship Project: Improving outcomes for survivors of cancer

The Barwon South West Survivorship Project developed a general health assessment tool (non-validated). All participants completed this and the Distress Thermometer and Problem List. Survivors of various cancers participated in this pilot, which included a nurse-led intervention. Problems identified during screening were not reported. Limitations of the Distress Thermometer for a survivor population were noted as it was not tailored to reflect effect of treatment.

Survivorship Connections: A model of youth-friendly survivorship care

This pilot incorporated the Assessment of Quality of Life – 6D for Adolescents (AQoL-6D) and the AYA Survivorship Screening tool. Assessments were repeated at different times through the pilot. Fear of recurrence, uncertainty about fertility status and concerns about general appearance were three of the six most commonly identified concerns at baseline and 3 months.

Moving Forward with Confidence project: Increasing the capacity for self-management in cancer survivors

This pilot used the Distress Thermometer and Problem List to screen for supportive care needs. Survivors of various cancer types participated in this pilot. Assessments were undertaken at baseline and then at 4 months. Fatigue, worry, sadness and difficulty sleeping were the most commonly reported problems at both times.

Part III: Which tool to use?

Introduction

The tool will depend on the demographics of the target group. Depending on your cancer service, one or more tools may be used to assess need in the post-treatment phase. For example the Survivorship Program for Patients Completing Definitive Breast Cancer Treatment (undertaken as part of the VCSP) used a mix of three needs assessment and quality of life tools ⁽¹⁾.

This section provides examples of relevant needs assessment tools. Table 5 gives an overview of the tools.

While the ACSC does not hold licences to the tools listed, further information on how to access these resources can be found on the ACSC website or by contacting the ACSC management team. The ACSC contact information can be found at the beginning of this document.

Quality of life tools are commonly used in the research setting to assess factors that affect patients' quality of life but they do not assess needs. For example, a quality of life tool may assess a patient's level of sadness or physical capability but a needs assessment tool will identify if patient has a need for assistance in that area. Quality of life assessments consist of several domains including physical functioning, psychological wellbeing (such as levels of anxiety and depression) and social support⁽⁶⁾. Quality of life assessments can be used at diagnosis; in predicting prognosis; for assessment, patient monitoring, clinical decision-making and communication; and during treatment⁽⁶⁾.

Further discussion about these tools can be found in the ACSC [Needs Assessment Tools for Post-treatment Cancer Survivors: Literature Review](#). The feasibility of using these tools in a clinical setting is discussed in the review.

The box at the conclusion of this section gives the experience of using needs assessment tools for cancer survivors in Victoria through the VCSP. For more information on the VCSP pilot projects, refer to the [Supporting cancer survivors in Victoria: summary report](#)

Use of needs assessment tools in research versus clinical settings

The tools listed below have all been used in research settings either to validate the tool itself or to assess needs for research studies. There is limited literature describing the application of these tools in a clinical setting. This may not reflect a lack of use in clinical settings, but instead reflect limited research in this setting.

Research settings tend to use needs assessment tools to measure changes in needs as a result of an intervention. This may result in a tool that includes more in-depth questioning than is necessary or practical in a clinical setting. In clinical practice, clinicians are more concerned with identifying things that are of concern to patients and then referring them to services to address these issues. It should be noted when choosing a tool for use in a clinical setting any tool may be appropriate as long as the tool identifies or helps patients to identify needs.

Needs assessment tools for adult cancer survivors

The Survivor Unmet Needs Survey (SUNS)

The Survivors' Unmet Needs Survey (SUNS) is used to provide a direct assessment of unmet needs of cancer survivors. Items for the SUNS were initially generated by cancer survivors and supplemented with needs items identified from the literature. These items were then reviewed by behavioural science expert panels⁽⁷⁾.

The first section of the SUNS has 89 unmet need items that are included in one of the following five domains: emotional health, access and continuity of care, relationships, financial concerns, and information needs. The second section comprises closed ended questions relating to demographic characteristics, disease-related factors and treatment-related factors⁽⁷⁾.

Short Form Survivor Unmet Needs Survey (SF-SUNS)

The Short Form Survivor Unmet Needs Survey (SF-SUNS) is a shortened version of the SUNS and contains 30 items derived from the original 89 items from the SUNS⁽⁸⁾.

Cancer Survivors' Unmet Needs (CaSUN)

The CaSUN was developed and validated in cancer survivors. The CaSUN contains 35 unmet need items, six positive change items and an open-ended question.

Distress Thermometer (DT) with Problem List (PL)

A needs assessment tool is defined as a tool that identifies and measures level of unmet needs in patients. Although the DT does not meet the definition of a needs assessment tool, as it measures overall distress rather than specific needs it is commonly used in cancer patients with the PL and is recommended by the National Comprehensive Cancer Network (NCCN) for cancer patients at all stages of their disease including survivorship⁽⁹⁾.

Patients rate their distress level from a range of 0 (none) to 10 (extreme) in the past 7 days on the DT and tick off the problems on the PL concerning them. The PL places a greater emphasis on physical problems. The NCCN recommends further clinical assessment if the patient shows clinical evidence of moderate-to-severe distress or has a score of 4 or more on the screening tool.

The DT has the advantage of being simple and fast to use and can easily be implemented in clinics. The PL allows patients to tick off what they perceive as problems and acts as prompts in clinic for further review and referrals. Patients who are identified as being highly distressed require additional psychological assessment.

The DT has good sensitivity when considering anxiety and depression as it was validated against the Hospital Anxiety and Depression Scale. The DT may not detect a range of other concerns.

For more information on the use of the Distress Thermometer in clinical practice refer to the ACSC [*Needs Assessment Tools for Post-treatment Cancer Survivors: Literature Review*](#).

Please note that at the time of publication the DT is not validated for use for cancer survivors. It does not include fear of cancer recurrence specifically and some of the physical problems may be more relevant for patients during treatment. It also does not include weight management and a number or wellbeing/lifestyle behaviour fields that are commonly relevant for survivors.

Needs assessment tools for young adult survivors

Cancer Needs Questionnaire – Young People (CNQ-YP)

The CNQ-YP contains items modified to reflect life events applicable to young adults such as education, early employment and supporting young families.

The questionnaire has 70 items and six factors: treatment environment and care (33 items), feelings and relationships (14 items), daily life (12 items), information and activities (5 items), education (3 items), and work (3 items)⁽¹⁰⁾.

Needs assessment tools for survivors of childhood cancer

Childhood Cancer Survivor Study Needs Assessment Questionnaire (CCSS-NAQ)

Survivors of childhood cancers are a group with high needs. While greater than 80% of children who develop a cancer in childhood will survive into adulthood, this population is known to experience higher rates of physical and chronic health conditions than the general public⁽¹¹⁾.

The CCSS-NAQ is the only needs assessment tool developed and validated for adult survivors of childhood cancer. The questionnaire consists of 135 items comprising nine subscales (psycho-emotional, health system concerns, cancer-related health information, general health, survivor care and support, surveillance, coping, fiscal concerns, and relationships)⁽¹²⁾.

Other assessment tools

Supportive Care Needs Survey (SCNS)

The SCNS is often used to assess needs in cancer patients and has also been used to assess needs in cancer survivors. The original version of the SCNS contains 59 items, while the recommended short form SCNS-SF-34 contains five domains with 34 items: psychological (10 items), health system (11 items), physical and daily living (5 items), patient care and support (5 items), and sexuality (3 items). Patients rate needs on a Likert-type scale ranging from 0 (no need) to 5 (high need).

The SCNS-SF-34 takes approximately 10 minutes to complete and has a reading level of Grade 7 to 8.

Table 5: Needs assessment tools for cancer survivors

Tool	Details	Validated for cancer survivors?	Time to complete (approx.)	Reading level
Survivor Unmet Needs Survey (SUNS)	First section 89 tick box questions covering 5 domains Second section closed questions	Yes	24 minutes	Grade 4–6
Short Form Survivor Unmet Needs Survey (SF-SUNS)	A shortened version of the SUNS Contains 30 items derived from the original 89 SUNS items	Yes	Not known	Not known
Cancer Survivors' Unmet Needs (CaSUN)	Contains 35 unmet need items, 6 positive change items and an open-ended question	Yes	10 minutes	Grade 5–6
Distress Thermometer (DT) with Problem List (PL)	Patients rate their distress level from a range of 0 (none) to 10 (extreme) in the past 7 days on the DT and tick off relevant problems on the PL	No	10 minutes	Not known
Cancer Needs Questionnaire – Young People (CNQ-YP)	Has 70 items encompassing 6 domains: treatment environment and care, feelings and relationships, daily life, information and activities, education, and work	Yes, for young people	Not known	Grade 6
Childhood Cancer Survivor Study Needs Assessment Questionnaire (CCSS-NAQ)	Consists of 135 items comprising 9 subscales (psycho-emotional, health system concerns, cancer-related health information, general health, survivor care and support, surveillance, coping, fiscal concerns, and relationships)	Yes, for adult childhood survivors	Not known	Grade 4–5
Supportive Care Needs Survey (SCNS)	Contains 59 items, while the recommended short form SCNS-SF-34 contains 34 items encompassing 5 domains: psychological, health system, physical & daily living, patient care & support, and sexuality	No	10 minutes	Grade 7–8

Specific needs assessment tools

As noted in the ACSC literature review, a number of tools have been developed to assess a particular area of need or be specific to a cancer survivor group. Depending upon the patient population, these tools may be used in assessment alongside other validated tools.

Distress

The Brief Symptom Inventory-18 (BSI-18) consists of 18 descriptions of physical and emotional complaints; respondents are asked to indicate on a scale from 0 (*not at all*) through 4 (*very much*) to what extent they are troubled by the complaints⁽¹³⁾.

The CancerSupportSourceSM web-based tool (CSS-25) was designed to target seven key areas of psychosocial needs identified in the Institute of Medicine report (*From Cancer Patient to Cancer Survivor: Lost in Transition*) and integrates a 25-item self-report measure with automated links to information and referral for support services. Patients are asked to complete CSS at baseline and are rescreened at 30–45 days. Participants rate their current concerns and identify specific types of assistance they desire for each concern (e.g. talk to a staff member, online resources, print information). CSS is web-based and can be completed in the clinic or at home. Reports are generated in real time for both patients and clinicians, allowing for efficient follow-up and referral. A personal support care plan based on the patient's responses to CSS is printed and/or given to the patient. For the healthcare team, a distress management report for each patient is automatically generated⁽¹⁴⁾.

The Distress Screener is a 36-item questionnaire. Patients are asked to rate each of the 36 problems according to 'how much of a problem is this for you?' on a five-point scale. In addition, patients are asked for each item if they are requesting to 'talk with a member of the team', have the team 'provide written information', or 'nothing needed at this time'⁽¹⁵⁾.

Depression and Anxiety

The Edinburgh Depression Scale (EDS) and the Hospital Anxiety and Depression Scale (HADS) have both been used to address depression and anxiety in cancer survivors.

The EDS is a 10-item self-report questionnaire. Each question has four possible answers and the result is determined by the total score⁽¹⁶⁾.

The Hospital Anxiety and Depression Scale (HADS) is a 14-item scale that generates ordinal data. Seven of the items relate to anxiety and seven relate to depression⁽¹⁷⁾.

As noted in the ACSC [Needs Assessment Tools for Post-treatment Cancer Survivors: Literature Review](#), the HADS has often been used as a comparator when assessing psychological properties of cancer survivor needs and distress assessment tools.

Fatigue

Fatigue is a common symptom for cancer patients and survivors. It can be a distressing and debilitating effect of cancer and can seriously impact on a person's wellbeing. As per the [Needs Assessment Tools for Post-treatment Cancer Survivors: Literature Review](#), the Piper Fatigue Scale, the Multidimensional Fatigue Inventory and the Modified Brief Fatigue Inventory have been tested in some cancer survivors.

The Piper Fatigue Scale is a 22-item scale that measures four subscales: behaviour (6 items), affect (5 items), sensory (5 items), and cognition/mood (6 items). Each item has 11 response categories on a 0 to 10 metric with verbal descriptors anchoring the endpoints. Each subscale is scored individually and then aggregated together for an overall score, with higher scores reflecting more fatigue⁽¹⁸⁾.

The Multidimensional Fatigue Inventory (MFI) is a self-report questionnaire that assesses the impact of fatigue and comprises five dimensions: general fatigue, physical fatigue, mental fatigue, reduced motivation and reduced activity. Each subscale contains four items, with two items formulated in a positive direction (e.g. 'I feel fit') and two formulated in a negative direction (e.g. 'I feel fatigued')⁽¹⁹⁾.

Other

Other tools found in the literature search included assessment of insomnia, neuropathic pain, post-traumatic stress disorder, fear of recurrence, information needs, neurocognitive impairment, ability to work, physical activity and fertility. Depending on your cancer service the use of these additional tools may be appropriate.

Appendix A: Needs assessment of cancer survivors - the Victorian experience

The Victorian Department of Health and Human Services initiated the Victorian Cancer Survivorship Program (VCSP) in 2011 to pilot new models of survivorship care within the health system. The VCSP was established to develop innovative models of follow-up care to address the needs of survivors post-treatment. The program initially funded six pilot projects to test new models of care within the health system. Three of these projects were funded to implement the new model of care in other Victorian cancer services and support sustainability.

Four of the six projects conducted needs assessments to inform care coordination and survivorship care plan development. Screening tools were commonly used to identify supportive care needs and the impact of symptoms, while some projects used needs assessment findings to inform risk stratification⁽¹⁾. Most of the projects acknowledged that needs changed over time and repeat assessment may be required.

Survivorship Program for Patients Completing Definitive Breast Cancer Treatment

This pilot used the Distress Thermometer and Problem List to identify areas of need. The pilot also translated a version of the Distress Thermometer and Problem List into six languages to reflect the demographics of their patient population (non-validated). They also incorporated the Menopause Rating Scale (MRS) and the Functional Assessment of Cancer Therapy – Breast, (FACT-B) to assess specific needs of breast cancer survivors. Psychosocial issues were more commonly reported than physical symptoms. The most common referrals were to peer support, menopause and psychology/mindfulness services.

Barwon South West Survivorship Project: Improving outcomes for survivors of cancer

The Barwon South West Survivorship Project developed a general health assessment tool (non-validated). All participants completed this and the Distress Thermometer and Problem List. Survivors of various cancers participated in this pilot, which included a nurse-led intervention. Problems identified during screening were not reported. Limitations of the Distress Thermometer for a survivor population were noted as it was not tailored to reflect effect of treatment.

Survivorship Connections: A model of youth-friendly survivorship care

This pilot incorporated the Assessment of Quality of Life – 6D for Adolescents (AQoL-6D) and the AYA Survivorship Screening tool. Assessments were repeated at different times through the pilot. Fear of recurrence, uncertainty about fertility status and concerns about general appearance were three of the six most commonly identified concerns at baseline and 3 months.

Moving Forward with Confidence project: Increasing the capacity for self-management in cancer survivors

This pilot used the Distress Thermometer and Problem List to screen for supportive care needs. Survivors of various cancer types participated in this pilot. Assessments were undertaken at baseline and then at 4 months. Fatigue, worry, sadness and difficulty sleeping were the most commonly reported problems at both times.

Glossary

Cancer survivor

The US National Comprehensive Cancer Network defines a 'cancer survivor' as someone 'who has been diagnosed with cancer, from the time of diagnosis throughout his or her life. The impact of cancer on family members, friends, and caregivers of survivors is also acknowledged as part of survivorship'⁽²⁰⁾. In Australia, 'cancer survivor' 'is generally used to refer to people who have completed initial cancer treatments, who are apparently free from cancer. As this definition does not implicitly include family and caregivers, we should be mindful of the effect of cancer on those other than the person immediately affected'⁽²¹⁾.

Cancer survivorship

Survivorship encompasses the health and life of a person with cancer post-treatment until the end of life. It covers the physical, psychosocial, and economic issues of cancer from diagnosis and beyond treatment. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers and quality of life⁽²²⁾.

Needs assessment tools

A collection of questions, scales and other means of obtaining information that, together, provide a consistent and comprehensive system through which patients' range of needs for support and care can be explored⁽²³⁾.

Patient needs assessment

Needs assessment measures are (standardised) tools that allow for the identification of the areas for which patients perceive they require additional assistance. Such information allows for appropriate care to be developed and delivered to cancer patients in a timely manner.

Survivorship care

The US Institute of Medicine report *From Cancer Patient to Cancer Survivor: Lost in Transition* recommends that post-treatment care for cancer survivors include four components: prevention and detection of new cancers and recurrent cancer; surveillance for cancer spread, recurrence, or second cancers; intervention for consequences of cancer and its treatment; and coordination between specialists and primary care practitioners to ensure that all of the survivor's health needs are met⁽²⁴⁾.

Unmet needs

Unmet supportive care needs in cancer survivors have been defined as 'those needs which lack the level of service or support an individual perceives is necessary to achieve optimal wellbeing'⁽²⁵⁾. Some survivors report unmet needs including problems with physical health and activities of daily life, financial, relationship and emotional problems and information and communication needs.

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