Needs Assessment Tools for Post-treatment Cancer Survivors: Literature Review

January 2016
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Acknowledgements

The Australian Cancer Survivorship Centre – a Richard Pratt Legacy (ACSC) was established in 2009 with funding from The Pratt Foundation, the Victorian Department of Health and Human Services and the Peter MacCallum Cancer Centre (Peter Mac). The centre is located at Peter Mac and provides expertise in survivorship care, information, support and education. Our purpose is to provide optimal survivorship care both at Peter Mac and beyond which translates to improved health and wellbeing of cancer survivors and their carers.

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 needs assessment literature review and toolkit are considered important resources for the VCSP and health services nationally with an interest in survivorship care. More information on the toolkit can be found here.

The needs assessment literature review report has been reviewed by the Health Behaviour Research Group, School of Medicine and Public Health at the University of Newcastle, New South Wales. The ACSC would like to thank Dr Alix Hall for her valuable contribution to this report.

The report 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 report 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 report:

- Michael Cooney – Oncology Nurse Practitioner, The Northern Hospital
- Bogda Koczwara AM – Professor of Medical Oncology, Flinders University and NHMRC Translating Research into Practice Fellow, Department of Medical Oncology, Flinders Medical Centre.

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 literature review rests entirely with the ACSC.

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

Recommended citation:


January 2016
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.
Summary

Background

Needs assessment measures are standardised tools that allow for the systematic 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. As the number of cancer survivors increases, it is imperative that our healthcare system addresses the unique and specific needs of this population. This requires cancer-survivor–specific needs assessment tools that are comprehensive, valid and reliable. However, no review has specifically focused on needs assessment tools for cancer survivors. This literature review has aimed to identify needs assessment tools for cancer survivors, specifically the clinical utility of such tools. This review has been developed with an accompanying toolkit to assist with the implementation and delivery of needs assessment tools in organisations. The toolkit can be found [here](#).

Methods

Electronic databases including Medline Ovid, Cochrane, CINAHL and PsychInfo were searched using relevant subject headings and key words. Papers that met the inclusion criteria were included and were screened by two reviewers for eligibility. The grey literature—including forums, key journals, guidelines and recommendations from international cancer groups—was also searched.

Results

Nine comprehensive needs assessment tools specific to cancer survivors were identified. The Distress Thermometer and Problem List was included as one of the six tools reviewed, as it is commonly used to identify the needs of cancer survivors and has undergone some validation testing with cancer survivors. Most of the measures had undergone some form of psychometric assessment; however the extent and psychometric rigour of the measures was highly variable. Few of the measures identified had been evaluated for use in a clinical environment.

Conclusion

There is little empirical evidence to guide recommendations on the most appropriate process of conducting routine needs assessment with cancer survivors. Presently, healthcare providers should select a needs assessment tool based on the relevance of the scale to their specific patient population and consider the psychometric rigour and practicality of the measure. In terms of how, when and by whom needs assessments should be done, more research is required to evaluate the most effective and appropriate process before any firm recommendations can be made. At present, healthcare providers should be guided by current recommendations outlined in consensus guidelines.
Part I: Needs assessment tools literature review

Introduction

In many parts of the world, particularly in developed countries, the numbers of people surviving cancer are increasing. This is a consequence of early diagnosis and improved cancer treatments and follow-up care. The National Cancer Institute (NCI) report for 2009 estimated 12.6 million survivors in the United States alone\(^1\).

In Australia, relative 5-year survival rates increased from 47% in 1982–6 to around 66% in 2006–10 for all cancers combined\(^2\). The World Health Organization World Cancer Report estimated that approximately 25 million people were alive in 2008 with a prior diagnosis of cancer, and that this figure would increase to 75 million cancer survivors within 5 years of diagnosis by 2030\(^3\). As a consequence of people living longer after a cancer diagnosis, the focus of care has been extending well beyond treatment; this is particularly the case in developed countries.

An individual is considered a cancer survivor from the time of diagnosis for the remainder of his or her life. Family members, friends and caregivers are also impacted by the survivorship experience\(^4\). For the purpose of this literature review, survivorship will focus on the post-treatment phase.

Cancer survivors across a number of cancer types and age groups have been found to experience poorer health and social outcomes than regular patients in the same age group\(^5\). 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; some cancer survivors experience physical or psychological symptoms more than 10 years after treatment completion\(^6\).

Unmet needs are the physical, emotional, psychological, spiritual, informational, social and practical concerns experienced by cancer patients for which they require additional assistance\(^7\). Supportive care services may improve a patient’s quality of life. Such services may include social, medical or psychological support through information, counselling, treatment or referrals. Patient needs may continue throughout short- and long-term survivorship\(^8\).

Patients may encounter new challenges and problems as they transition to life beyond cancer treatment. They no longer have frequent visits to hospital and regular access to allied health and specialist care. Their care is often transferred to a primary care practitioner who may not be trained in or familiar with cancer survivorship care. Patients have noted inadequate care for psychosocial late effects such as anxiety, depression and body image issues, and physical late effects such as fatigue, pain, sexual issues and cognitive dysfunction\(^9\). Prevalence of unmet need in cross-sectional studies of survivors has ranged from 30% to 50%\(^10\). Greater unmet needs have been linked to certain patient characteristics including younger or older age, ethnicity, more intense treatment, cancer type, poor quality of life, low income, anxiety and depression\(^10\)-\(^14\).

Optimal patient-centred care requires services that are relevant and appropriate to patients’ specific concerns. Needs assessment tools are designed to identify patient concerns, to allow for relevant, appropriate and timely care. A formalised assessment is beneficial as patients may be reluctant to talk about distress or social problems with their doctor, resulting in these issues not being raised during appointments\(^15\). Health professionals may not readily recognise these needs \(^16\). In addition, there may be differences between what health professionals perceive to be important compared to what patients perceive as important\(^17\). A standardised tool can improve communication and the relationship between the patient and provider\(^18\). Data collected from needs assessment tools can also be used to direct appropriate resources and plan support programs.
Previous reviews on needs assessment tools in cancer patients have found a lack of feasibility data and validation in routine care. Available research has been centred on the application of tools in a research setting rather than a clinical setting. However, one notable randomised clinical trial by Ruland et al. (2010) on the effect of interactive tailored patient assessments (ITPAs) in patients starting treatment for leukaemia or lymphoma found significant effects on patient outcomes. Patients who had their ITPA provided to physicians and nurses had a significant reduction in symptom distress and need for symptom management support over time. This provides evidence that effective needs assessment can result in positive patient outcomes.

Further data on needs assessment tool implementation, effectiveness and outcome in clinical practice are essential to support and guide practice.

**Aim of literature review**

This review aimed to: (1) identify comprehensive needs assessment tools that have been assessed for use with cancer survivors and report on the quality of evidence; and (2) provide recommendations on what tool/s might be useful in the routine care of cancer survivors.

**Data extraction and analysis**

**Search strategy**

The electronic databases Medline Ovid, Cochrane, CINAHL and PsychInfo were searched (search strategy for Medline shown in Table 1). The search strategy used for each database was adapted for the specifications of each individual database. Grey literature was screened for relevant papers. These included forums, guidelines and recommendations from international cancer groups. The reference lists of key journals were scanned for additional papers.

**Table 1: Search strategy used for Medline**

<table>
<thead>
<tr>
<th>Search strategy</th>
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<tbody>
<tr>
<td>1. Exp Neoplasms</td>
<td>2. Exp Survivors</td>
</tr>
<tr>
<td>3. 1 AND 2</td>
<td>4. Post treatment.mp.</td>
</tr>
<tr>
<td>5. 1 AND 4</td>
<td>6. Cancer survivor$.mp.</td>
</tr>
<tr>
<td>7. 3 OR 5 or 6</td>
<td>8. Exp Needs Assessment’</td>
</tr>
<tr>
<td>15. 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14</td>
<td>16. 7 AND 15</td>
</tr>
<tr>
<td>17. Limit 16 to (English language)</td>
<td></td>
</tr>
</tbody>
</table>

* Search strategy adapted for the specifications of the different databases.

Subject headings and key words for ‘cancer survivors’ were searched together with the subject heading and key words for ‘needs assessment tools’. We took care not to restrict the number of results by using the linking term OR to expand the search. The results were limited to papers published in the English language. The title or abstract of all results from the search were scanned to identify relevant papers. Full
papers were retrieved to identify the papers to be analysed in this review. Two reviewers assessed whether these papers met the inclusion criteria (included papers listed in Table 3). The quality of the evidence available on the needs assessment tools were analysed. We looked at psychometric properties including reliability and validity, responsiveness to the common needs of cancer survivors and acceptability. We also noted if it had been tested in both short-term (<5 years post-diagnosis) and long-term survivors.

Search terms
Subject headings and key words were identified through previous literature searches and the indexing of key papers in electronic databases.


Inclusion/exclusion criteria
Inclusion criteria:
- Needs assessment tools used for cancer survivors.

Exclusion criteria:
- Needs assessment tools for end-of-life care
- Needs assessment tools for children or carers
- Needs assessment tools measuring a specific measure (e.g. fatigue, depression)
- Needs assessment tools designed to measure needs for a specific cancer type
- Needs assessment tools designed for cancer patients currently receiving treatment.

‘Needs assessment tool’ was defined as a tool that identifies and measures level of unmet needs in patients. Although the Distress Thermometer and Problem List does not meet this definition, it was included in the search as it is commonly used for needs assessment of cancer survivors in clinical practice and is recommended by the National Comprehensive Cancer Network (NCCN) for use with cancer patients at all stages of their disease, including survivorship. The sensitivity and specificity of this measure has also been assessed in survivor populations, which provide a particular measure of psychometric rigour relevant to the visual analogue structure of the Distress Thermometer. These results are summarised in Table 5.

Search limitations
When interpreting the results of this review, a number of limitations should be considered. First, this was not a systematic review. As a result, it is possible that a number of relevant studies were omitted from this review. Second, there is no commonly accepted definition of cancer survivor, with a number of different definitions recognised in the research and clinical area of cancer care. Consequently, our decision to define a ‘cancer survivor’ as someone who has completed treatment may have missed some relevant needs assessment tools used for cancer survivors who are defined differently.

Furthermore, we did not include the search term ‘cancer survivor care plan’. Descriptive papers on cancer survivor care plans may have included detail on the implementation of a specific needs assessment tool and potentially effects on patient outcome.

Analysis
The following four areas were assessed for those tools that had been psychometrically evaluated in a cancer survivor population.
1. Characteristics of how the tool was evaluated: for example, the cancer types included in development, and the stage of survivorship of the study sample.

2. Psychometric properties: the appraisal criteria was adapted from Smith et al. (2005) and Pearce et al. (2008) and is outlined in Table 2. The rating guide from Smith et al. (2005) was used for Table 6: weak evidence for each measure was defined as limited evidence in favour of the tool; adequate evidence was defined as some acceptable evidence in favour of the tool but failing some criteria or was not reported; good evidence was defined as acceptable evidence in favour of the tool.

3. Domains assessed: the comprehensiveness of each tool was assessed by evaluating whether or not each tool assessed the following seven areas of need: physical, emotional, lifestyle or information, practical, family/relationships, sexual and cognition.

4. Implementation in clinical care: whether the implementation of each tool in the clinical setting had been assessed was also reviewed.

Table 2: Psychometric analysis

<table>
<thead>
<tr>
<th>Measure</th>
<th>Definition</th>
<th>Examples</th>
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<tr>
<td>Validity</td>
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<tr>
<td>Content validity</td>
<td>Extent the tool measures what it is meant to measure</td>
<td>Qualitative evidence such as literature review, peer review, patient feedback, pilot study</td>
</tr>
<tr>
<td>Construct validity</td>
<td>Degree to which the tool measures the characteristic being investigated</td>
<td>Factor analysis Ability to detect known group differences (discriminant validity)</td>
</tr>
<tr>
<td>Convergent validity</td>
<td>Correlation with a tool that assesses a construct known to be related to unmet needs (e.g. anxiety and depression)</td>
<td>Measured by moderate correlation coefficient ≥0.4</td>
</tr>
<tr>
<td>Reliability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal consistency</td>
<td>Scale items are homogenous and measure a single underlying construct</td>
<td>Measured by Cronbach’s alpha ≥70 (total score and subscale scores). Item-total correlations r ≥0.20</td>
</tr>
<tr>
<td>Reproducibility</td>
<td>Measure of stability of tool over time</td>
<td>Test–retest reliability with acceptable retest timeframe usually between 2 and 14 days. Measured by a correlation coefficient, either interclass correlation coefficient (ICC) &gt;0.75 or Pearson’s correlations coefficient &gt;0.70, or kappa index of agreement &gt;0.60</td>
</tr>
<tr>
<td>Responsiveness</td>
<td>Ability to detect changes of importance to patients and detects clinically meaningful change</td>
<td>Longitudinal data. Floor and ceiling effects&lt;10%</td>
</tr>
<tr>
<td>Acceptability/feasibility</td>
<td>Measure of how acceptable the tool is for the patient to complete</td>
<td>Measured by time to complete, reading level, proportion of missing scores &lt;5%. Patient feedback</td>
</tr>
<tr>
<td>Cross-cultural reliability</td>
<td>Appropriateness of tool for different cultural populations</td>
<td>Psychometric testing of tool in different cultural populations</td>
</tr>
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</table>
Results

Result of literature search

As shown in Figure 1, 1407 articles were identified from the database search, of which 276 abstracts were inspected, 40 full-text articles were assessed and 16 relevant papers were identified. A significant proportion of the results assessed quality of life (QoL) tools and tools assessing a specific need (e.g. fatigue) and were not included in this analysis. A fair number of papers assessed needs in groups of cancer survivors but did not provide information on the validity, reliability, implementation or impact of the needs assessment tool. The majority of the research was conducted in a research setting, not a clinical setting. There were no clinical trials that examined the impact of needs screening in the post-treatment phase and minimal literature reviews. Table 3 details the papers that met the inclusion criteria.

Review of the grey literature revealed broad guidance on the implementation of survivorship care but did not specify needs assessment tools.

Nine needs assessment tools were identified in the literature (see Figure 1). Six of these tools had been validated in cancer survivors. The Distress Thermometer (DT), although a specific tool for measuring distress, was included in the analysis as it is often used with the Problem List (PL) to assess needs in cancer survivors and furthermore the sensitivity and specificity of the DT has been assessed in survivor populations, which is an indication of particular psychometric properties relevant to this type of scale (see also Table 5).

Figure 1: Search results
Table 3: Studies meeting inclusion criteria

<table>
<thead>
<tr>
<th>Study (identified by principal author)</th>
<th>Publication</th>
<th>Level of evidence*</th>
<th>Sample and setting</th>
<th>Methods</th>
<th>Results</th>
<th>Conclusion</th>
</tr>
</thead>
</table>
| Campbell (2010) | Cross-sectional study | IV | A stratified random sample of 550 cancer survivors, selected from a population-based cancer registry to complete the survey | • The Survivor Unmet Needs Survey (SUNS) was developed from a comprehensive literature review, qualitative analysis, review by survivors and experts, cognitive interviews and a pilot test of 100 survivors  
• Cancer survivors were mailed the survey to establish reliability and validity | • The final 89-item SUNS has high acceptability, item test–retest reliability and internal consistency, face, content and construct validity | • The SUNS has strong psychometric properties. |
| Hall (2014) | Cross-sectional study | IV | 529 haematological cancer survivors aged 18–80 years recruited from 4 Australian cancer registers | • The relevance, content and face validity of the SUNS to haematological cancer survivors was assessed using qualitative interviews  
• Haematological cancer survivors were sent the SUNS and the results assessed | • Exploratory factor analysis supported the original five-factor structure of the SUNS.  
• Evidence for convergent validity was established using the Depression Anxiety and Stress Scale (DASS-21).  
• Good internal consistency | • The SUNS demonstrates evidence for multiple features of validity and reliability. However, there was poor discriminant validity and significant floor effects. |
<table>
<thead>
<tr>
<th>Study (identified by principal author)</th>
<th>Publication</th>
<th>Level of evidence*</th>
<th>Sample and setting</th>
<th>Methods</th>
<th>Results</th>
<th>Conclusion</th>
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</table>
| **Campbell (2014)**<sup>(25)</sup>   | Cross-sectional study | IV                 | A heterogeneous sample of 1589 cancer survivors, aged 19 years or over at diagnosis, diagnosed with cancer in the previous 12 to 60 months, completed the SUNS | • A combined theoretical and statistical method of reducing the number of items in the SUNS was used  
• The shortened survey was examined for construct validity, internal consistency, discriminant validity and floor and ceiling effects | • 59 items removed from the original SUNS  
• Construct validity closely reflected the original structure of the SUNS  
• Good internal consistency | Future studies should confirm the test–retest reliability and predictive validity of the Short Form Survivor Unmet Needs Survey (SF-SUNS) utilising large, independent, population-based samples of cancer survivors. |
| **Hodgkinson (2007)**<sup>(26)</sup> | Cross-sectional study | IV                 | 353 cancer survivors recruited from 2 hospital outpatient clinics (breast and mixed cancer) | • Questionnaire items generated based upon previous qualitative research  
• Psychometric properties of the Cancer Survivors Unmet Needs (CaSUN) assessed and modified | • CaSUN included 35 unmet need items, 6 positive change items and an open-ended question | Good acceptability, internal consistency and validity were demonstrated, although test–retest reliability was low. |
| **Clinton-Mcharg (2012)**<sup>(27)</sup> | Cohort study | IV                 | 139 adolescent and young adult (AYA) cancer patients and survivors recruited through 7 treatment centres | • Items generated from literature, focus group with AYA survivors and professional feedback  
• Pilot in 32 AYA survivors  
• Survey mailed to | • The final survey had 6 domains and 70 items  
• The Cancer Needs Questionnaire Young People (CNQ-YP) has established face and content validity, and | The small sample size has implications for the reliability of the statistical analysis undertaken.  
Future large longitudinal studies are |
<table>
<thead>
<tr>
<th>Study (identified by principal author)</th>
<th>Publication</th>
<th>Level of evidence*</th>
<th>Sample and setting</th>
<th>Methods</th>
<th>Results</th>
<th>Conclusion</th>
</tr>
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<tr>
<td><strong>Cox (2013)</strong>(28)</td>
<td>Cross-sectional study</td>
<td>IV</td>
<td>1178 randomly selected stratified Childhood Cancer Survivor Study participants. Minorities and rural residents were oversampled at a 2:1 ratio</td>
<td>patients&lt;br&gt;- Exploratory factor analysis performed and measure assessed for internal consistency, discriminative validity, potential responsiveness and acceptability. Test-retest reliability was tested</td>
<td>acceptability</td>
<td>recommended.</td>
</tr>
<tr>
<td><strong>Taylor (2012)</strong>(29)</td>
<td>Descriptive study</td>
<td>—</td>
<td>18 colorectal cancer (CRC) survivors at low risk of cancer recurrence attending a new nurse-led</td>
<td>CRC clinical nurse specialists (CNS) introduced holistic needs assessment</td>
<td>Patients’ concerns often interrelated&lt;br&gt;CNS picked up concerns not stated on</td>
<td>Good communication skills are important for needs assessment.&lt;br&gt;Patients may be more...</td>
</tr>
<tr>
<td>Study (identified by principal author)</td>
<td>Publication</td>
<td>Level of evidence*</td>
<td>Sample and setting</td>
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<tr>
<td>Schlairet (2010)&lt;sup&gt;(30)&lt;/sup&gt;</td>
<td>Cross-sectional study</td>
<td>IV</td>
<td>307 adult cancer survivors receiving care in a community cancer centre</td>
<td>- Voluntary completion of a modified Pearlman-Mayo Clinic survey of the HNA tool</td>
<td>- Patients who had recently completed treatment expressed a higher level of concerns</td>
<td>- Survey data can help to direct survivorship program development.</td>
</tr>
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</table>

- Modified Concerns Checklist completed prior to clinic
- Patient needs assessed and appropriate information and support provided
- Referrals and appointments provided as necessary
- Clinic letter summarising the assessment process sent to patient and general practitioner (GP)
- Once patient needs were addressed, discharged from CRC service and provided with CNS helpline
<table>
<thead>
<tr>
<th>Study (identified by principal author)</th>
<th>Publication</th>
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<th>Conclusion</th>
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</table>
| Vickers (2010) (31) | Pilot study | — | Prostate cancer survivors asked to register for the electronic patient Self-Assessment and Management (SAM) system. Number of participants not provided | • Emails at regular intervals to complete online questionnaires  
• Responses analysed to provide real time online information about progress and tailored medical advice  
• Patient data uploaded to healthcare provider clinic notes | • Complete SAM system yet to be implemented and evaluated for usability and effectiveness | • Information technology may improve transfer of information between patient and healthcare provider.  
• This may result in better understanding of patient progress and patient care based on best practice. |
<p>| MacMillan Cancer Support | Pilot study | — | 6-month trial of an Electronic Holistic Needs Assessment (e-HNA) tool | • Assess impact of eHNA on assessment and care planning | • Greater number of assessments and care plans completed | • Benefits are shown with eHNA. |</p>
<table>
<thead>
<tr>
<th>Study (identified by principal author)</th>
<th>Publication</th>
<th>Level of evidence*</th>
<th>Sample and setting</th>
<th>Methods</th>
<th>Results</th>
<th>Conclusion</th>
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<tr>
<td>(National Cancer Survivor Initiative) (2012)(^{(32)})</td>
<td></td>
<td></td>
<td>at 4 sites Number of participants not provided</td>
<td>care planning • Interviews with patient and staff to evaluate implementation of tool at the different sites</td>
<td>compared to paper version • Some technological difficulties largely related to wi-fi access • Some patients required talk-through • Patients and staff found eHNA useful and effective • Potential to aggregate data • Strong local leadership important</td>
<td>Further evaluation is required.</td>
</tr>
<tr>
<td>Shewbridge (2014)(^{(33)})</td>
<td>Pilot study — 124 early breast cancer survivors attending a nurse-led post-treatment consultation clinic</td>
<td></td>
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<td>The clinic was staffed with experienced breast cancer nurses who had completed advanced assessment and communication skills training • Patients sent a self-assessment form to complete prior to clinic • Later in project an eHNA was used in clinic</td>
<td>Partnership between the clinical team and patients was required to establish the new service • The clinic did not dramatically increase referral to services • Time was required to develop the structure of the consultation and gain experience in delivering the</td>
<td>Consultation is a good time to provide contact details for advice and support. • HNA identified core needs for patient group. • eHNA significantly reduced time to complete documentation after clinic.</td>
</tr>
<tr>
<td>Study (identified by principal author)</td>
<td>Publication</td>
<td>Level of evidence*</td>
<td>Sample and setting</td>
<td>Methods</td>
<td>Results</td>
<td>Conclusion</td>
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<tr>
<td>Wilkinson (2010)</td>
<td>Pilot study</td>
<td>—</td>
<td>11 test sites tested assessment and care planning (ACP) and treatment record summaries at the end of initial treatment over a 6-month period. 10/11 sites used the DT/PL. 213 patients assessed. 128 people interviewed including doctors, nurses, project managers, administrative staff, patients and carers.</td>
<td>• 45 minutes consultation included review and discussion of concerns identified in HNA. • Treatment summary and care plan provided to patient and GP. • Information and/or referrals provided where appropriate.</td>
<td>intervention succinctly</td>
<td>• Adequate training and support and capacity planning is necessary prior to establishing a ACP service. • Patients need to have greater control over the process and have access to self-assessment tools at any point in the care pathway.</td>
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</table>

*Level of evidence: Pilot study
<table>
<thead>
<tr>
<th>Study (identified by principal author)</th>
<th>Publication</th>
<th>Level of evidence*</th>
<th>Sample and setting</th>
<th>Methods</th>
<th>Results</th>
<th>Conclusion</th>
</tr>
</thead>
</table>
| Roerink (2013) [35] | Cross-sectional study | IV | 145 survivors of differentiated non-medullary thyroid carcinoma (DTC) under follow-up at the outpatient clinic of a university hospital | Patients asked to fill out DT, PL, Hospital Anxiety and Depression Scale (HADS), illness cognition questionnaire and an ad hoc questionnaire  
- Respondents were asked to indicate whether they would like to be referred to a professional for | There was a significant correlation between DT scores and the total number of reported problems on the PL ($r = 0.827; p < 0.001$)  
There was a significant correlation between the DT score and the wish for referral for additional support ($r = 0.193, p = 0.025$) | DT and PL are useful screening instruments for distress in DTC patients and could easily be incorporated into daily practice.  
A high DT score does not always correlate with patient referral. Problems may be resolved without referral (e.g. |
<table>
<thead>
<tr>
<th>Study (identified by principal author)</th>
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<th>Sample and setting</th>
<th>Methods</th>
<th>Results</th>
<th>Conclusion</th>
</tr>
</thead>
</table>
| Doyle (2014) *(36)*                  | Review      | —                  | —                  | —       | —       | • HNA should explore and discover the person’s perceptions of their own needs  
• Tools are essential to keep focus on actual needs of patient  
• Caution in over-reliance on tools  
• Needs assessment should be undertaken during changes in patient needs, at times judged appropriate by the healthcare professional and at the patient’s request  
• HNA is an important part of cancer survivorship and assists in patient-centred care. |
| Lavoie Smith (2012) *(37)*          | Pilot cross-sectional study | IV                  | 547 cancer patients recruited from a breast cancer registry, a cancer centre, 9 community-based clinics serving urban and rural populations, and 3 cancer websites over 3 months | • Participants completed a web-based cancer survivor needs assessment survey  
• Some respondents required assistance from study staff because of a lack of computer access/skill (n = 15)  
• Survivor sample lacked adequate representation of patients with less | Web-based technology can facilitate future exploration of unmet needs.  
• It can be used to identify gaps in care, as well as which resources survivors are likely to utilise. |
<table>
<thead>
<tr>
<th>Study (identified by principal author)</th>
<th>Publication</th>
<th>Level of evidence*</th>
<th>Sample and setting</th>
<th>Methods</th>
<th>Results</th>
<th>Conclusion</th>
</tr>
</thead>
</table>
| Gates (2012) (38)                       | Pilot study | —                  | • Specialist cancer nurse-led health-promoting intervention  
• 30 patients recruited from referral lists to the haematology late effects clinic | • Intervention was led by advanced practice nurses (APN)  
• The Late Effects Supportive Care Needs Screening Tool was completed by patients | • Patients valued the opportunity to complete the needs assessment tool as it allowed discussion of their emotional needs  
• Patients felt | • Direct data entry can minimise the risk of data entry errors and missing data. |

- Direct data entry can minimise the risk of data entry errors and missing data.
<table>
<thead>
<tr>
<th>Study (identified by principal author)</th>
<th>Publication</th>
<th>Level of evidence*</th>
<th>Sample and setting</th>
<th>Methods</th>
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<th>Conclusion</th>
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<td>prior to clinic</td>
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<td></td>
<td>• Tool was used to measure the patient’s communication and understanding, physical health, emotional health, activities of daily living, support and coping, support services and information needs</td>
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<td></td>
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<td>• Patients were provided with a tailored educational package based on needs identified and an individualised survivorship care plan (SCP) which was also mailed to their GP</td>
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<td>empowered with receiving a copy of their SCP</td>
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<td>• Participants no longer having face-to-face contact with the APN required more encouragement to adhere to study requirements</td>
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</tbody>
</table>

* Level of evidence as defined by National Health and Medical Research Council (NHMRC)
Comparison of needs assessment tools in cancer survivors

The needs assessment tools varied in their content and the population within which they had been studied.

Table 3: Comparison of needs assessment tools

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Cancer type</th>
<th>Participant numbers</th>
<th>Survivorship stage</th>
<th>Items and domains</th>
<th>Question format</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Survivor Unmet Needs Survey (SUNS)</strong>&lt;sup&gt;(22,23)&lt;/sup&gt;</td>
<td>Breast, prostate, colorectal, lung, lymphoma, leukaemia, myeloma, other</td>
<td>$n = 550$ (mixed cancer survivors), $n = 529$ (haematologic al cancer survivors)</td>
<td>1–5 years post-diagnosis (mixed cancer type)</td>
<td>5 domains; 89 items: emotional health (33 items), access and continuity of care (22), relationships (15), financial concerns (11), information (8)</td>
<td>A 5-point Likert-type scale ranging from 0 (no unmet need) to 4 (very high unmet need) for items in the past month</td>
</tr>
<tr>
<td><strong>Short Form Survivor Unmet Needs Survey (SUNS-SF)</strong>&lt;sup&gt;(24)&lt;/sup&gt;</td>
<td>Breast, prostate, colorectal, lung, non-Hodgkin’s lymphoma, other</td>
<td>$n = 1589$</td>
<td>1–5 years post-diagnosis</td>
<td>4 domains; 30 items: emotional health (8 items), access and continuity of care (6), relationships (5), financial concerns (8), information (3)</td>
<td>A 5-point Likert-type scale ranging from 0 (no unmet need) to 4 (very high unmet need) for items in the past month</td>
</tr>
</tbody>
</table>
| **Cancer Survivors Unmet Needs (CaSUN)**<sup>(25)</sup> | Breast, gynaecology, prostate, colorectal, other | $n = 353$ | 1–15 years post–diagnosis | 5 domains: existential survivorship, comprehensive care, information, quality of life and relationships 35 unmet need items, 6 positive change items and an open-ended question | Indicate for each item (a) ‘no unmet need/not applicable’, or, (b) if they do experience a need, how strong the need is (‘weak’/’moderate’/’strong’). The positive change domain included 6 items with 4 response options (‘yes, but I have always been like this’, ‘yes, this has been a positive outcome’, ‘no, and I would like help to
<table>
<thead>
<tr>
<th>Instrument</th>
<th>Cancer type</th>
<th>Participant numbers</th>
<th>Survivorship stage</th>
<th>Items and domains</th>
<th>Question format</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Cancer Needs Questionnaire Young People (CNQ-YP)(^{(27)})</td>
<td>Heterogeneously sample</td>
<td>(n = 139)</td>
<td>16–30 years of age</td>
<td>6 domains; 70 items: treatment and care (33), feelings and relationships (14), daily life (12), information and activities (5), education (3), and work (3)</td>
<td>Items were rated using a 5-point response scale from ‘no need’ to ‘very high need’ from any time since cancer diagnosis</td>
</tr>
<tr>
<td>Childhood Cancer Survivor Study Needs Assessment Questionnaire (CCSS-NAQ)(^{(28)})</td>
<td>Leukaemia, CNS tumour, Hodgkin lymphoma, non-Hodgkin lymphoma, Wilm tumour, neuroblastoma, soft tissue sarcoma, bone tumour</td>
<td>(n = 1178)</td>
<td>(\geq 25) years of age (mean age 39.5 years)</td>
<td>9 domains; 135 items: psychoemotional (17), health system concerns (10), cancer-related health information (11), general health (16), survivor care and support (20), surveillance (9), coping (12), fiscal concerns (24), and relationships (16)</td>
<td>Indicate that there was no need, because either (1) no need existed or (2) the need was met, or that there was a low (3), moderate (4), or high (5) level of need</td>
</tr>
<tr>
<td>Distress thermometer (DT) + Problem list (PL)(^{(20)})</td>
<td>---</td>
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<td>---</td>
<td>5 domains; 32 items: practical problems (5 items), family problems (2), emotional problems (4), spiritual/religious concerns (2), physical problems (19)</td>
<td>Rate distress level from a range of 0 (none) to 10 (extreme) in the past 7 days on the DT and tick off problems on the PL</td>
</tr>
</tbody>
</table>
Survivor Unmet Needs Survey (SUNS)

The Survivor Unmet Needs Survey (SUNS) tool was developed and validated in cancer survivors. It was tested in a large number of mixed and haematological cancer survivors. It appears to have high acceptability, internal consistency, content and construct validity.

In the original development of the scale, which included a heterogenous sample of Canadian cancer survivors, patient demographics was skewed towards an older group with only 4.2% of patients younger than 40 years of age. Missed items >10% were removed in the development phase except for items which have previously been identified as frequently endorsed by cancer survivors. Items removed included reproductive, sexual and spousal issues and childcare. These needs are more applicable to younger patients. As younger patients represented a minority in the development of the tool, care must be taken to ensure all unmet needs are identified if the SUNS is used in this group.

The tool showed high floor effects, which may impact on the SUNS' ability to observe reductions in an individual's levels of unmet needs. The authors speculate the high floor effect may be an indication of patients experiencing low unmet needs across all domains.

Less than 50% of cancer survivors contacted returned the surveys in both studies so there is risk of response bias. Future longitudinal studies in a clinical setting are required to test for tool responsiveness over time and confirm the reliability and validity of the tool. Although feedback for acceptability is positive, 89 items places a greater burden on patients compared to other available tools; however a short form version of this measure has been developed and psychometrically evaluated (see below).

Content validity
Literature review, cancer survivor input, professional input, pilot test with feedback

Construct validity
Factor analysis

In the haematological cancer survivor sample, poor discriminant validity was found – 67% of hypotheses relating to known group validity were supported. Disease recurrence, younger survivors (<60 years at diagnosis) and currently receiving treatment had higher median scores for some or all domains.

Convergent validity
In the haematological cancer survivor sample, there was moderate positive correlation with all three subscales of the Depression Anxiety and Stress Scale (DASS-21), range 0.44–0.73.

Internal consistency
In the Canadian sample of mixed cancer types, Cronbach’s alpha was 0.990 with the subscales ranging from 0.983 for emotional health, 0.973 for relationships, 0.967 for access and continuity of care, 0.936 for financial concerns and 0.932 for information.

All Cronbach's alpha values were >0.9 and corrected item-total correlations were >0.2 (0.61 to 0.88) for the haematological cancer survivor sample.

Reproducibility
The paper by Campbell et al. (2010) reported high test–retest reliability but this data was not shown. Surveys returned <20 days were included in the test–retest reliability analysis.

In the haematological cancer survivor sample, weighted Kappa coefficients between item responses from Time 1 and Time 2 ranged from 0.25 to 0.76 (M = 0.58; SD = 0.09).

Forty items (45%) met the criteria for acceptable item test–retest reliability. Test–retest reliability was acceptable in only three of the five domains for haematological cancer survivors.

Test-retest time mean of 28 days (SD = 16.1 days)
Responsiveness

Significant floor effects for all domains

In the haematological cancer survivor sample, high floor effects were observed for all five domains and few ceiling effects were observed (information 37%, financial concerns 51%, access and continuity of care 42%, relationships 47%, emotional health 33%).

Feasibility

Grade 4–6 reading level

Average time to complete 24 minutes

Missing data for the items ranged from 2 to 5.3%

Feedback from the study suggests the survey length and content were acceptable.

Cross-cultural reliability

Developed for a Canadian population and psychometric evaluation also conducted in Australian haematological cancer patients, which indicated face and content validity for this population.

Short Form Survivor Unmet Needs Survey (SF-SUNS)

The development and validation of the SF-SUNS was conducted in a large study (n = 1589) by Campbell et al. (2014)(25) in mixed early cancer survivor patients. The SF-SUNS is a shortened version of the SUNS and contains 30 items derived from the original 89 items from the SUNS. It appears to have good construct validity and internal consistency. The study did not establish the content validity or test–retest reliability although the SF-SUNS was derived from the SUNS, which illustrates evidence of these psychometric properties. Patient demographics were slightly skewed with a higher percentage of prostate cancer survivors and responders aged 50–59 years and a lower percentage of breast cancer survivors. The patients who were consulted in the refining of the tool were the same patients used to validate the tool. Similar to the SUNS studies, there was a less than 50% response rate to the survey, increasing the chance of response bias. The SF-SUN is a convenient tool that may have better acceptability in clinical care due to its shortened form. However it will require more validity and reliability studies in the research and clinical setting.

Content validity

Derived from the SUNS

Construct validity

Factor analysis

Intra-class correlation with the original 3 SUNS domains were high (>0.9) indicating a high level of agreement.

Discriminant validity

Survivors who had received treatment in the last month had significantly higher median scores for all four domains.

Internal consistency

All Cronbach's alphas ≥ 0.85 for all domains

Reproducibility

Test–retest validity was not conducted in the SF-SUNS.
Responsiveness

Over a quarter of participants obtained the lowest possible score on all four domains of the SF-SUNS (information 44%, financial concerns 53%, access and continuity of care 53%, relationships and emotional health 36%). There were few ceiling effects.

Feasibility

All items had <5% missing data.

**Cancer Survivors’ Unmet Needs (CaSUN)**

The CaSUN is developed and validated in cancer survivors. The CaSUN contains 35 unmet need items, six positive change items and an open-ended question. It appears to have good internal consistency with an overall Cronbach’s alpha of 0.96 and evidence of face, content and construct validity. However, test–retest reliability was low. This may have been affected by the poor retention rate (34.6%), small numbers and long length of time between retest.

The demographics of study participants used to construct the CaSUN were not representative of the general cancer survivor population. A large proportion of study participants were female (81%) and had breast cancer (59.2%) followed by gynaecological cancer (16.9%). The average age was older (average 59.6 years) and had been diagnosed with cancer 2.3 years earlier (range 1–15 years). The CaSUN may not reliably identify needs in all cancer survivor groups. However, the inclusion of a final open question at the end of the questionnaire allows identification of additional needs not brought up in the survey. More psychometric analysis and assessment in the clinical setting is required for this tool.

**Content validity**

Previous qualitative research, literature review

**Research panel review**

Evaluation sheet and feedback from cancer survivor participants

**Construct validity**

Factor analysis

Discriminant validity: number of significant correlations between CaSUN scores and variables hypothesised to influence level of need (age, number of cancer treatments, anxiety, depression and poorer QoL). Four out of seven hypotheses (57%) were supported.

Cronbach alpha for CaSUN = 0.96

Cronbach alphas for the five domains ranged between 0.78 and 0.93 indicating good internal consistency.

The majority of items total correlation ranged between 0.4 and 0.7.

**Reproducibility**

Test–retest time was ~3 weeks apart.

The test–retest correlations for the CaSUN between Time 1 and Time 2 assessment was 0.19, indicating a low level of agreement in total scores over time.

The average item Kappa co-efficient was 0.13, and the average percentage agreement between Time 1 and Time 2 assessment was 66%.

**Responsiveness**

No data
Feasibility
Reading level grade of 5.6

Approximately 10 minutes to complete
Items were excluded if endorsed by <10% of participants and exclusion was clinically and theoretically appropriate.

Young adult survivor needs assessment
Younger cancer survivors have been identified as patients with high unmet needs. Young cancer survivors are still undergoing physical, emotional, social and cognitive development and the impact of cancer can cause disruptions to key developmental stages. Hall et al. (2012) found young adult survivors (18–40 years) had significantly lower levels of social functioning and higher levels of financial difficulty, sexuality needs, health system and information needs than older cancer survivors (64+ years)\(^{(39)}\). Isolation, lack of age appropriate information, and psychosocial support were identified as predominant needs\(^{(40)}\).

In a study by Zebrack et al. (2009), more than 50% of respondents indicated their needs for information and services have been unmet\(^{(41)}\). This was mirrored in another study by Keegan et al. (2012), who found 56–75% of young cancer survivors who required a support group, pain management specialist, physical or occupational therapist, mental health worker or financial advice did not receive these services. Factors associated with unmet service need included not currently being in treatment, reporting that their physical health or emotional problems interfered with their social activities or having ≥3 physical symptoms\(^{(42)}\).

More attention and support is required for this survivor population as prognosis is good and the number of young cancer survivors is growing. Among patients aged 19 years and younger at the time of their diagnosis in 2002, 83.9% survived cancer for at least 5 years\(^{(4)}\). Until recently, no needs assessment tool was available for this specific patient group\(^{(43)}\). As seen in the previous analysis, young adult cancer survivors were poorly represented in the development of new needs assessment tools. This population is often understudied as they often relocate and follow up is difficult\(^{(9)}\).

The Cancer Needs Questionnaire Young People (CNQ-YP)\(^{(27)}\) was created and validated in young adult cancer patients and survivors.

Cancer Needs Questionnaire Young People (CNQ-YP)
The CNQ-YP contains items modified to reflect life events applicable to young adults such as studying, early employment and supporting young families. However, sexual health issues and intimacy were not included in the tool despite being a known unmet need in this patient group. This may be because the focus and pilot group consisted of younger participants aged 14–19 years ho did not have these needs.

The limitations in the development of the CNQ-YP must be acknowledged. The study number was small \((n = 139)\), the response rate was lower than other needs assessment studies (24.1% of all patients contacted consented, 50% of these completed the survey) and there were significant differences in consenters and non-consenters (consenters were younger and predominantly female).

The end tool was reported to have high validity because items of low validity were removed during development, however the complete tool was not re-validated.

Future large longitudinal studies in clinical practice to establish psychometric properties are required.

Content validity

Literature review

Focus group with adolescents and young adults (AYA)
Feedback from 12 health professionals with experience working with AYA cancer populations, eight researchers and 12 individuals from the general population.

Pilot study

**Construct validity**

**Factor analysis**

**Internal consistency**

All domains achieved Cronbach's alpha values greater than 0.80 (0.94–0.97).

Item-total correlations for items within all five domains were >0.20 and ranged from 0.33–0.88.

**Reproducibility**

Item-to-item test–retest reliability was high, with all but four items reaching weighted kappa values >0.60, and these four items had weighted kappas >0.49.

Long test–retest time with median of 24 days (9–64 days)

**Responsiveness**

Large floor effect for all domains. The proportion of participants ranged from 8.3–43% for the minimum score, with large proportions of participants having floor effects in the education and work factors (42% and 43% respectively).

Did not appear to have ceiling effects

**Feasibility**

Reading level grade 6

Items answered by ≤10% of respondents were excluded from the measure.

Acceptability of survey was assessed through feedback on ease of completion.

**Childhood cancer survivor needs assessment**

Survivors of childhood cancer are another group with high needs. Long-term survival into adulthood is expected for >80% childhood cancer survivors and they have a higher rate of physical illness due to chronic health conditions compared to normal patients.

Physical late effects of cancer treatment include cardiovascular disease, fertility issues and growth and bone mineral issues. Disruptions to schooling and central nervous system tumours and treatment may cause educational, behavioural and social problems. These late effects vary depending on the site of cancer and cancer treatment.

A study by Geenen et al. (2007) found after a median follow-up of 17 years, nearly 75% of childhood cancer survivors had experienced at least one adverse event. Forty per cent of survivors experienced at least one severe or life-threatening or disabling event and 23.4% a high or severe burden of events. This is a high burden of disease considering the young age of the study population (88% <35 years at end of follow-up). It is important that these patients are adequately followed up after their cancer treatment is complete.

The Childhood Cancer Survivor Study Needs Assessment Questionnaire (CCSS-NAQ) is the only needs assessment tool developed and validated in this survivor group.

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

The CCSS-NAQ appears to have good construct and content validity. The demographics of the patients used in the development of the tool were skewed. A higher proportion of participants were female,
married, college educated and employed. The population was relatively young (mean cohort 39 years) and ethnic and racial diversity was poor. Poor participation rate (38%) increases the risk of response bias. In addition, the end tool was not re-validated.

With 135 items there is an increase in patient burden, however the tool may offer a more comprehensive assessment in this group of survivors. Large longitudinal studies in clinical practice to ensure a diverse childhood cancer survivor population is included are required.

**Content validity**
- Literature review
- Expert review
- Pilot study for content validity and feasibility
- Focus group

**Construct validity**
- Confirmatory factor analysis and person-item fit variable maps established construct validity.
  
  There was a high degree of item reliability (item reliability index range 0.97–0.99), person reliability was 0.80–0.90 and separation index scores were 2.00–3.01.

**Internal consistency**
- Cronbach’s alpha for all domains ranged from 0.94–0.97.

**Reproducibility**
- The 4-week test–retest correlations were high (0.52–0.91). This declined with increasing assessment intervals.

**Responsiveness**
- No data

**Feasibility**
- The original 190 item tool took 20–30 minutes to complete.
  - Reading level grades 4–5
  - Acceptability of survey assessed in pilot study.

**Cross-cultural reliability**
- Minorities and rural residents were oversampled at a 2:1 ratio.

**Distress Thermometer (DT) with Problem List (PL)**

The Distress Thermometer is commonly used in cancer patients with the Problem List and is recommended by the NCCN for cancer patients at all stages of their disease including survivorship. The NCCN defines distress as ‘a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment’[47].

Patients rate their distress level from 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/PL has the advantage of being simple and fast to use and can easily be implemented in clinics. The checklist 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 in high distress require additional psychological assessment.

The Distress Thermometer has good sensitivity and specificity in cancer patients\(^{48}\); however, several studies have demonstrated that this may not be the case in cancer survivors (see Table 5).

Area under the curve (AUC) is assessed by receiver operating characteristic (ROC) analysis. Values vary from 0 to 1, with values ≥0.80 reflecting good discrimination and values ≥0.90 reflecting excellent discrimination. Sensitivity and specificity vary from 0–1.0, with higher values reflecting better agreement. Previous studies of depression and anxiety screening instruments in cancer patients have used sensitivities ≥0.90 and specificities ≥0.75.\(^{49, 50}\)

**Table 4: Comparison of Distress Thermometer/Problem List papers**

<table>
<thead>
<tr>
<th>Study (identified by principal author)</th>
<th>Population</th>
<th>Study design and methods</th>
<th>Results</th>
<th>Conclusion</th>
<th>Recommended cut-off</th>
</tr>
</thead>
</table>
| **Hong (2013)\(^{51}\)** | Long-term Chinese nasopharyngeal cancer survivors visiting hospital (\(n = 442\), 72% male) | • Longitudinal cohort study  
• Self-administered questionnaire, results compared with HADS*  
• (Single score ≥8 or total score ≥16 = positive case) | All potential cut-off scores showed poor sensitivity (<0.90). Cut-off score of ≥4 had a sensitivity of 0.421 and a specificity of 0.852. Cut-off score of ≥3 had a sensitivity of 0.486 and a specificity of 0.811. Cut-off score of ≥2 had a sensitivity of 0.664 and a specificity of 0.674 | • The ROC analysis showed poor discrimination  
• Poor sensitivity in this group of patients | — |
| **Boyes (2013)\(^{52}\)** | Mixed survivors (\(n = 1323\), early survivorship) | • Cross-sectional survey  
• Patients recruited from 2 large state-based registries completed DT and HADS 6 months post-diagnosis | A DT cut-off score of ≥2 had sensitivity 87–95% and specificity 60–68%, ≥3 had sensitivity 77–88% and specificity 72–79%, ≥4 had sensitivity, 67–82% and specificity 81–88% for detecting cases of anxiety, | • The recommended DT cut-off score of ≥4 was not supported  
• ≥4 was best for research use  
• A DT cut-off score of ≥2 was best for clinical use | ≥2 for clinical setting |
<table>
<thead>
<tr>
<th>Study (identified by principal author)</th>
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<th>Results</th>
<th>Conclusion</th>
<th>Recommended cut-off</th>
</tr>
</thead>
</table>
| **Merport (2012)**<sup>(48)</sup> | Mixed survivors (<i>n = 120</i>) | • Cross-sectional study  
• Patients recruited from a survivorship clinic  
• DT compared with BSI-18**  
• (GSI T score, or any two subscale t scores ≥ 63 = clinical case) | At a DT cut-off score of 4, 12 of the 21 BSI-18 positive cases were identified (sensitivity 51.7%; specificity 89.9%) | • The results do not support the validity of the DT in survivors of adult cancers | — |
| **Craike (2011)**<sup>(53)</sup> | Colorectal cancer (CRC) survivors (<i>n = 59</i>) | • Prospective, multicentre cohort study, involving public and private health services across Melbourne  
• DT compared with HADS  
• (Total score ≥15 for positive case) | DT cut-off score ≥4 had sensitivity 60% and specificity 81%. DT cut-off score ≥3 had sensitivity 72% and specificity 64.6% | • The results do not support the validity of the DT in CRC survivors  
• The study also found the use of the DT may underestimate depression but overestimate anxiety | — |
| **Recklitis (2007)**<sup>(42)</sup> | Childhood cancer survivors (<i>n = 119</i>) | • Cohort study  
• Recruitment from survivor clinic during visits  
• DT results compared with SCL-90-R***  
• (GSI t-score, or any two subscale t-) | DT cut-off score of 4 identified 23 of the 36 SCL-90-R-positive cases (sensitivity 63.9%; specificity 65.1%). AUC = 0.72 | • Results do not support the validity of the DT in adult survivors of childhood cancer | — |
The above studies investigated the sensitivity and specificity of the Distress Thermometer in a variety of cancer survivor patients including mixed cancers, nasopharyngeal cancer, colorectal cancer, thyroid cancer and adult survivors of childhood cancer. It has been assessed against several accepted psychosocial measures. None of these studies demonstrated a cut-off score that had acceptable sensitivity and specificity. However, acceptable sensitivity and specificity may vary depending on the intended use. All studies except one showed a low sensitivity at the recommended cut-off score of 4 and reducing the cut-off score resulted in lower specificity.

Boyes et al. (2013) recommended a cut-off score of 2 for clinical use with a sensitivity of 87–95% and specificity of 60–68%\(^{(52)}\). The authors reason that it is more important to capture all cancer survivor patients with distress rather than accurately identify patients with distress but miss out on some patients with distress. Further assessment of these patients will identify patients who require treatment or referral. This approach may be impractical depending on the clinical setting and may place burden on available resources.

Roerink et al. (2013) found a good correlation between the DT scores and the total number of reported problems on the PL \(r = 0.827; \ p < 0.001\)\(^{(35)}\). Their patient population had high needs with 89.9% of patients reporting at least one item of concern on the PL. Of the patients reporting a DT score ≥5, 19.1% wished to be referred for additional support and 34.0% were considering it. There was a significant correlation between the DT score and the wish for referral for additional support \(r = 0.193; \ p = 0.025\).

These studies highlight that there is limited and only low-level evidence available in scientific publications regarding the validity of the Distress Thermometer in assessing distress in cancer survivors. However, the DT with the PL may be useful for identifying areas of need that the patient wishes to discuss in clinic. Patients and clinicians found the DT and PL useful in a National Cancer Survivorship Initiative (NCSI) multi-site test; however, the usefulness and relevancy of the tool was dependent on how it was used and communicated\(^{(34)}\). The items on the PL may need to be modified to suit the patient population. A study by Brennan et al. (2012) on cancer patients found that the PL did not contain some commonly endorsed items such as loneliness and isolation\(^{(54)}\).

<table>
<thead>
<tr>
<th>Study (identified by principal author)</th>
<th>Population</th>
<th>Study design and methods</th>
<th>Results</th>
<th>Conclusion</th>
<th>Recommended cut-off</th>
</tr>
</thead>
</table>
| Roerink (2013)\(^{(35)}\) | Long-term thyroid cancer survivors \((n = 145)\) | • Cross-sectional study  
• Patients recruited from outpatients clinic  
• DT compared with HADS  
• (Cut-off score ≥15) | AUC = 0.82 (standard error 0.043; 95%CI = 0.739 – 0.906; \(p < 0.001\)). Cut-off score of 4 had sensitivity 80% and specificity 66%; cut-off score of 5 had sensitivity 77% and specificity 77% | The DT and PL are useful time efficient screening instruments for psychosocial distress in thyroid cancer survivors and can easily be incorporated into daily practice | Cut-off score of 5 |

* Hospital Anxiety and Depression scale; ** Brief Symptom Inventory-18; ***Symptom Checklist-90-revised (parent of BSI-18).
Similar tools to the DT and PL are available. The London Cancer Alliance Holistic Needs Assessment tool\(^{55}\) was adapted from the DT and PL and is indicated for use throughout the cancer pathway. Additional items are included in the emotional concerns and spiritual concerns domains and it includes an additional checkbox ‘discuss’ if the patient wishes to speak about a concern during their appointment. A project is currently underway by the Gloucestershire Hospitals NHS Foundation Trust to roll out the HNA at several cancer sites throughout the United Kingdom. No results from this implementation have been published as yet. No papers were found on its development and validation.

The Concerns Checklist was produced by the NCSI for cancer patients and survivors and is described below. It contains more items than the DT and PL in the practical concerns, emotional concerns and spiritual or religious concerns domains and has an additional domain: lifestyle or information needs.

**Other tools**

The following tools were not included in the analysis as they are not validated for use with survivors. However they are have been used with survivors and are included as they may be used in conjunction with a validated needs assessment.

**Concerns Checklist**

The Concerns Checklist published by the NCSI is similar in format to the Distress Thermometer and Problem List. Patients rate their overall level of concern felt in the past week from 1 to 10. A checklist consists of six domains and 65 items: physical concerns (23 items), practical concerns (9 items), family/relationship concerns (3 items), emotional concerns (9 items), spiritual or religious concerns (9 items), lifestyle or information needs (9 items). No papers assessing validation or outcome in cancer survivors were found on this tool.

A modified Concerns Checklist was piloted in a CRC survivor clinic by Taylor et al. (2012)\(^{29}\) where a small number (\(n = 18\)) of low-risk patients were serviced by nurse-led care at the end of cancer treatment. The tool was modified to focus on bowel and sexual function, body image and dietary concerns, which are relevant to this patient group. Patients completed the survey prior to their appointment. Identified needs were recorded on a care plan and referrals and future appointments were made as appropriate. Additional concerns were picked up during appointments that were not stated by the patients on the checklist, mostly of a personal nature (e.g. sexual concerns, fears of cancer recurrence). Some of these concerns were interrelated. This study highlights the importance of face-to-face interactions with a healthcare provider to discuss issues identified on a checklist.

A pilot study by Dennison et al. (2000) involved implementation of a checklist in cancer patients during outpatient clinic\(^{18}\). Patients with emotional and social concerns were seen by the nurse or specialist nurse prior to seeing their doctor. The use of the checklist was shown to improve communication and improve the relationship between patient and healthcare provider.

**Cancer Survivors Survey of Needs**

The Mayo Clinic Cancer Centre has published a Cancer Survivors Survey of Needs. The survey was created from survivorship literature and developer experience and was reviewed by members of the cancer patient education network. Data collected from this tool is intended to direct appropriate resources and plan supportive programs for patient groups.

Patients rate their quality of life during the past week from 1 to 10 and their current concerns from 1 to 5 (no concerns to extreme concerns). It has five domains: physical effects, social issues, emotional aspects, spiritual issues and other issues. The survey contains additional questions on preferred learning on topics and what specific topics the patient is interested in learning about. A modified version of this tool was used in a pilot study to guide development of a survivorship program for a community cancer centre (Schlairet et al. 2010)\(^{30}\). Needs in the cancer centre were evaluated to guide development of a survivorship program model to address these needs. Educational needs varied between patients and suggests that needs may differ between patient variables such as age and gender.
Supportive Care Needs Survey (SCNS)\textsuperscript{[56]}

The SCNS is often used to assess needs in cancer patients and has been used to assess needs in cancer survivors in studies. 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.

Despite its use in cancer survivors, the SCNS has not been validated in this group and contains some medical care needs questions. There are limited items on practical and relationship needs and it may not cover an adequate range of unmet needs in cancer survivors. Several modules are available to supplement or be used as an alternative to the SCNS including breast cancer, melanoma, prostate cancer, colostomy, partners and carers of cancer survivors and access to health care and ancillary support services.

A survivor module for early breast cancer survivors (6–24 months post-treatment) is available as a supplement to the SCNS-SF (Thewes et al. 2004)\textsuperscript{[57]}. The module has been piloted in a small number of patients ($n = 95$) and appears to have good construct validity and internal consistency although further research is required. It contains five domains with 46 items specific to breast cancer survivors. Thewes et al. (2004) noted that the top 10 most commonly reported moderate-to-high unmet needs were selected by 25.3–40.0\% of the respondents compared to 14.9–24.2\% for the SCNS-SF-34. This indicates that the module assessed issues of greater relevance to breast cancer survivors.

A long-term cancer survivor module is currently under development by Allison Boyes et al.\textsuperscript{[58]}

Quality of Life (QoL) tools

The literature search revealed many papers on the use of quality of life tools in cancer survivors. A literature review by Muzatti et al. (2013)\textsuperscript{[59]} identified eight validated QoL tools used in adult cancer survivors. 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 QoL tool may assess a patients level of sadness or physical capability but a needs assessment tool will identify if patient has a need for assistance in that area. It is difficult to use data from a QoL tool to inform appropriate and relevant service delivery. QoL tools may be useful in the clinical setting to identify if a survivorship care intervention has had an impact on patient outcome.

Item-specific needs assessment tools

A number of tools have been developed to assess a particular area of need or are specific to a cancer survivor group. It is worthwhile being aware of these tools as they may be used as a supplement, especially if there is a known high need in a specific cancer survivor group. The Canadian Partnership Against Cancer and the Canadian Association of Psychosocial Oncology guidelines recommend ‘disease, treatment, or phase-specific psychosocial healthcare needs assessments should be added to routine, standardised assessment across populations (generic), in order to tailor assessments to problems that are unique to a specific cancer treatment modality, or phase in the cancer continuum\textsuperscript{[60]}.

Some specific needs assessment tools are mentioned here; however, we did not conduct a comprehensive literature search of these tools as this was not the aim of this review. The symptoms most commonly reported in cancer survivors, regardless of cancer type and treatment, included depression, anxiety and fatigue (Harrington et al. 2010)\textsuperscript{[6]}. Ongoing pain and insomnia are also commonly reported symptoms in cancer survivors (Mao et al. 2007)\textsuperscript{[61]}.

Distress

Distress is a common symptom in cancer patients and cancer survivors. As defined by the NCCN, it is unpleasant emotion caused by emotional, physical or social stressors and can include anxiety and depression. In a cross-sectional study of 258 breast cancer survivors in an outpatient clinic, 36\% were
found to experience distress 5 years after treatment completion\(^{(62)}\). A cross-sectional study by Hoffman et al. (2009) of a US national survey of 4636 long-term cancer survivors at least 5 years after cancer diagnosis identified 5.6% had serious psychological distress\(^{(63)}\). High indicators of distress include disruptions to work, school or home life, feeling sad or depressed, fatigue and concerns about the future\(^{(64)}\). A high distress score warrants further review or referral to psychosocial care. The most common tool to assess distress in cancer survivors is the Distress Thermometer as has been discussed above; however, other tools are available. The Brief Symptom Inventory-18 (BSI-18), CancerSupportSourceSM web-based tool (CSS-25)\(^{(65)}\) and the 36-item Distress Screener have been tested in cancer survivors\(^{(66)}\).

### Depression and anxiety

The Edinburgh Depression Scale (EDS) and the Hospital Anxiety and Depression Scale (HADS) have been used to assess for anxiety and depression in cancer survivors\(^{(67)}\). The HADS has often been used as a comparator when assessing psychological properties of cancer survivor needs and distress assessment tools.

### Fatigue

Fatigue is commonly experienced by cancer patients and cancer survivors and may be associated with significant distress. It can have a high impact on a patient's normal functioning ability. A cohort study by Meeske et al. (2007) found 41% of 1183 breast cancer survivors 2 to 5 years from diagnosis had moderate-to-severe levels of fatigue\(^{(68)}\). Fatigue was associated with poorer health-related QoL, with patients reporting significant deficits in role functioning and social functioning.

There are many tools developed to assess fatigue. A review by Seyidova-Khoshknabi et al. (2011) identified 40 instruments measuring fatigue in cancer patients with five optimally tested for validity and reliability\(^{(69)}\). The Piper Fatigue Scale (PFS), the Multidimensional Fatigue Inventory (MFI) and the Modified Brief Fatigue Inventory (MBFI) have been tested in some cancer survivors.

Some late symptoms are specific to certain cancers. For example, early menopause, lymphoedema and upper limb disability are more common in breast cancer survivors, swallowing and speech difficulties in head and neck cancer survivors, and incontinence in colorectal cancer survivors. It is important to be aware of these specific symptoms so that these patients are monitored and additional information provided. Some tools have been developed for these symptoms as supplements to general needs assessments tools.

Other specific 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.

### Tools validated in languages other than English

The studies included focused on an English-speaking population of survivors. Consequently, the generalisability of the six identified needs assessment tools to survivors from culturally and linguistically diverse backgrounds is questionable.

In Australia’s multicultural population it is important to recognise the need for validated needs assessment tools available in languages other than English. Butow et al. (2013)\(^{(12)}\) undertook the largest study internationally to explore differences between immigrant and native-born cancer survivors. The Australian study aimed to document unmet needs, and variables associated with these, in a population-based sample of first-generation immigrants and Anglo-Australians who had survived cancer. Overall they found that greater effort is required to meet the needs of immigrants who have survived cancer, to ensure these citizens do not experience compromised quality of life. McGrane et al. (2014)\(^{(70)}\) undertook research in the Australian setting to assess the invariance of a culturally competent multilingual unmet needs survey. They noted that in the Australian context, past research examining needs assessment of cancer patients has focused primarily on the non-migrant population. Their work highlighted the intricacies in developing culturally competent tools for migrant cancer patients and survivors but also
recognised the importance of ensuring the needs assessed are culturally relevant to the target language groups.

**Comparison of tools**

The literature review revealed limited papers on the use of needs assessment tools in the clinical setting. Papers described the development and psychometric analysis of the tools in the research setting although they are intended for clinical use. However, the limited literature identified as assessing the clinical use of these tools may not be a reflection on a lack of their clinical use, but instead reflect limited research assessing the clinical use of such tools.

The development and validation of the needs assessment tools analysed were conducted in cross-sectional or cohort studies with low level of evidence (level IV). Recruitment of patients in the studies was poor with 37–57% participation rate. Consequently, these studies run the risk of response bias, the extent of which is difficult to determine as most of the studies did not collect comprehensive demographic data on non-participants. Participation samples were generally not representative of a broad cancer survivor population. The patients recruited were often middle aged and non-ethnic with a better social economic background. Non-participants may have included patients who were too unwell to participate in the study, had cognitive impairment, non-English speaking background or lived in rural areas. This may have also affected the high level of floor effects found for a number of studies as many of these characteristics are related to higher levels of unmet needs.

It is difficult to assess the validity of the needs assessment tools as there is no gold standard tool for comparison. Instead, future research in the clinical setting is required to assess for effectiveness in assessing needs. There were no head-to-head comparisons between needs assessment tools. The development of these tools were derived from literature reviews, patient and peer reviews and pilot studies. Future research will require large longitudinal studies in the clinical setting to capture all cancer survivor groups, reassess validity and reliability and assess acceptability and feasibility.

The psychometric properties of the needs assessment tools were assessed by two reviewers. Currently, the SUNS appears to be the tool with the strongest psychometric properties (see Table 6). The disadvantage of this tool is that it is fairly lengthy with 89 items. The SUN-SF, the short form tool of the SUNS, with 30 items, may be the next suitable alternative; however, it requires further assessment.

<table>
<thead>
<tr>
<th></th>
<th>SUNS</th>
<th>SUN-SF</th>
<th>CaSUN</th>
<th>CNQ-YP</th>
<th>CCSS-NAQ</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Content validity</strong></td>
<td>+++</td>
<td>+</td>
<td>+++</td>
<td>++</td>
<td>+++</td>
</tr>
<tr>
<td><strong>Construct</strong></td>
<td>++</td>
<td>++</td>
<td>+</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td><strong>Convergent validity</strong></td>
<td>+++</td>
<td>0</td>
<td>+</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Internal consistency</strong></td>
<td>+++</td>
<td>+++</td>
<td>+++</td>
<td>+++</td>
<td>+++</td>
</tr>
<tr>
<td><strong>Cross-cultural</strong></td>
<td>+</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>+</td>
</tr>
<tr>
<td><strong>Reproducibility</strong></td>
<td>+</td>
<td>0</td>
<td>−</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td><strong>Responsiveness</strong></td>
<td>−</td>
<td>−</td>
<td>0</td>
<td>−</td>
<td>0</td>
</tr>
<tr>
<td><strong>Acceptability</strong></td>
<td>+</td>
<td>+</td>
<td>++</td>
<td>++</td>
<td>+</td>
</tr>
</tbody>
</table>

0 = no results reported, − = no evidence in favour, + = limited evidence in favour, ++ = some acceptable evidence in favour, but some aspects fail criteria or not reported, +++ = acceptable evidence in favour
Note: The DT/PL was not included in Table 5 as the psychometric properties commonly assessed for the DT/PL in survivors are sensitivity and specificity, which are described in Table 4.

Tables 7 and 8 provide examples of domains and items and the domains that the tools include. Table 9 provides a summary of the limitations of the tools described.

### Table 6: Examples of domains and items

<table>
<thead>
<tr>
<th>Domain</th>
<th>Items</th>
<th>Assessment (examples from tools)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>Fatigue, Pain, Insomnia, Cognition, Sexual</td>
<td>• Being able to manage pain, physical side effects of treatment, loss of mobility, feeling tired.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Help with managing late effects of cancer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Help with feeling unwell a lot of the time</td>
</tr>
<tr>
<td>Practical</td>
<td>Work, Education, Finance, Daily living</td>
<td>• Being able to cope with not being able to do things as other people my age</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Being able to get guidance about study options or future career paths</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Paying household bills or other payments</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Doing work around the house</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Help climbing one flight of stairs</td>
</tr>
<tr>
<td>Family/relationships</td>
<td>Family, Friends, Partner, Health professionals, People in general</td>
<td>• Dealing with people not understanding what I’m going through</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Coping with changes in my relationship with my partner</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• My doctors to talk to each other to coordinate my care</td>
</tr>
<tr>
<td>Emotional</td>
<td>Depression, Anxiety, Spiritual, Stress</td>
<td>• Dealing with feeling worried (anxious)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Reduce stress in my life</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Dealing with not being able to set future goals or make long-term plans</td>
</tr>
<tr>
<td>Lifestyle or information</td>
<td>Cancer recurrence, Late effects of treatment, Smoking cessation, Social information (e.g. finance, home help, legal), Cancer services, Complementary or alternative therapies</td>
<td>• Finding information that was specifically designed for me</td>
</tr>
<tr>
<td>needs</td>
<td></td>
<td>• Local healthcare services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Understanding the information I was given</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Finding information about the signs of cancer and when I should be concerned</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Knowing which sources of information to trust</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Finding out what is involved in follow-up care</td>
</tr>
</tbody>
</table>
### Table 7: Addressed domains

<table>
<thead>
<tr>
<th>Tool</th>
<th>Physical</th>
<th>Emotional</th>
<th>Lifestyle or information needs</th>
<th>Practical</th>
<th>Family/relationships</th>
<th>Sexual</th>
<th>Cognition</th>
</tr>
</thead>
<tbody>
<tr>
<td>SUNS</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SF-SUNS</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CASUN</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>CNQ-YP</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CCSS-NAQ</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DT/PL</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCNS</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X*</td>
<td>X*</td>
<td></td>
</tr>
</tbody>
</table>

* Only question about changing attitude and behaviour of others and concerns about financial situation

### Table 8: Summary of limitations

<table>
<thead>
<tr>
<th>Tool</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>SUNS</td>
<td>• Tool contains 89 items&lt;br&gt;• Validated in cancer survivors 1–5 years post-diagnosis&lt;br&gt;• 4.2% of patients in the heterogonous cancer study were &lt;40 years&lt;br&gt;• No questions on reproductive, sexual and spousal issues and childcare (removed), which may be applicable to younger patients&lt;br&gt;• Does not contain questions on physical symptoms&lt;br&gt;• No studies on validation and implementation in clinical practice or patient outcome</td>
</tr>
<tr>
<td>SF-SUNS</td>
<td>• Validated in cancer survivors 1–5 years post-diagnosis&lt;br&gt;• Derived from SUNS but content validity of the short form tool was not completely reassessed&lt;br&gt;• Does not contain questions on physical symptoms&lt;br&gt;• No studies on validation and implementation in clinical practice or patient outcome</td>
</tr>
<tr>
<td>CASUN</td>
<td>• A large proportion of study participants in the development and validation study were female (81%) and had breast cancer (59.2%) or gynaecological cancer (16.9%)&lt;br&gt;• The average age was older (average 59.6 years) and had been diagnosed with cancer 2.3 years earlier (range 1–15 years)&lt;br&gt;• Limited test–retest reliability&lt;br&gt;• No studies on validation and implementation in clinical practice or patient outcome</td>
</tr>
<tr>
<td>Tool</td>
<td>Limitations</td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| CNQ-YP       | • Tool contains 70 items  
                          • Validated in young cancer survivors (16–30 years)  
                          • The study number was small (n = 139) and the response rate was lower than other needs assessment studies  
                          • No questions addressing sexual unmet needs although this may be relevant in this patient group  
                          • No studies on validation and implementation in clinical practice or patient outcome |
| CCSS-NAQ     | • Tool contains 135 items  
                          • Validated in adult survivors of childhood cancer  
                          • A higher proportion of participants in the development and validation study was female, married, college educated and employed. The population was relatively young (mean cohort 39 years) and ethnic and racial diversity was poor  
                          • No studies on validation and implementation in clinical practice or patient outcome |
| DT/PL        | • May not reliably identify distress in cancer survivors  
                          • Does not measure level of unmet need  
                          • Items may need to be modified or added according to patient demographics  
                          • Usefulness and relevance of the tool is dependent on how it is used and communicated  
                          • Must be accompanied by clinical review |
| SCNS         | • Although often used in cancer survivors, the SCNS was developed and validated in cancer patients receiving treatment  
                          • Potentially missing needs relevant to cancer survivors  
                          • Limited questions on social and practical needs |

**Which tool to use?**

There is no needs assessment tool that currently covers the needs of all cancer survivor groups. Needs may differ between cancer types, patient characteristics and stage of survivorship. The needs assessment tool for use in clinical practice should be chosen based on its relevance to the target population and the items included.

It may be useful to conduct a baseline screening of unmet needs prevalence prior to implementation. Alternative or additional needs assessment tools may be required for specific patient groups to ensure all unmet needs are identified. In addition, an open question at the end of the needs assessment tool may allow patients to voice other concerns not included in the needs assessment tool.

Needs assessment tools are useful to ensure that all important domains are screened for unmet needs. However, clinical review and individual assessment are still required to ensure all patient concerns are identified.
Part II: Implementation of needs assessment in survivorship care

Part II of this review looks at the recommendations, expert opinions and consensus of guidelines provided by major international cancer organisations, including examples from Australian healthcare facilities and the emerging literature in order to guide implementation.

Available guidelines and recommendations for needs assessment in survivorship care

There are currently no published Australian guidelines focusing on the use of needs assessment tools for survivors. However the Clinical Oncology Society of Australia (COSA) is developing a position statement on cancer survivorship which highlights the importance of the use of needs assessment.

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. These organisations are listed below and a summary of the components specific to needs assessment is provided in Table 9.

- The American Society of Clinical Oncology (ASCO)\textsuperscript{(71)} has guidelines on the assessment and management of peripheral neuropathy, fatigue, depression and anxiety in cancer survivors.
- The National Comprehensive Cancer Network (NCCN)\textsuperscript{(47)} has published guidelines on the assessment, management and treatment of anxiety and depression, cognitive function, fatigue, pain, sexual function, sleep disorders, healthy lifestyles and immunisations and infections in cancer survivors in the form of treatment algorithms. A list of questions for baseline needs assessment is available. It also provides information on use of the distress thermometer and problem list.
- The National Cancer Survivor Initiative (NCSI)\textsuperscript{(32)} website contains resources for holistic needs assessment and care planning. NCSI is a partnership between the MacMillan Cancer Support and the UK National Health Service. It contains links to information for cancer survivor patients and an online learning module on needs assessment for healthcare providers.
- MacMillan Cancer Support website provides information and recommendations on holistic needs assessment and survivorship care.
- The Canadian Partnership Against Cancer\textsuperscript{(72)} has published guidelines on assessment of psychosocial healthcare needs in adult cancer patients including survivors. It also has guides for assessing distress and fatigue in cancer patients.
- The Children’s Oncology Group (COG)\textsuperscript{(73)} has published long-term follow-up guidelines for survivors of childhood, adolescent and young adult cancers. It provides brief clinical practice guidelines for screening and management of late effects resulting from cancer treatment. It is useful in that it specifies common late effects associated with a specific intervention and provides recommendations on periodic screening. The guidelines recommend yearly psychosocial assessment with any cancer experience. Some of the recommendations are applicable to adult cancer survivors.
- The Institute of Medicine (IOM) published a comprehensive guide to survivorship care in 2006\textsuperscript{(74)}.
- The President’s Cancer Panel 2003–2004 Annual Report provides comprehensive information and recommendations on survivorship care.
<table>
<thead>
<tr>
<th>Organisation</th>
<th>Statements/recommendations for needs assessment/survivorship care</th>
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| American Society of Clinical Oncology (ASCO)                              | • Needs assessment should be conducted as part of a survivorship care planning program.  
|                                                                             | • Needs assessment can be used to define what resources are required.  
|                                                                             | • Survivorship care should have a focus on risk-based screening and health promotion.                                                                                                                                                                                               |
| National Comprehensive Cancer Network (NCCN)                              | • Assessment should be conducted by a healthcare provider at baseline and at regular interviews.  
|                                                                             | • Do not assume all survivor issues will be addressed at every visit. Recommend periodic screening assessments and appropriate follow-up as clinically indicated.  
|                                                                             | • Coordinate care between primary care practitioners and specialists to ensure that all of the survivor’s health needs are met.  
|                                                                             | • Needs assessment is designed to provide a framework for general survivorship care and management of potential long-term and/or late effects of cancer.                                                                                                                               |
| National Cancer Survivor Initiative (NCSI)                                 | • Everyone should be offered a holistic needs assessment and care plan.  
|                                                                             | • This is recommended at the end of cancer treatment and repeated whenever health and social needs change.  
|                                                                             | • Needs assessment should be conducted using a standard tool to ensure consistency in considering all of the domains of assessment and in stimulating the assessment conversation.  
|                                                                             | • Tools are not to be used as an end in themselves but to provide structure to assessment conversation and prioritise patient concerns.  
|                                                                             | • Good listening and communication skills are important.  
|                                                                             | • A survivorship care plan (SCP) should be developed from the needs assessment. The patient should receive a copy to enable self-management.  
|                                                                             | • Needs assessment results should be included in the care plan.  
|                                                                             | • Survivorship care should be patient centred.  
|                                                                             | • Audits should be conducted to assess efficacy of needs assessment program.                                                                                                                                                                                                       |
| Canadian Partnership Against Cancer                                         | • A routine, systemic and standardised assessment of psychosocial healthcare needs across cancer populations is recommended.  
|                                                                             | • Routine psychosocial healthcare needs screening for distress and assessment is recommended at critical time points in the cancer continuum including transition to survivorship, at recurrence or progression, and during times of personal transition or re-appraisal.  
|                                                                             | • Disease-, treatment- or phase-specific psychosocial healthcare needs assessments should be added to routine, standardised assessment across populations (generic), in order to tailor assessments to problems that are unique to a specific cancer treatment modality, or phase in the cancer continuum.  
|                                                                             | • Routine psychosocial healthcare needs screening for distress and assessment is recommended as an interpersonal process to elicit comprehensive information regarding patients’ needs for psychosocial and support interventions. |
• Routine psychosocial healthcare needs screening for distress and assessment should be followed by evidence-based interventions and targeted care processes appropriate to the identified need in order to improve patient outcomes including relief of symptoms, emotional wellbeing and quality of life.

• A comprehensive assessment tool with sound psychometric properties that addresses all domains of psychosocial healthcare needs is recommended for use in routine clinical practice.

• Ongoing education of all members of the healthcare team is critical to ensure competent psychosocial healthcare needs assessment and appropriate clinician response to findings of ‘red flag’ screening for distress, and comprehensive and focused assessments.

• Interdisciplinary collaboration is recommended for routine, standardised psychosocial healthcare needs assessment and screening for distress and targeting of interventions consistent with practice scope.

Institute of Medicine (IOM)

• Healthcare providers should use systematically developed evidence-based clinical practice guidelines, assessment tools and screening instruments to help identify and manage late effects of cancer and its treatment.

• Essential to survivorship care is a patient-centred approach, including responsiveness to patients’ needs, effective communication and information.

• Cancer survivors should be informed care partners. Empower and prepare patients to manage their health and health care.

• Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained.

• The SCP should be written by the principal providers who coordinated oncology treatment.

• Coordination between specialists and primary care practitioners is required to ensure that all of the survivor’s health needs are met.

• Optimally a designated individual is responsible for coordinating survivorship care.

• Existing survivorship guidelines should be refined and new evidence-based guidelines should be developed.

• The health system should anticipate patient needs, rather than simply reacting to events.

• Quality assurance programs should be implemented by health systems to monitor and improve the care that all survivors receive.

President’s Cancer Panel

• At completion of cancer treatment, patients should be provided with a record of all care received and disease characteristics. This should include full contact information of treating institutions and key individual providers.

• The care plan should incorporate available evidence-based standards of care.

• Patients and primary care practitioners should be made aware of the long-term psychosocial issues and how to intervene.

• Age appropriate, culture and literacy-sensitive educational patient and care-giver tools should be provided to enable self-management.

The above organisations provide broad statements on survivorship care but there is a lack of definitive guidelines for needs assessment implementation. In summary, holistic needs assessment should be conducted at the end of cancer treatment and at times of need (e.g. health and social need changes), should be offered to all cancer survivors and be tailored to the individual patient. The results of needs
assessment should be used to generate a survivor care plan and collated data may be used to direct survivorship programs.

Almost all groups emphasised the importance of communicating patient needs between specialist and primary care practitioner to ensure continuity of care. Continuation of care should be coordinated with the patient with appropriate information and education to enable patient self-management and advocacy. The IOM recognises the lack of evidence for many aspects of survivorship care and encourages research and development of guidelines based on patient population and best available evidence.

**Method of implementation**

**Who should carry out needs assessment?**

It is recommended that the patient complete the needs assessment survey if possible. Patient's responses in surveys have been found to differ to those provided by proxies\(^75, 76\). Proxies (such as doctors or carers) may base their assessment on their impression of the patient rather than the actual situation.

Staff implementing needs assessment tools should be adequately trained. Data shows that there is a lack of education and training in cancer survivorship\(^77\). Lack of time and funding and lack of knowledge on survivorship issues have been identified as barriers to providing survivorship care\(^77\). Survivorship programs require a dedicated leader to drive the process and clearly defined roles for providing needs assessment. Clinical nurse specialists may be well placed to conduct or coordinate needs assessment\(^78\).

Due to the growing cancer survivor population, there is a growing shift in the United Kingdom towards patient empowerment\(^79\). This involves education of patients on their survivorship for self-management and self-referral to health services. Patients are placed in a position to self-assess their needs in a less formalised setting. There are already steps towards information provided through phone services and web-based technology. These methods of assessment allow a greater number of patients to be reached.

Some web-based survivorship care programs have been piloted\(^80, 81\). Electronic patient Self-Assessment and Management (SAM) is a web-based framework developed and piloted by the Memorial Sloan-Kettering Cancer Centre (MSKCC) and the University of California, San Francisco (UCSF)\(^31\). SAM is designed to contain a patient's case history, assess individual patient needs, provide tailored information to assist with patient self-management and improve communication between patient and provider through the transfer of data. SAM is still undergoing development but there are plans to evaluate usability and effectiveness in the future.

**How should needs assessment be carried out?**

Most needs assessment tools are carried out in paper form prior to clinic visits. This may be posted out to the patient to be completed prior to appointments or completed in clinic. Completion and review of a screening survey prior to appointments can increase discussion of patient concerns and psychological problems (Hoodin et al. 2013)\(^82\). Ghazali et al. (2011) found no difference in the number of referrals to support services after implementation of a holistic needs assessment in an outpatient clinic; however, this may be because concerns were dealt with in clinic with allied health professionals being available\(^83\). Use of needs assessment tools may help to direct focus and improve communication between patient and provider\(^83\).

There is increasing research on electronic cancer survivorship care and there are some benefits for electronic needs assessment tools. Some oncology centres have tested a computer-based or touch screen form of a needs assessment tool in cancer patients. This provides a real-time, rapid assessment of the patient that can be stored electronically. The SCNS is available in an electronic version. Boyes et al. (2002) found moderate agreement between both paper and electronic versions of the SCNS; however, they noted that patients reported lower level of need when the question and response format
were simplified in the electronic version\(^{(58)}\). Electronic questionnaires may have better acceptability for some patients\(^{(84)}\).

Macmillan Cancer Support’s eHNA prototype project is developing an electronic version of the holistic needs assessment\(^{(85)}\). Patients can complete the questionnaire on a touch screen tablet and this information is sent to the clinician through a secure website to begin the process of care planning. This is being piloted at different cancer services in the United Kingdom. This form has the advantage of storing patient details electronically to be accessed and compared at a later stage. A pilot study of 181 patients has been conducted at four sites. The use of the eHNA resulted in a greater number of assessments and care plans completed compared to the paper version in a similar timeframe.

A study by Shewbridge et al. (2014) on the use of electronic HNA on an iPad prior to appointments in early breast cancer survivors showed significantly reduced time to complete documentation after the clinic compared to the paper copy\(^{(33)}\).

The interactive tailored patient assessments implemented by Ruland et al. (2010) in patients with leukaemia or lymphoma allowed tailored recommendations, patient care and follow-up assessment of patient needs and resulted in better patient outcomes\(^{(19)}\). Electronic needs assessment tools are useful as they can be completed faster, reduce paperwork and can aggregate data. Some technical difficulties may be experienced in the initiation phase and some patients will require assistance with use.

Needs assessment tool should always be accompanied by clinical review. As described by Taylor et al. (2012), needs assessment tools, especially checklists, may not identify all patient concerns\(^{(29)}\). Healthcare providers should be aware of patient needs that may not be included in the needs assessment tool. Mitcheson et al. (2003)\(^{(86)}\) describes how over-reliance on needs assessment tools may result in missing cues. Good listening and communication skills are required\(^{(78)}\) to establish a good relationship and trust with the patient to effectively identify needs including issues they may otherwise be reluctant to discuss. Patients should be included in the needs assessment process as active participants in their own care.

**What is required after needs assessment?**

Screening needs of a patient is only the first step of survivorship care. A plan must be in place on how to address identified needs (see ACSC Survivorship Care Plans: Literature Review and Toolkit for more detail). Some unmet needs may be resolved immediately at consultation or with the provision of information. Stanton et al. (2006) describe how minimal intervention such as orientation and provision of information can make a difference to patient outcome in the short term\(^{(87)}\). Problems identified and discussed at appointments can alleviate patient worries and relieve distress. Other unmet needs will require directing the patient to services (e.g. support group, exercise) or referral to a service. Patients may require referrals to psychosocial oncology, occupation therapy, nutritional services, physiotherapy, social work or pastoral care. There is also a possibility that the unmet need may not be resolved. Local guidelines should be established to direct course of action for identified needs.

A small pilot study\(^{(88)}\) by Fulcher et al. (2007) describes the effective implementation of the Distress Thermometer and Problem List in a busy radiation oncology clinic. Staff found the checklist helpful to identify concerns and allowed patients to express concerns that they don’t normally. Their program involved a well-defined referral process. Social work referrals increased over the 3 months. The authors state that ongoing education and evaluation of the implementation is critical to maintain the success of the tool in practice; outcomes such as compliance with guidelines, cost and patient satisfaction should be measured. Quality assurance is important to ensure that effective needs assessment is maintained.

**How often should needs assessment be carried out?**

There is a lack of consensus guidelines on the frequency of follow-up for needs assessment. This may be due to a lack of evidence on when it is most useful and relevant to conduct needs assessment. Available guidelines tend to focus on disease recurrence rather than a holistic review of needs in cancer
survivors. Low-risk patients are often discharged without plans for follow-up. It is therefore important to develop local protocols. Guidelines recommend assessing unmet need at various points of high stress and change in a patient’s cancer continuum as clinically indicated.

The type of cancer patient should be taken into consideration as there are certain groups with higher survivor needs that require additional monitoring. Female survivors, younger survivors and those who receive more intensive treatment have higher levels of unmet need and are less likely to have received post-treatment care, according to a large cross-sectional study of patients conducted by the Livestrong Foundation(14).

Needs assessment should be conducted soon after completion of cancer treatment and followed up regularly for the first few years after treatment completion as patients adjust back to normal life. Patients have described depression, stress and uncertainty following the end of treatment and a lack of assistance in making this transition(9). Breast cancer survivors <1 year since surgery experienced significantly higher unmet needs than breast cancer survivors >1 years since surgery(13). Breast cancer survivors with a survival duration of 1–3 years experienced significantly higher psychological and information needs than long-term breast cancer survivors >5 years(13).

Frequency of follow-up and surveillance should involve a discussion between patient and provider and may vary between individuals based on needs. Follow-up may also be informed by the wishes and needs of the patient. All issues may not be addressed at each visit. In long-term survivorship, patients should be equipped with the information on how to access additional cancer-related health services if required.

**Who should carry out follow-up?**

There is a lack of clarity and coordination of responsibilities for follow-up care. There are several survivorship care models published in the literature(79, 89, 90). Ongoing survivorship care may be implemented in community or hospital settings depending on available resources and level of need. It is essential that good communication and transition to the primary care practitioner is in place as the primary care practitioner is currently the most accessible healthcare service for patients. The primary care practitioner may not be familiar or adequately trained in survivorship care. The use of survivorship care plans can assist and is described below.

Skinner et al. (2006) states that nurses may be in a key position to coordinate these services from hospital care(91). Nurse-led follow-up may be a practical alternative to conventional care and is acceptable, appropriate and effective(92, 93).

**Survivorship care plans**

The Institute of Medicine identifies coordination between specialist and primary healthcare providers as an important part of survivorship care. Survivorship care plans formalise the transition to survivorship and can be a useful tool for needs assessment follow-up. Survivorship care plans are provided to patients after treatment completion or after a patient’s initial needs assessment. They usually include comprehensive health information, patient diagnosis and treatment history, resources, and instructions for obtaining health information in the future. Expected late effects and preventive strategies should be included. Survivorship care plans need to include a plan on future follow-up and monitoring.

Patients and primary care practitioners have expressed a desire for these care plans; however, barriers to implementation include time, training and staffing(94). The completeness of information from discharge plans and timeliness of transmission of information to primary care practitioners is variable(95). Electronic programs may assist in the creation of comprehensive survivorship care plans(80, 81).

The IOM states that despite the lack of evidence to support the use of survivorship care plans, they have strong face validity and can reasonably be assumed to improve care unless and until evidence accumulates to the contrary(74).
The Australian context

In 2011, the Victorian Department of Health initiated the Victorian Cancer Survivorship Program (VCSP) to pilot new models of care within the health system. The VCSP funded six projects to pilot different models of care across a range of settings and populations of survivors. Four of the six projects conducted needs assessments to inform the care coordination as well as the development of survivorship care plans. In most cases the screening tools were used to identify supportive care needs, symptom impact/management and quality of life. In some of the projects needs assessments findings were used to inform risk stratification. Most of the projects identified that needs of survivors change over time and that repeat assessment may be required(109).

Cost effectiveness

Ideally, a needs assessment tool should be easy and quick to implement and effective in identifying needs to minimise the resources required. However, it must be recognised that needs assessment tools are only screening tools and follow-up may still be required.

A needs assessment tool may be useful for prioritising resource allocation without unnecessarily increasing burden on the healthcare system(83). They can draw attention to needs early so they don’t have to be addressed later. For example, depression and anxiety has been linked to poor patient outcomes and quality of life. Patients with significant mood disturbances have increased rates of utilisation of healthcare services for psychological and physical manifestations(86).

No cost analysis studies on needs assessment tools were found specific to cancer survivors. Hollingworth et al. (2013) conducted a cost analysis study in cancer patients starting radiotherapy or chemotherapy. They found that the Distress Thermometer and Problem List was a fast and inexpensive tool to implement but found no evidence for psychological wellbeing, quality of life or reduced healthcare costs(87). This was despite one-third of patients reporting high distress and most patients reporting at least one physical or emotional problem. These results may have been affected by poor participation rates or discrepancies in staff training and supportive care.

Issues remain regarding evidence and funding for survivorship clinics that are staffed by adequately trained personnel. There is no evaluation of their effectiveness or value There is also a lack of evidence on effective interventions to meet identified needs(88, 99). More research is required on the effective implementation of needs assessment tools and their cost benefit. This lack of evidence is not only limited to cancer survivors; a review by Richardson et al. (2007) also found a lack of feasibility data and validation in routine care for needs assessment tools in cancer patients(100). The authors found no tool to be complete for all dimensions of needs assessment.
Recommendations

Due to high variability between different cancer survivor groups, a single needs assessment tool is unlikely to be appropriate for all patients. Needs assessment tools should be tailored to the population of cancer survivors at a particular centre. Any needs assessment tool should be accompanied by a conversation with the patient during which concerns can be elicited and clarified. The feasibility of the tool for the clinical practice should be considered, for example, the time required and the feasibility of an electronic tool.

When choosing a needs assessment tool, healthcare providers should select one that contains items most relevant to their patient population. Be aware of the limitations of the tool and compensate where possible. An additional tool that covers disease-specific issues for survivors of a particular cancer type (e.g. head and neck or breast cancer) may be added. A supplemental quality of life tool may be available to identify possible areas of need in cases where a needs assessment tool is not available. Keep in mind that QoL tools do not assess whether patients want help with a concern; they only provide an indication of the level of concern. Further items or tools may be added for particular symptoms of interest such as depression or fatigue.

Table 10 contains the recommendations resulting from this literature review.

Table 10: Recommendations for needs assessment

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<tr>
<th>Consideration</th>
<th>Recommendation</th>
<th>Addition</th>
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<tbody>
<tr>
<td>Which needs assessment tool to use</td>
<td>• 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.</td>
<td>o An additional open question may be added to elicit other patient concerns. o Supplement with additional needs assessment tool for specific patient groups or needs.</td>
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<td>When to assess need</td>
<td>• Assess soon after treatment completion as part of survivorship care planning. • Periodic follow up may be required during short-term survivorship (&lt;5 years post-diagnosis) as clinically indicated. • Reassess needs at significant times (e.g. health or social changes).</td>
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<tr>
<td>Who should assess need</td>
<td>• When possible encourage patients to self-complete the tool. • All staff undertaking needs assessment must be adequately trained in needs assessment</td>
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<tr>
<td>Consideration</td>
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<td><strong>Choosing assessment format</strong></td>
<td>• Assess whether paper or electronic assessments is most practical.</td>
<td>o 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.</td>
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<td></td>
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<td>o Not all tools are available in electronic form, implementation is time consuming and there is limited experience regarding successful implementation.</td>
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<td><strong>Preparation prior to needs assessment implementation</strong></td>
<td>• 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.</td>
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<td></td>
<td>• Allocate a clinical leader to facilitate needs assessment implementation.</td>
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<td></td>
<td>• Allocate the staff responsible for needs assessment (e.g. cancer nurse) and plan for adequate staff training (in needs assessment and communication skills).</td>
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<td></td>
<td>• Ensure resources and services for referral are available prior to implementation.</td>
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<td></td>
<td>• Create local guidelines for needs assessment and how this process fits in with follow-up care.</td>
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<tr>
<td><strong>Use of needs assessment results</strong></td>
<td>• Be guided by published evidence and guidelines.</td>
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<td></td>
<td>• Use the needs assessment to identify when a survivorship care plan is needed.</td>
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<td></td>
<td>• Communicate survivorship care plans to the patient and relevant team members including the general practitioner.</td>
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<tr>
<td></td>
<td>• Aggregated data from needs assessment for service planning. Ideally this should result in survivors reporting fewer unmet needs and/or appropriate allocation of resources.</td>
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</tbody>
</table>
**Consideration** | **Recommendation** | **Addition**
---|---|---
**Other** | • Monitor needs assessment implementation and service usage.  
• Identify people who may require help or further consideration to complete the tool. | ○ People from CALD backgrounds, with poor literacy and with intellectual and other disabilities may require alternative modes of delivery or assistance.

Although needs assessment tools are useful to direct services to address unmet needs in patients, the impact of this strategy in clinical practice is unknown. It is suggested that audits on patient outcomes and wellbeing will be beneficial for quality improvement in survivorship practices.

**Conclusion**

Needs assessment and interventions to address issues is an essential element of survivorship care. Needs assessment tools may be used to assess individual patient needs or collect data for a survivorship program. The tools must be able to identify high unmet needs, have good acceptability and be easy to implement for patients and into clinical practice. This is especially important as the cancer survivor population and the burden on the healthcare system continues to grow.

The review highlights the lack of evidence regarding the impact of using needs assessment tools in clinical practice and lack of guidance regarding implementing needs assessment outside of a research setting. Limited studies and low level evidence were found on the implementation of needs assessment tools and their effect on patient outcome. Only a small number of studies were found on validation of these tools—in the research setting, not the clinical setting—and there was not enough data available to directly compare tools. The patients recruited in the studies lacked a representative group of rural patients, non-English speaking, ethnic and long-term survivors. No tool was able to provide a holistic review of all patient needs.

Future research could include large longitudinal studies in clinical practice. Studies could focus on validation in a broad selection of patients and include data on implementation, patient outcomes and cost analysis. Until then, healthcare providers should carefully consider the most relevant and psychometrically rigorous needs assessment tool for use with their patient group. A tailored approach to needs assessment and follow-up should be used to ensure that needs are identified and optimal patient-centred care is delivered.
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\(^\text{(101)}\). 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\(^\text{(102)}\).

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\(^\text{(103)}\).

Cohen's kappa
Cohen’s kappa is a measure of the agreement between two raters who determine which category a finite number of subjects belong to whereby agreement due to chance is factored out. The two raters either agree in their rating (i.e. the category that a subject is assigned to) or they disagree; there are no degrees of disagreement (i.e. no weightings)\(^\text{(104)}\).

Cronbach’s alpha
Cronbach’s alpha is a numerical coefficient of reliability\(^\text{(105)}\). It determines the internal consistency or average correlation of items in a survey instrument to gauge its reliability\(^\text{(105)}\).

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\(^\text{(106)}\).

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\(^\text{(107)}\).
Unmet needs

Those needs that lack the level of service or support an individual perceives is necessary to achieve optimal well-being (108). 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.
References


