

Australian Cancer Survivorship Centre

A Richard Pratt Legacy



Survivorship Care Plans: Literature Review



Peter Mac

Peter MacCallum Cancer Centre
Victoria Australia



email: contactacsc@petermac.org

www.petermac.org/cancersurvivorship

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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 follow-up 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 survivorship care plan 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](#).

This 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 the literature review 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 valuable contribution to this report:

- Professor Patsy Yates, Head, School of Nursing, Queensland University of Technology, and Director, Centre for Palliative Care Research and Education, Queensland Health
- Ms Vicki McLeod, Oncology Nurse Practitioner, Monash Cancer Centre, Southern Health, Victoria.

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 report rests entirely with the ACSC.

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

This document is available as a PDF at: www.petermac.org/cancersurvivorship.

Recommended citation:

Nicole Kinnane, Rosemary Moore, Michael Jefford, Amanda Piper, Linda Nolte. 2015. Survivorship care plans: literature review. Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre, Melbourne.

January 2016

Disclaimer

This work is the result of a collaborative effort between the Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre and the Victorian Department of Health and Human Services. 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

The landmark 2005 Institute of Medicine report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, highlighted survivorship care plans (SCPs) as an important aspect of care provision to assist survivors to transition to the post-treatment phase. The Institute of Medicine recommended that all survivors receive an SCP. The SCP is a multi-purpose communication tool designed to guide clinical care and coordination following acute treatment, meet survivor information needs, and augment the supportive care process through the post-treatment transition phase. Despite overwhelming support, uptake of the Institute of Medicine recommendations has been limited. Barriers to widespread implementation of SCPs have been noted. In Australia, SCPs are not a standard of clinical practice. The aim of this report is to review the current literature regarding SCP use in adult cancer survivors, summarising evidence from published scientific studies and grey literature. The review has been informed by three questions:

- What evidence exists regarding the impact of SCPs for both survivors and healthcare professionals?
- What guidance exists regarding designing content for SCPs?
- What guidance exists regarding implementation of SCPs in practice?

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 Cochrane Database, MedLine, CINAHL and PsychInfo were searched using relevant subject headings and key words. Manuscripts that met the inclusion criteria were assessed on their ability to address the three research questions. Grey literature was sourced from select key survivorship organisations within the United Kingdom, the United States, Canada and Australia.

Results

A total of 69 articles were included in the review. The majority of the publications reported on outcomes for breast cancer survivors. A number of studies were observational. Some reported on the development of SCPs, the implementation process and patient satisfaction. Positive outcomes have been identified for survivors; however, the evidence focuses on survivor satisfaction. Health professional perceptions of the value of SCPs are they are generally useful.

Guidance regarding designing content of SCPs addresses a range of factors including differing preferences of patients and health professionals, essential content requirements, use of plain language, and recommendations concerning paper-based and electronic formats.

To date, implementation of SCPs remains sporadic/inconsistent. Guidance regarding implementation of SCPs arises predominantly from consensus documents. These acknowledge common barriers to SCP implementation, including time and resources. They suggest providing targeted organisational support to facilitate SCP implementation. Although systematic reviews and integrative reviews concluded there were limited measurable benefits of SCPs and limited evidence supporting SCP use in practice, the general consensus is that more research is required to determine long-term impacts.

Conclusions

Evidence regarding the benefits of SCPs is accumulating. The perceptions of SCP value for survivors are generally positive. Potential benefits have been identified for both survivors and health professionals. Enablers and barriers to SCP use have been identified. It is critical to address these when planning and implementing SCP initiatives and survivorship care in general. There is no long-term outcome data and the long-term value of SCPs for patients and healthcare professionals remains equivocal. There is call for improved processes and policies to facilitate the implementation process.

Part I: Literature review

Introduction

A cancer survivor is 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'⁽¹⁾. In Australia, 'cancer survivor' 'is generally used to refer to people who have completed initial cancer treatments and 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'⁽²⁾.

Globally, the number of cancer survivors is estimated at 28 million⁽³⁾. In 2007, it was estimated that about 774,700 Australians had been diagnosed with cancer in the previous 26 years—about 3.6% of the population⁽⁴⁾. The relative 5-year survival rates increased from 47% in 1982–6 to around 66% in 2006–10 for all cancers combined⁽⁴⁾. Approximately 230,000 survivors live in Victoria⁽⁵⁾. Victoria accounts for 24.9% of the Australian population⁽⁶⁾. Therefore it could be estimated that there are currently at least 900,000 survivors in Australia. As the Australian population ages and treatments improve, these numbers will increase.

Health systems will need to adapt to the increasing numbers of cancer survivors who are often living with pre-existing health conditions⁽⁷⁾. Challenges lie with the current acute health system, which is primarily focused on illness management, with little emphasis on the role that survivors can play in self-management of their health and wellness⁽⁸⁾. For some people, a cancer diagnosis can provide incentive to make positive lifestyle changes⁽⁹⁾. For healthcare professionals, the post-treatment phase is an opportunity to support patients to self-manage their care⁽¹⁰⁾ and to communicate timely information to other healthcare professionals about the survivor's ongoing care needs, which range from follow-up to effects from cancer treatment to financial and emotional needs⁽¹¹⁾. Attention to better coordination between specialist oncology and primary and community healthcare will be required, if, as is expected, cancer is to be increasingly managed in the community setting⁽¹²⁾.

The landmark 2005 Institute of Medicine report *From Cancer Patient to Cancer Survivor: Lost in Transition* highlighted survivorship care plans (SCPs) as an important aspect of care provision to assist survivors to transition to the post-treatment phase, recommending that all survivors receive one⁽¹³⁾. The SCP is a multi-purpose communication tool, designed to guide clinical care and coordination following acute treatment, to meet survivor information needs and to augment the supportive care process through the post-treatment transition period^{(13, 14), (15), (16), (3)}. It is a formal, written document, detailing some or all of the following: the patient's cancer diagnosis and treatment, potential late and long-term effects arising from the cancer and its treatment, signs of recurrence, recommended follow-up, and strategies to remain well. The SCP may be the treatment plan or the follow-up care plan or both, and may include other documentation as determined by the healthcare provider, organisation or as requested by the survivor and their carers/family.

The Institute of Medicine recommendation regarding SCPs was not supported by evidence at that time. However, on face-value, SCPs act as a communication tool between healthcare professionals and address potential health implications faced by survivors as they transition from treatment to post-treatment^{(13) (17)}. Accordingly, various professional groups and cancer organisations have recognised and promoted the use of SCPs in clinical practice. For example, the Livestrong *Essential Elements of Survivorship Care* (recommendations for oncology care settings in the United States) identified five elements that are essential to provide direct access to or referral for survivorship care. Of these five, providing access to an SCP was given the highest priority. Earle and Ganz (2012)⁽¹⁷⁾ encourage healthcare providers to focus their efforts on providing the 'Livestrong essential elements' as a minimum standard. They refer to these elements as important in achieving improvement in care for cancer survivors post-treatment⁽¹⁷⁾. In its statement on survivorship care, the American Society of Clinical Oncology (ASCO) promotes the use of written treatment summaries and care plans⁽¹⁸⁾. The ASCO Quality Oncology Practice Initiative (QOPI) includes several survivorship care measures, so the system of care delivery can identify and respond to areas demonstrating a need for improvement (see www.asco.org/practice-research/measuring-quality-survivorship-care). The George Washington

University (GW) Cancer Institute recommends SCPs are delivered and quality measured within health organisations/the health system⁽¹⁹⁾. The National Cancer Survivorship Initiative (NCSI) in the United Kingdom emphasises the use of treatment summaries within a patient-centred, coordinated care model⁽²⁰⁾. More recently, the American College of Surgeons Commission on Cancer has adopted implementation of SCPs as a clinical standard required for accreditation. By 2015, all accredited programs will need to have implemented SCPs and treatment summaries^{(21) (3)}.

In Australia, SCPs are not a standard of clinical practice. Various states and territories in Australia are in the early stages of incorporating survivorship issues as considerations for future cancer planning and some individual healthcare centres have introduced SCPs in specific clinics. Through the Victorian Cancer Survivorship Program (VCSP) the Victorian Government funded six programs to pilot different models of survivorship care across a range of settings and populations, with each of these projects incorporating SCPs with varying degrees of success⁽²²⁾. Since the Institute of Medicine report, much research has been undertaken into SCP development and provision, predominantly in the United States and Canada. A number of recent reviews have endeavoured to summarise the current state of knowledge of SCPs for adult cancer survivors^{(23) (24) (25) (3)}.

Despite overwhelming support, there has been limited uptake of the Institute of Medicine recommendations regarding the provision of SCPs^{(17) (14)}. Barriers to widespread implementation of SCPs have been noted. For healthcare professionals, commonly experienced barriers to using and implementing SCPs in clinical practice include limited time, concerns about cost and remuneration, uncertainty about the evidence of their effectiveness, and limited long-term outcome data^{(17) (26) (27) (28)}. It has also been suggested that limited uptake of SCPs leads to negative perceptions of their worth⁽²³⁾.

The aim of this report is to review the current literature regarding SCP use in adult cancer survivors, summarising evidence from published scientific studies and grey literature. The review has been informed by three questions:

- What evidence exists regarding the impact of SCPs for both survivors and healthcare professionals?
- What guidance exists regarding designing content for SCPs?
- What guidance exists regarding implementation of SCPs in practice?

Search methodology

Search strategy

This review focused on articles published between January 2010 and October 2014. The Cochrane Database of Systematic Reviews was searched for published systematic reviews within the relevant time criteria. MedLine, CINAHL and PsychInfo were searched for any systematic review not yet updated in the Cochrane database and for other relevant scientific literature. The grey literature included in this review was published between 2005 and 2014. This timeframe was chosen as coinciding with the release of the Institute of Medicine report *From Cancer Patient to Cancer Survivor: Lost in Transition*. Grey literature was sourced from select key survivorship organisations within the United Kingdom, the United States, Canada and Australia. This literature provided an additional source of supporting material.

It should be noted that this report is not a systematic review of the literature.

Search terms

The following search terms were used separately and in combination: 'cancer', 'survivorship care plans', 'post-treatment care plans', 'treatment summary', 'communication strategies in transitional care', 'care coordination', 'shared care model' and 'electronic care plans'.

Evidence

Inclusion/exclusion criteria

Studies that assessed the use of SCPs and their implementation or impact on patients in the post-treatment phase were included. The sample was limited to manuscripts which included survivors of cancer from completion of primary treatment to 5 years post-treatment.

Studies with participants aged under the age of 18 years were excluded. End-of-life and palliative care studies were also excluded.

Data extraction and synthesis

A matrix was developed to record all collected data against each research question, including the source, study population, design, method, description of included studies, results and outcomes, and other information (e.g. bias).

Titles and abstracts from search results were scanned for relevance, and full manuscripts were assessed on their ability to address the three research questions.

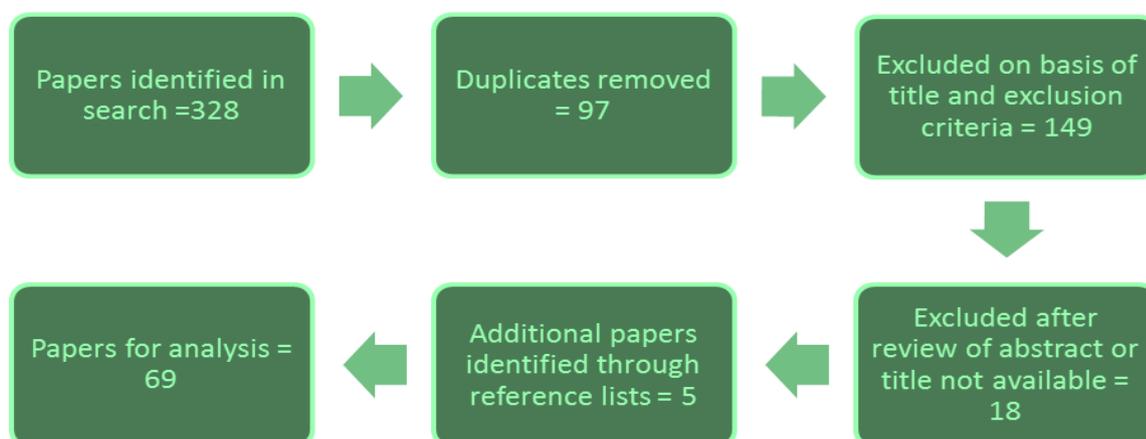
Search results

In total, 328 articles were captured and retrieved. Ninety-seven duplicates were removed (some articles appeared in more than two databases but were only measured once as a duplicate) and 149 titles were rejected due to exclusion criteria. Five articles not captured in the initial search were added. Eighty-seven abstracts were then reviewed by one reviewer, with a further 18 abstracts removed (unable to source full journal, were books or did not meet search criteria). A total of 69 articles were included in the review. Refer to Figure 1. Of these, only six randomised controlled trials, three systematic reviews and one integrative review were identified for inclusion. The majority of the publications reported on outcomes for breast cancer survivors. A number of studies were observational. Some reported on the development of SCPs, the implementation process and patient satisfaction. Most publications originated from the United States. Australian studies reported on breast and colorectal cancer survivors.

Details of the publications are listed in Table 1.

The systematic reviews and integrative review concluded there were limited measurable benefits of SCPs and limited evidence supporting their use in practice and called for more research. An overview of the outcomes from systematic reviews is detailed in Table 2.

Figure 1: Search results



Search limitations

The search terms chosen omitted 'models of survivorship care' and 'models of follow-up care'. As SCPs are considered a key component in models for delivering survivorship care, omitting this search term may have resulted in some papers being excluded that may have incorporated this information under the umbrella term of 'models of survivorship/follow-up care'.

Table 1: Details of publications

Study Design	Number (n=69)	Author
Qualitative study	12	Ashing-Giwa et al. 2013 (US) ⁽²⁹⁾ , Chubak et al. 2012 (US) ⁽³⁰⁾ , Hahn & Ganz 2011 (US) ⁽³¹⁾ , Jackson et al. 2013 (US) ⁽³²⁾ , Mayer et al. 2012 (US) ⁽³³⁾ , Marbach & Griffie 2011 (US) ⁽³⁴⁾ , Schootman et al. 2013 (US) ⁽³⁵⁾ , Shalom et al. 2011 (US) ⁽³⁶⁾ , Sprague et al. 2013 (US) ⁽³⁷⁾ , Collie et al. 2014 (Canada) ⁽³⁸⁾ , Haq et al. 2013 (Canada) ⁽³⁹⁾ , Singh-Carlson et al. 2013 (Canada) ⁽⁴⁰⁾ , Smith, Singh-Carlson et al. 2011 (Canada) ⁽⁴¹⁾ .
Quantitative study	26	Birken et al. 2013 (US) ⁽⁴²⁾ , Birken et al. 2014a (US) ⁽⁴³⁾ , Birken et al. 2014b (US) ⁽⁴⁴⁾ , Blinder et al. 2013 (US) ⁽⁴⁵⁾ , Campbell et al. 2012 (US) ⁽⁴⁶⁾ , Casillas et al. 2011 (US) ⁽⁴⁷⁾ , Faul et al. 2012 (US) ⁽⁴⁸⁾ , Forsythe et al. 2013 (US) ⁽⁴⁹⁾ , Hill-Kayser et al. 2013 (US) ⁽⁵⁰⁾ , Mayer, Gerstel et al. 2014 (US) ⁽⁵¹⁾ , Merport et al. 2012 (US) ⁽⁵²⁾ , Nissen et al. 2013 (US) ⁽⁵³⁾ , Nissen et al. 2012 (US) ⁽⁵⁴⁾ , Rechis et al. 2014 (US) ⁽⁵⁵⁾ , Sabatino et al. 2012 (US) ⁽⁵⁶⁾ , Rosales et al. 2014 (US) ⁽⁵⁷⁾ , Salz, Oeffinger, Lewis et al. 2012 (US) ⁽⁵⁸⁾ , Salz, McCabe et al. 2014 (US) ⁽⁵⁹⁾ , Stricker et al. 2011 (US) ⁽⁶⁰⁾ , Tevaarwerk et al. 2014 (US) ⁽⁶¹⁾ , Blaauwbroek et al. 2012 (Netherlands) ⁽⁶²⁾ , Brennan et al. 2010 (Australia) ⁽⁶³⁾ , Brennan, Butow et al. 2014 (Australia) ⁽⁶⁴⁾ , Coyle et al. 2014 (Canada) ⁽⁶⁵⁾ , Smith, Wai et al. 2011 (Canada) ⁽⁶⁶⁾ .
Mixed method	2	Blanch-Hartigan et al. 2014 (US) ⁽⁶⁷⁾ , Dulko et al. 2013 (US) ⁽⁶⁸⁾ .
Systematic review	3	Brennan, Gormally et al. 2014 (Australia) ⁽²⁴⁾ , Keesing et al. 2014 (Australia) ⁽⁶⁹⁾ , Howell, Hack et al. 2012 (Canada) ⁽⁷⁰⁾ .
Randomised control trial	6	Brothers et al. 2013 (US) ⁽⁷¹⁾ , Hershman et al. 2013 (US) ⁽⁷²⁾ , Oeffinger et al. 2011 (US) ⁽⁷³⁾ , Rocque et al. 2014 (US) ⁽⁷⁴⁾ , Grunfeld et al. 2011 (Canada) ⁽⁷⁵⁾ , Nicolaije et al. 2014 (Netherlands) ⁽⁷⁶⁾ .
Review	8	Cowens-Alvarado et al. 2013 (US) ⁽¹⁴⁾ , Faul et al. 2010 (US) ⁽⁷⁷⁾ , McCabe, Bhatia et al. 2013 (US) ⁽¹⁸⁾ , McCabe, Partridge et al. 2013 (US) ⁽⁷⁸⁾ , McCorkel et al. 2011 (US) ⁽⁷⁹⁾ , Salz, Oeffinger, McCabe et al. 2012 (US) ⁽²⁶⁾ , Daudt et al. 2014 (Canada) ⁽²⁵⁾ , Earle & Ganz 2012 (Canada) ⁽¹⁷⁾ .
Report	4	Guy et al. 2013 (US) ⁽⁸⁰⁾ , Makari Judson et al. 2013 (US) ⁽⁸¹⁾ , Mayer, Nekhlyudov et al. 2014 (US) ⁽²⁸⁾ , National Cancer Survivorship Initiative 2010 (UK) ⁽⁸²⁾ .
Phase 1 study	1	Jefford et al. 2011 (Australia) ⁽⁸³⁾
Commentary	3	Mayer 2014 (US) ⁽⁸⁴⁾ , McCabe, Faithfull et al. 2013 (US) ⁽¹⁶⁾ , Parry et al. 2013 (US) ⁽²⁷⁾ .
Integrative Review	1	Mayer, Birken et al. 2014 (US) ⁽²³⁾

Case management	1	McCabe & Jacobs 2012 (US) ⁽⁸⁵⁾
Descriptive paper	2	Nekhlyudov & Schnipper 2012 (US) ⁽⁸⁶⁾ , Stricker & O'Brien 2014 (US) ⁽³⁾

Impact of SCPs for survivors and healthcare professionals

Benefits of SCPs

Several studies including systematic reviews have sought to determine the impact of SCPs. Positive outcomes have been identified; however, the evidence is not robust. The general consensus is that more research is required to determine long-term impacts. Refer to Table 2.

Table 2: Overview of outcomes from systematic reviews

Author	Journal & Year	Review Type	Title	Aim/Question	No of study/ guideline	Outcomes
Brennan, Gormally et al.	British Journal of Cancer 2014	Syst	Survivorship care plans in cancer: a systematic review of care plan outcomes	To systematically review the evidence evaluating outcomes following the development and implementation of SCPs in cancer survivorship	10	<ul style="list-style-type: none"> Measurable benefits of SCPs limited High levels of survivor satisfaction Barriers related to resources required to implement
Howell, Hack et al.	Journal of Cancer Survivorship 2012	Syst	Models of care for post-treatment follow-up of adult cancer survivors: a systematic review and quality appraisal of the evidence	To determine the optimum organisation and care delivery structure for cancer survivorship service (including SCP components)	19	<ul style="list-style-type: none"> SCPs can be used to assist in reducing stress associated in transition from active treatment to post-treatment Need for more research to inform development of survivorship services including cost-effectiveness
Keesing et al.	Journal of Cancer Survivorship 2014	Syst	Cancer survivors' experiences of using survivorship care plans: a systematic review of qualitative studies	To document and review available published qualitative literature describing cancer survivors' experiences of using SCPs	11	<ul style="list-style-type: none"> Recommends using SCPs, however they are not consistently used Limited consensus regarding content, format and development Currently limited evidence that supports use in practice More research needed
Mayer, Birken et al.	Cancer 2015	Int	Summing it up: An integrative review of studies of cancer survivorship care plans (2006–2013)	To summarise the state of scientific knowledge currently available regarding SCPs for adult cancer survivors and identify gaps to be addressed by future research	42	<ul style="list-style-type: none"> Future studies required to identify SCP 'active ingredients' Limited reported survivor outcomes re impact of SCP on health benefits, long-term improvements and care coordination May be null effect in some RCT studies. Several observational studies reported positive impact of SCPs on survivor outcomes

For patients

Results regarding the benefits of SCPs are equivocal. In a very recent systematic review, Brennan and colleagues (2014)⁽²⁴⁾ found no significant effect on survivor distress, satisfaction with care, cancer-care coordination or oncological outcomes in randomised controlled trials (RCTs)⁽²⁴⁾. Nevertheless, in their review of qualitative studies of cancer survivors' experiences of SCPs, Keesing and colleagues (2014)⁽⁶⁹⁾ concluded that there was great potential for SCPs to assist cancer survivors⁽⁶⁹⁾.

At this time, the results from RCTs have not found benefits for patients. Grunfeld and colleagues (2011)⁽⁷⁵⁾ found no benefit in terms of patient-reported outcomes⁽⁷⁵⁾ and Brothers and colleagues (2013)⁽⁷¹⁾ found no benefit in terms of rating satisfaction with care and health services⁽⁷¹⁾. Hershman and colleagues (2013)⁽⁷²⁾ found no significant improvements in most patient-reported outcomes⁽⁷²⁾. Mayer and colleagues (2014)⁽²³⁾, reviewing these trials, observed that results indicating limited benefits for patients may be due to factors such as sampling highly informed patients, use of survivor-reported outcomes, or null effect ('survivors who do not receive an SCP do not know that anything is missing from their care')⁽⁴⁴⁾.

Despite limited Level 1 evidence suggesting a positive effect for survivors receiving SCPs, both qualitative and quantitative studies have suggested some benefits, notably a high level of survivor satisfaction^{(24) (83) (48)} and self-reported understanding of the information included in the SCP^{(24) (57)}. Hershman and colleagues (2013)⁽⁷²⁾ identified a short-term decrease in overall patient worry (increased peace of mind)⁽⁷²⁾. Lifestyle change⁽⁵⁰⁾; increased compliance with recommended surveillance⁽⁷³⁾; an increase in survivor knowledge^{(53) (74)}; greater awareness of the doctor responsible for follow-up care⁽⁷⁵⁾; and increased knowledge about diagnosis and treatment⁽⁵³⁾, particularly in relation to follow-up care⁽⁵⁴⁾ have also been reported.

A care plan was seen to be very important to understanding late effects of treatment, although not necessary to clarify the roles of primary care providers and oncologists in survivorship care⁽³⁷⁾. Survivors appreciated the fact that having an SCP and choosing to share it with their primary care provider and other health professionals involved in their care may reduce duplicate testing and/or screening for other cancers⁽⁴⁸⁾.

Patients who received a treatment summary were more likely to report that their needs had been met, including receiving information about possible late effects, care they received during treatment and care they received after treatment⁽⁵⁵⁾. SCPs may improve communication with and between healthcare providers^{(50) (33) (45) (38)}. They can also be used to assist in promoting healthy practices and to enhance general knowledge about cancer among other family members⁽⁴⁸⁾.

Perceived benefits of SCPs for patients/survivors are outlined in Table 3.

Table 3: Benefits of SCPs for patients/survivors

Evidence of/perceived benefit	Study
Survivor satisfaction; SCP well received	Brennan et al. 2014; Jefford et al. 2011; Faul et al. 2012; Spain et al. 2012
Decrease health worry/increase peace of mind	Hershman et al. 2013; Faul et al. 2012; Blinder et al. 2013
Communicate risk and increase compliance with recommended medical surveillance	Oeffinger et al. 2011
Self-reported understanding of the SCP	Brennan et al. 2014; Rosales et al. 2014
Increase survivor knowledge	Nissen et al. 2013; Rocque et al. 2014
Increase survivor knowledge of follow-up care	Nissen et al. 2013
Awareness of doctor responsible for follow-up care	Grunfeld et al. 2011
Improve cancer survivors' knowledge of details about their diagnosis and treatment (treatment summary)	Nissen et al. 2013
Improve communication with healthcare providers and/or between healthcare providers	Hill-Kayser et al. 2013; Mayer et al. 2012; Blinder et al. 2013; Collie et al. 2014
Understand late effects of treatment	Sprague et al. 2013
Feel that their needs had been met, including receiving information about possible late effects, care they received during treatment, and care they received after treatment	Rechis et al. 2014
Reduce duplicative procedures	Faul et al. 2012
Promote lifestyle and behavioural change (survivors)	Hill-Kayser et al. 2013
Promote healthy practices and enhance general knowledge about cancer (family members)	Faul et al. 2012
No significant improvements	
Most patient-reported outcomes	Hershman et al. 2013
No evidence of benefit	
Patient-reported outcomes	Grunfeld et al. 2011
Rate health services and satisfaction with care	Brothers et al. 2013
No evidence of effect (summary data from a systematic review)	
Survivor distress	Brennan et al. 2014
Satisfaction with care	
Cancer care coordination	
Oncological outcomes	

Long-term benefits for patients

This review found no significant information about long-term outcomes for patients who receive an SCP. One study by Campbell and colleagues (2012)⁽⁴⁶⁾ found very limited recall of the documents three years after receiving them and uncertainty about their value⁽⁴⁶⁾. Prospective studies are required to support long-term outcomes for the impact of SCPs for patients.

For health professionals

Studies examining the benefits of SCPs for healthcare providers have generally been about perceptions of their usefulness. Perceptions of the value of SCPs are generally useful⁽⁸²⁾. Outcomes of an Australian survey of specialist oncologists, breast physicians and breast care nurses reported support for the use of SCPs in potentially improving care⁽⁶³⁾. Similarly, a study of healthcare professionals working with colorectal cancer patients expressed strong support for the development and use of SCPs for bowel cancer survivors⁽⁸⁷⁾. Primary care practitioners identify that a follow-up care plan would help them improve their survivorship practices⁽⁸⁸⁾. SCPs could help to improve coordination of survivor care between healthcare providers⁽⁴⁸⁾. Blanch-Hartigan and colleagues (2014)⁽⁶⁷⁾ found that increased awareness of survivorship care promoted increased use of SCPs and greater likelihood that the oncologist would discuss survivorship care planning with survivors⁽⁶⁷⁾.

Primary care practitioners have reported receiving too little information about treatment problems, increased risk of secondary cancers, monitoring and other issues, and endorse the idea of SCPs as a possible solution⁽⁵⁸⁾. Primary care practitioners value SCPs and report their use would help them to feel more confident and better prepared to care for survivors^{(36) (39)}. Provision of SCPs by oncologists to primary care practitioners prompted more discussion by primary care practitioners of survivorship care with survivors⁽⁶⁷⁾.

For health systems/programs efficiency

Few studies have looked at the potential impact of SCPs on health systems and program efficiency. An interesting study by Makari-Judson and colleagues (2013)⁽⁸¹⁾ sought to evaluate whether SCPs affected waiting times and volume of patients seen. They found that SCPs contributed to reduced waiting times and an increase in the volume of new patients seen by breast surgeons⁽⁸¹⁾. Rosales and colleagues (2014)⁽⁵⁷⁾ evaluated the expenses and reimbursement for survivorship visits that incorporated the development and use of SCPs at the St Luke's Mountain States Tumor Institute. At this institute, expenses associated with development of the SCPs were covered by reimbursement received for the survivorship visits⁽⁵⁷⁾.

Coyle and colleagues (2014)⁽⁶⁵⁾ looked at the cost-effectiveness of SCPs for women who had completed initial breast cancer treatment. They found no associated cost benefit for the use of SCPs and concluded that in this experience, the SCP was costly to introduce and not a cost-effective use of health resources⁽⁶⁵⁾. In contrast, respondents in Haq and colleagues' study (2013)⁽³⁹⁾ reported that SCPs used by primary care practitioners had the potential to reduce referrals back to specialists and increase efficiency of clinic visits⁽³⁹⁾.

Discussion and limitations

Most studies assessing the benefits of SCPs have used an observational design, relied on self-reported outcomes and had a limited number of participants⁽²³⁾.

These findings provide some insight into the *potential* effect of SCPs in clinical practice; however, further research is required to support their implementation and adoption.

More information is required to determine the impact and value of using SCPs in a discharge consultation. More information is needed about long-term outcomes of SCP receipt for survivors.

Content of SCPs

Considering the audience

More emphasis is now placed on SCPs being designed to meet the needs of healthcare professionals, survivors and family/carers. Attention to differing literacy levels requires information to be presented in a clear and easy-to-understand manner. At times, more detailed additional information may be required for healthcare professionals⁽²⁸⁾. In practice, studies have shown that most SCPs are developed principally for survivors and at times copies may be sent to other health professionals involved in the patient's care and may be shared by the survivor with family and healthcare providers⁽²⁴⁾.

When developing an SCP, it is recommended that 'a one size fits all approach' be avoided. McCorkel and colleagues (2011)⁽⁷⁹⁾ recommend that oncology practices engage with survivors and families to develop mutually agreed care plans⁽⁷⁹⁾. Survivor needs vary, depending on their circumstances, disease, stage of survivorship and information preferences. Therefore SCPs should be patient centred and dynamic^{(39) (32) (40)}. It is recommended they include information relevant to the patient's age and include information about accessing community-based resources^{(40) (32)}.

Preferences of patients

In their integrative review, Mayer and colleagues (2014)⁽²³⁾ highlight that survivors and healthcare providers have differing information preferences and requirements of what to include in SCPs⁽²³⁾. Haq and colleagues (2013)⁽³⁹⁾ found survivors of breast cancer wanted a breadth of medical and psychosocial information ranging from basic follow-up scheduling information to detailed information concerning their specific diagnosis and stage of disease. They reported needs may differ within a particular cancer group according to age and life stage, and that needs may change throughout the cancer journey depending on the person's individual circumstances; family members' needs may also change. Of note, survivors requested that information included in the SCP be reflective of current research and international best practice⁽³⁹⁾. Survivors also expressed a desire to be informed about the amount and type of information being sent to their primary care practitioners⁽⁴⁰⁾.

Survivors reported a preference for SCPs to include information about: symptoms to watch for post-treatment^{(29) (40) (33)} and who to contact and report these symptoms to^{(29) (33)}; the potential to develop depression⁽⁴⁰⁾ and the emotional benefits of accessing peer support^{(40) (33)}; existing comorbidities; and current medications⁽²⁹⁾.

It is also recommended that existing SCP templates be adapted to include culturally sensitive approaches to information and references to health issues experienced by particular cultural groups, for example potential differences in skin healing processes experienced by people of African descent when exposed to surgery/radiotherapy/chemotherapy⁽²⁹⁾.

Outcomes of studies exploring the requirements of particular patient groups in the post-treatment phase advocate using a targeted approach to SCP content based on unmet needs. For example, in a study of women with breast cancer, Brennan and colleagues (2014)⁽⁶⁴⁾ reported all women desired the SCP to include information that clearly indicated who would be responsible for care management in the post-treatment phase. Younger women in the study reported needing support regarding fear of recurrence⁽⁶⁴⁾.

McCorkle and colleagues (2011)⁽⁷⁹⁾ urge practitioners to formulate mutually agreed care plans with patients and their families. They recommend regular reviews of SCPs to ensure the plan remains current, as survivor requirements of their SCPs and their ability and preferences in managing their care may change over time⁽⁷⁹⁾.

Table 4 lists the identified patient/survivor preferences for information to include in SCPs. Of note: the importance of these aspects is unknown. These recommendations are from single studies surveying limited numbers.

Table 4: Patient/survivor preferences for information to include in SCPs

Information preference	Study
Overview of purpose of document	Ashing-Giwa et al. 2013
Contact information for healthcare provider	Ashing-Giwa et al. 2013; Mayer et al. 2012
Information about diagnosis and prognosis	Singh-Carlson et al. 2013; Mayer et al. 2012; Haq et al. 2013
Individualised information	Singh-Carlson et al. 2013; Haq et al. 2013
Past medical history	Ashing-Giwa et al. 2013
Overview of their cancer-related information (treatment summary)	Ashing-Giwa et al. 2013; Singh-Carlson et al. 2013; Mayer et al. 2012
Follow-up schedule	Ashing-Giwa et al. 2013; Singh-Carlson et al. 2013; Mayer et al. 2012; Haq et al. 2013
Symptom management	Ashing-Giwa et al. 2013; Mayer et al. 2012
Guidance regarding recurrence signs and symptoms	Ashing-Giwa et al. 2013; Singh-Carlson et al. 2013; Mayer et al. 2012
Expected side effects, including late and long-term effects	Ashing-Giwa et al. 2013; Singh-Carlson et al. 2013; Mayer et al. 2012
Potential to develop depression	Singh-Carlson et al. 2013
Referrals made to other services	Ashing-Giwa et al. 2013
Pre-cancer and post-cancer comorbidities	Ashing-Giwa et al. 2013
List of current medications	Ashing-Giwa et al. 2013
Sexual health and related care	Ashing-Giwa et al. 2013
Healthy lifestyle options (nutrition and exercise)	Ashing-Giwa et al. 2013; Singh-Carlson et al. 2013; Mayer et al. 2012
Community-based peer support/resources	Singh-Carlson et al. 2013; Mayer et al. 2012; Haq et al. 2013
Career, financial and legal	Ashing-Giwa et al. 2013; Haq et al. 2013
Spirituality	Ashing-Giwa et al. 2013
Clinical practice guidelines	Haq et al. 2012
Information for carers/family	Ashing-Giwa et al. 2013; Mayer et al. 2012
Knowledge	Singh-Carlson et al. 2013

Preferred language and format for the SCP

The language and format of SCPs needs to be clear and accessible. To aid survivors' understanding, it is important that the information content be presented in non-medical terms⁽³⁾ and be available in the person's first language⁽⁴⁰⁾. Use of a template with a process that includes revision of 'oncospeak' may be helpful⁽³⁾. Mayer and colleagues note that in some instances plain language summaries may be difficult to provide if some medical terms are required to be used⁽²³⁾.

Survivors have identified both paper and electronic records as useful; some prefer both⁽²³⁾. Paper-based SCPs or an electronic document using preexisting templates are the most common formats in current use. Healthcare professionals and survivors may also prefer internet-based applications to create individualised SCPs⁽⁵⁰⁾.

Electronic SCP options are being trialled as a solution to overcome reported barriers for SCP use, for example to reduce time to design, prepare and implement SCPs in practice^{(76) (50) (61)}. Haq and colleagues (2013)⁽³⁹⁾ consulted stakeholder groups (breast cancer survivors, primary care practitioners and oncology specialists) to design an SCP consisting of both web-based and paper-based components. They concluded that directing and assisting survivors to navigate web-based platforms that focus on post-treatment health and wellness was an acceptable part of the SCP delivery process. Doing so has the added potential to allow survivors to access targeted information and advice at a time when the survivor is ready to engage with this information. They report this approach as having the added benefits of reducing information overload often experienced if numerous brochures are provided all at once⁽³⁹⁾.

In a study comparing different SCP formats, Mayer and colleagues (2012)⁽³³⁾ found that survivors appreciated Journey Forward's 'clean and clear format'⁽³³⁾.

Preferences of health professionals

A number of researchers have investigated primary care practitioner requirements of the SCP^{(58) (33) (36) (66) (14) (39) (87)}. Information concerning diagnosis, treatment summary and ongoing surveillance was identified as *mostly/very* useful information to include⁽⁶⁶⁾, as well as stage of the disease, documentation of surgery and type of treatment prescribed⁽⁵⁸⁾. Information about follow-up monitoring was reported as a key requirement of primary care practitioners⁽³⁹⁾.

Healthcare providers require delineation of the elements of care that they are responsible for and follow-up treatment schedules^(23, 27, 28, 63). Ninety-eight per cent of primary care practitioners questioned in one study felt it was *very important* to have information that documented their responsibilities of care, such as whether the oncologist would monitor for recurrence and secondary cancers⁽²⁶⁾.

Preferred language and format for the SCP

Use of plain language in SCPs may benefit primary care practitioners as well as survivors⁽³⁾, although in some circumstances using plain language in summaries for primary care practitioners has also been identified as a barrier to their use, namely in situations where health professionals require more detailed medical information that may not be included in a plain language summary⁽²⁸⁾.

Mayer and colleagues (2012)⁽³³⁾ found that primary care practitioners wanted a brief summary including diagnosis, an overview of treatment (no abbreviations), symptoms to look for regarding recurrence or late effects, surveillance needed, identified/nominated clinician responsible for surveillance identified, and for the SCP to be included in the patient's health record⁽³³⁾.

Most oncology providers identify use of a template with specified fields as a means to overcome the barriers of time and personnel resource constraints for implementation⁽⁵⁹⁾. Brennan and colleagues (2010)⁽⁶³⁾, found a willingness among Australian oncologists, breast physicians and breast care nurses to use a proforma⁽⁶³⁾. Incorporating SCPs in electronic medical records may facilitate patient identification, appropriate staff scheduling and timely SCP creation⁽⁶⁸⁾. Internet-based SCPs may be a useful communication tool to support shared care⁽⁶²⁾.

Discussion and limitations

Current literature provides some general guidance on SCP content. In the absence of robust evidence from RCTs, the guidance is based on expert opinion and what is considered best practice. Further research is required to extend the body of knowledge on sustainability of SCP use in particular tumour streams and the impact of their use on long-term patient outcomes. Further work is required to better understand the information needs/preferences of primary care practitioners and how using SCPs may support transition of care between acute and primary care settings.

Implementation

Development and distribution

Since the IOM report in 2006, a number of studies, mostly in the United States, have looked at the use of SCPs. Overall, in current practice environments, SCP use remains limited⁽²³⁾. The implementation and use of SCPs across cancer centres has been sporadic/inconsistent⁽⁴³⁾; this includes implementation within dedicated survivorship centres⁽⁶⁰⁾. For example, less than one-half (43%) of National Cancer Institute-designated cancer centres delivered SCPs to their breast or colorectal cancer survivors⁽²⁶⁾. Many clinicians and health administrators at institutions in the Cancer Research Network were not familiar with SCPs⁽³⁰⁾. Birken and colleagues (2013)⁽⁴²⁾ reported that less than one-quarter of cancer program providers had ever used an SCP⁽⁴²⁾.

In a survey of the use of cancer treatment summaries and care plans among cancer physicians and primary care physicians in Massachusetts, only 14% of cancer physicians reported preparing care plans and 16% of primary care physicians reported receiving a care plan⁽⁵²⁾. A large-scale US survey for people affected by cancer found that only one-third of post-treatment cancer survivors had received a treatment summary⁽⁵⁵⁾. Other studies report that many survivors indicated that they did not receive an SCP, treatment summary or a follow-up care plan/instructions post-treatment^(35, 47, 56).

In Australia, SCPs are not routinely provided post-treatment. Jefford and colleagues (2013)⁽⁸⁹⁾ have observed survivorship research as very active. They comment that work to improve provision of survivorship care is inconsistent and lacking in coordination. They do not make reference to SCP development or distribution⁽⁸⁹⁾.

Timing of delivery and who delivers

There is little evidence to indicate the optimum time for delivery of the SCP or to indicate which health professional is most appropriate to prepare and discuss it with the patient/survivor⁽²³⁾. The current structure of an SCP is aimed at the post-treatment phase; however, it is equally important to address information needs as they arise throughout the active treatment phase⁽³⁹⁾. It is also recommended that the SCP be continually updated at regular time points in the post-treatment phase⁽³⁹⁾.

Evidence indicates that patients don't want to be overwhelmed by information at time of diagnosis but do want to receive information about management of treatment side effects in a timely way⁽³⁹⁾. Mayer and colleagues (2012)⁽³³⁾ conducted focus groups to explore survivor and primary care physician preferences for SPCs. None of the participants had received an SCP, but they indicated they would have liked to receive some of the information included in the SCP (e.g. diagnosis, treatment plan, local resources and contact details for healthcare providers) 'upfront' at commencement of treatment. There was a preference for updated information to be provided at the end of treatment (including information about surveillance schedules, which symptoms to report and health promotion)⁽³³⁾. Other studies reported a range of preferred timeframes for patients to receive an SCP: before treatment ended to within the first 3 months post-treatment⁽⁵¹⁾; just before or soon after completion of treatment^(33, 86); or from within 6 months of diagnosis to up to 12 months following diagnosis⁽⁶⁸⁾.

Opinions vary with regards to who should prepare and deliver the SCP. An integrative review of studies of cancer SCPs by Mayer and colleagues (2014)⁽²³⁾ reported on both oncologist and nurses delivering SCPs. In this review, more studies reported on the SCP being delivered by the oncologist⁽²³⁾. It has been argued that nurses are well positioned to provide leadership in survivorship care⁽⁸⁵⁾ and that nurses are well positioned to develop and deliver SCPs⁽³⁴⁾. Nurse delivery of SCP is also reported as acceptable for survivors⁽⁴⁰⁾. Dulko and colleagues (2013)⁽⁶⁸⁾ found a preference for advanced practice professionals (nurse practitioners and physician assistants) to complete and review SCPs with patients⁽⁶⁸⁾. Casillas and colleagues (2011)⁽⁴⁷⁾ reported that most young adults identified the oncologist as the most important healthcare provider for test and treatment decisions⁽⁴⁷⁾.

Discussion and limitations

Studies reporting on the implementation of SCPs are generally observational and rely on self-reports from respondents⁽²³⁾. Use of SCPs in practice remains limited. In spite of limited evidence with regards to

timing of the delivery of SCPs and who should deliver them, several major cancer organisations recommend their implementation. For example, the American College of Surgeons Commission on Cancer recommends SCPs be given to all cancer survivors and provide guidance on preparation and delivery⁽²¹⁾; the American Society of Clinical Oncology (ASCO) promotes the use of written treatment summaries and care plans⁽¹⁸⁾; and the GW Cancer Institute (US) recommends SCPs are delivered and quality-measured within health organisations/the health system⁽¹⁹⁾. The UK National Cancer Survivorship Initiative emphasises the use of treatment summaries within a patient-centred, coordinated care model⁽²⁰⁾. As identified by Mayer and colleagues(2014)⁽²³⁾, more studies with a focus on the implementation of SCPs, whether survivors receive SCPs and what use they have for them are required⁽²³⁾. There is currently a dearth of information available regarding the use of SCPs in Australia. Further research into the implementation and use of the SCPs in an Australian context is desirable.

Barriers to the use of SCPs

Barriers for healthcare providers

Lack of evidence/gaps in robust evidence to support the use of SCPs in practice^(30, 49, 69) and limited advocacy for SCP from clinical leaders within some survivorship programs⁽⁴³⁾ are critical barriers to the use of SCPs for healthcare providers. Most commonly, barriers to use include concerns about duplication and allocation of resources; limited coordination processes between oncologists and primary care practitioners^(26, 28, 68); time to complete the SCPs^(28, 48, 59, 68, 76, 88) and lack of resources^(3, 42, 43, 49, 59). Other notable barriers include lack of clarity about who is responsible for preparing, delivering and then updating the SCP^(28, 43). Identified as a barrier to SCP development and use is the incompatibility of computer software programs with electronic health records⁽²⁸⁾ for development of SCPs. Even when IT solutions result in automatically generated SCPs, time to deliver them may remain a constraint for oncology providers⁽⁷⁶⁾. Remuneration for preparation of SCPs continues to obstruct use⁽⁴⁸⁾. Barriers to use for healthcare providers are summarised in Table 5.

Table 5: Barriers to use of SCPs by healthcare providers

Barrier	Examples of supporting evidence (not exhaustive)
Feasibility of implementation, including concerns over duplication and allocation of resources and lack of coordination between oncologists and primary care practitioners	Salz, Oeffinger, McCabe et al. 2012; Dulko et al. 2013; Mayer, Nekhlyudov et al. 2014
Remuneration/reimbursement	Faul et al. 2012
Time needed to complete SCP; burdensome	Faul et al. 2012; Nicolaije et al. 2014; Salz et al. 2014; Dulko et al. 2013; Hewitt et al. 2007; Mayer, Nekhlyudov et al. 2014
Lack of personnel to complete SCP and lack of other resources, including systems insufficiency	Salz et al. 2014; Birken et al. 2013; Forsythe et al. 2013; Tompkins Stricker 2014; Birken et al. 2014a
Lack of evidence/gaps in evidence to support the use of SCPs in practice	Keesing et al. 2014; Forsythe et al. 2013; Chubak et al. 2012
Lack of identification of personnel responsible for preparation, delivery and update of the SCP	Mayer, Birken et al. 2014a; Mayer, Nekhlyudov et al. 2014
Lack of compatibility between templates and electronic health records	Mayer, Nekhlyudov et al. 2014

Barriers for survivors

Despite a systematic review of qualitative studies reporting on cancer survivors' experiences of using SCPs, barriers to survivor use were not reported⁽⁶⁹⁾. There is limited if any research directly examining barriers for survivors using SCPs when they have received SCPs. Campbell and colleagues (2012)⁽⁴⁶⁾ question the benefits of head and neck cancer survivors receiving SCPs when the survivors themselves report they cannot remember receiving them and are unsure of their value⁽⁴⁶⁾. Dulko and colleagues (2013)⁽⁶⁸⁾ question the timing of the delivery of the SCP post-treatment as a potential barrier to for some survivors. In their study, some participants wanted the SCP much earlier in the treatment phase⁽⁶⁸⁾. Haq and colleagues (2013)⁽³⁹⁾ report that breast cancer survivors don't necessarily require information in a particular sequence (e.g. from diagnosis and treatment to follow-up); providing SCP information in a set way may well create a barrier to use for some survivors⁽³⁹⁾.

Discussion and limitations

Most studies on survivor experience of using SCPs report on survivor input into development of SCPs, the acceptability of content and the support for their use based on survivors reviewing pre-prepared documents, rather than specifically examining barriers to their use after survivors have received them⁽⁶⁹⁾. Research is needed addressing barriers to SCP use after survivors have received them.

Part II: Available guidelines and recommendations for SCPs

Development and delivery of an SCP is considered an essential element in the context of delivering survivorship care^(18, 90). Despite the lack of evidence supporting the use of SCPs in practice and lack of consensus on optimal content, format and means of delivery⁽⁶⁹⁾, a number of major international cancer organisations have recommended their implementation and use. These include the American College of Surgeons Commission on Cancer, the American Society of Clinical Oncology, the GW Cancer Institute (US), Livestrong (US) and the UK National Cancer Survivorship Initiative. In Victoria, the Department of Health and Human Services [Optimal Cancer Care Pathways](#) recommend cancer survivors (and their GP) receive a treatment summary and follow-up care plan.

Part II of this review looks at the recommendations, expert opinions and consensus of these and other above organisations, including examples from Australian healthcare facilities and the emerging literature. For further recommendations regarding implementation in practice, please refer to the companion document [Survivorship Care Plans: Toolkit](#).

Requirements for SCPs

Essential elements

In a 2005 fact sheet, the IOM provided the minimum recommendations for essential elements of an SCP⁽¹³⁾. Several groups have refined and expanded these recommendations. More research is required to determine the long-term value of these recommendations for survivors⁽³⁾. A list of the key recommendations from five different expert sources is included in Figure 2.

Figure 2: Essential elements of the SCP

Essential elements of the SCP

General information: patient name, date of birth, phone, email and the names of the primary and specialist care practitioners^(d)

TREATMENT SUMMARY^(a)

Diagnosis^{(a)(c)} including date of diagnosis^(d) histologic subtype where necessary^{(b)(d)}

Dates of treatment^{(a)(b)}

Tumour characteristics^(a) including site^{(a)(d)}, stage^{(a)(b)(d)} (if applicable), size^(a), Gleason score^(a), nodes^(a), pathology findings^(a), hormonal markers^(a), haematology^(a), stem cell transplantation^(a)

Treatment history^{(a)(c)} including surgery^(a), date of surgery^(d) with location on the body^(b), findings^(d), chemotherapy^(a) including names of systemic therapy agents administered and end date of chemotherapy^{(b)(d)}, radiotherapy^(a) with anatomic area treated and end date of radiation treatment^{(b)(d)}, hormonal therapy^(a), others^(a)

Persistent symptoms or side effects at completion of treatment^(d)

Ongoing toxicity or adverse effects of all treatments received^(b)

Genetic or hereditary risk factors or predisposing conditions and genetic testing results if performed^{(b)(d)}

Supportive services provided^(a)

Contact information for key treating institutions and practitioners^{(a)(b)}

Identification of a key point of contact and coordinator of continuing care^(a); an explanation of how the survivor's follow-up care will be coordinated between the oncology specialist, GP, nurses and allied health professionals

FOLLOW-UP CARE PLAN^(a)

Oncology team member contacts with location of treatment facility^(b)

Need for ongoing adjuvant therapy with therapy name, duration and possible adverse effects^{(b)(d)}

Treatment-related side effects (short term) with likely course of recovery^(a)

Goals of follow-up with frequency and timing^(c)

Schedule of follow-up visits in table format including who will provide, how often and where^{(b)(c)(d)}

Periodic tests^(a)/**surveillance tests**^(b) and **schedule**^(a) in table format including who will provide, how often and where^{(b)(c)(d)}

Cancer screening for early detection of new primaries, if different from general population in table format including who will provide, how often and where^(b)

Possible late and long-term side effects^{(a)(c)(d)} including likely or rare but clinically significant side effects based on the diagnosis and treatment^(b)

Signs of recurrence or second tumour^(a) or a general statement asking patient to bring any new, unusual, worrying or persistent symptoms to the attention of the healthcare provider^{(b)(c)(d)}

Psychosocial concerns including financial concerns^{(a)(b)(c)(d)} emotional, mental health, parenting, work/employment, insurance issues and a list of local and national resources to assist patient in obtaining proper services^{(b)(d)(e)}, also including rehabilitative issues^(c) and legal concerns^(c) and sexual functioning^(d) and fertility planning*

Recommendations for healthy behaviour^(a) to reduce the risk and severity of treatment side effects, prevent comorbid conditions and promote better health, including healthy diet, exercise, smoking cessation, alcohol use reduction^(b) along with sunscreen use and weight management^(d); tailor if pertinent to patient^(c)

The survivor's values and preferences regarding their care^(d)
Genetic counselling if needed^(a)
Chemoprevention, if appropriate^(a)
Referrals^(a)
Resource lists^{(a)(d)} including counselling services available in the local community^(c)
Prepared by, with date of delivery^(d)

*Note: Livestrong recommends including a psychosocial care plan along with the SCP and treatment summary (Livestrong 2011⁽⁹⁰⁾).

Sources: (a) Daudt et al. 2014⁽²⁵⁾; (b) Mayer, Nekhlyudov et al. 2014⁽²⁸⁾; (c) Howell et al. 2011⁽⁹¹⁾; (d) ASCO Treatment Summary and Survivorship Care Plan template⁽⁹²⁾

Templates

Figure 2 includes summary information from the ASCO Treatment Summary and Survivorship Care Plan template. Several online SCP templates are available, including templates from Journey Forward (www.journeyforward.org/professionals/survivorship-care-plan-builder), Livestrong (www.livestrongcareplan.org), ASCO (www.asco.org/practice-research/cancer-survivorship) and the National Cancer Survivorship Initiative (www.ncsi.org.uk/what-we-are-doing/treatment-summary).

Such templates have been developed based on consensus guidelines. For example, in 2010, the National Cancer Survivorship Initiative worked with oncology clinicians and primary care practitioners to test the content and information delivered in a treatment summary⁽⁹³⁾. Their treatment summary is aimed at primary care practitioners, patients, secondary care clinicians (e.g. in accident and emergency departments), and hospices and care facilities⁽²⁰⁾.

Similarly, ASCO undertook work to inform policy development. This work was conducted to refine the SCP process and tailor the SCP to the needs of the survivors and healthcare professionals⁽²⁸⁾.

While SCP templates are freely available, their usefulness in the Australian context remains unclear. In a study conducted Brennan and colleagues (2010)⁽⁶³⁾, Australian specialist oncologists (surgeons, medical and radiation oncologists), breast physicians and breast care nurses expressed a willingness to use an SCP proforma⁽⁶³⁾. However, to date, no template has been developed for the Australian context.

Preparation

A template should not imply a fixed document. ASCO recommends that the care plan be 'fluid' to consistently assess and meet changing care needs of the survivor⁽⁹⁴⁾. The templates identified above or the information provided in Figure 2 may be adapted to the needs of a particular patient.

There is reasonable agreement that the patient's oncology provider/s should prepare the SCP. The American College of Surgeons Commission on Cancer recommends in its 2012 standards that the SCP should be prepared by the principal providers of the cancer treatment with input from the patient's other healthcare providers⁽²¹⁾. ASCO advises that the treatment summary and care plan (which comprise the SCP) be developed by oncology providers and that the same providers should also have ongoing discussions with the survivor about any potential late and long-term effects of treatment⁽²⁸⁾. McCabe, Faithfull and colleagues (2013)⁽¹⁶⁾ recommend that the plan be developed at the conclusion of treatment by the main providers who coordinated the patient's cancer care⁽¹⁶⁾.

Strong consumer engagement can result in increased awareness of SCPs and SCPs tailored to survivor needs⁽²²⁾. Survivors play an important role in encouraging use of SCPs by their healthcare providers^(44, 56). Cancer organisations and consumer organisations within Australia may wish to follow the example of the National Cancer Institute, which recommends that 'Every cancer survivor should request a comprehensive care summary and follow-up plan from their doctor once they complete their treatment' (see www.cancer.gov/cancertopics/factsheet/Therapy/followup).

It is recommended that SCPS are prepared in consultation with the survivor^(20, 22, 39). Writing the SCP in plain language is critical^(32, 39, 40). Following these recommendations may increase SCP acceptability⁽⁷⁹⁾ by ensuring it contains the information the survivor wants and is presented in language that is easily understood^(32, 39, 40). In its survivorship recommendations, the GW Cancer Institute recommends that information for survivors be developed appropriate to all literacy levels⁽¹⁹⁾.

Completing a needs assessment is identified as a critical component in the development of SCPs, to ensure they are tailored to survivors' specific needs^(22, 39). However, there is a lack of screening tools developed for the post-treatment phase⁽²²⁾.

Development and preparation of a brief one-page summary of the SCP may be more suited to the needs of primary care practitioners^(22, 33).

Delivery

Timing of delivery

Parry and colleagues (2013)⁽²⁷⁾ have called for a guiding framework of implementation to determine the optimal time of SCP implementation and delivery to maximise benefit to the patient, primary care practitioner and the health service⁽²⁷⁾. Faul and colleagues (2012)⁽⁴⁸⁾ note that there is insufficient evidence to determine the optimal time to complete and administer an SCP⁽⁴⁸⁾. Howell and colleagues (2014)⁽²²⁾ note survivor readiness to engage in care planning may impact on timing of delivery of SCPs⁽²²⁾.

Some recommendations have been offered. In their 2014 integrative review, Mayer, Birken and colleagues (2014)⁽²³⁾ advise that:

- a treatment plan (outlining the planned treatment) should be given at the time of diagnosis
- a treatment summary (outlining the actual treatment delivered) should be given during/immediately following treatment
- a follow-up care plan should be provided at the end of treatment

This advice aligns with the American College of Surgeons Commission on Cancer, which recommends in its 2012 standards that the SCP be given to the patient on completion of treatment⁽²¹⁾. In the United Kingdom, the National Cancer Survivorship Initiative recommends providing a copy of the treatment summary to the patient and the GP at the end of treatment⁽²⁰⁾. They recommend survivors and their primary care practitioners engage in a cancer care review (CCR) 6 months after treatment. At this review, SCPs are used to evaluate and assess the patients' health status compared to immediately post-discharge. The National Cancer Survivorship Initiative also recommends generating treatment summary updates at key points, such as after recurrence or further treatment or upon beginning end-of-life care⁽²⁰⁾. It is noted that variations in the duration and type of the 6-month post-treatment review has meant that uptake of such reviews has been poor. Nevertheless, the combination of the treatment summary and the CCR was well received by the primary care practitioners, although primary care practitioners observed that the process of conducting the CCR was vulnerable to becoming a routine administrative task⁽⁹⁵⁾.

Who delivers the SCP?

There is no consensus about who should deliver the SCP. The Canadian Cancer Journey Survivorship Expert Panel recommends that the healthcare professional team should designate the person or persons responsible for completing the (parts of the) SCP and the survivor should receive a written treatment summary and follow-up care plan from a 'designated' member of the care team⁽⁹¹⁾. The American Society of Clinical Oncology argues that the survivor should review the SCP with a member of the healthcare team⁽²⁸⁾, without nominating which team member this should be.

Who receives the SCP?

SCPs are intended primarily for survivors and their primary care practitioners and should be made available to both the survivor and the healthcare professionals⁽³⁹⁾. It has been noted that a 'one size fits all' approach is not recommended and not all survivors may benefit from receiving an SCP. Flexible

approaches to SCP delivery are needed⁽²²⁾. The GW Cancer Institute suggests that institutions develop a protocol to determine which patients receive particular survivorship services⁽¹⁹⁾.

The Cancer Journey Survivorship Expert Panel recommends that the SCP be given to primary care practitioners and other providers designated for follow-up care⁽⁹¹⁾. Some patients prefer that the SCP is sent to the primary care practitioner before their visits rather than them having to take the document with them⁽³⁹⁾.

Infrastructure and resources

Administration support

Advances in clinical practice include the automation of patient health care records to populate SCPs, to reduce the amount of time required in processing and constructing the SCP. It is recommended that information technology solutions be developed to assist in populating treatment summaries⁽²²⁾. In the United Kingdom, electronic solutions or adaptations to suit local sites have resulted in the greatest success in the development of SCPs⁽⁹⁶⁾. The National Cancer Survivorship Initiative has developed a process where a treatment summary can be populated from a patient's electronic health record⁽²⁰⁾.

Promotion, development, implementation and evaluation of SCPs

Organisational leadership and promoting the concept of SCPs within the health system

Raising awareness of SCPs is important if they are to be widely adopted⁽¹⁹⁾ and the influence of organisational leadership cannot be overstated^(22, 82). SCP use may be promoted by the support and leadership of the healthcare organisation and treating team; professional societies' recommendations and membership of such associations; cancer quality improvement organisations; advocacy and use by influential people within a health organisation; and compliance requirements^(3, 17-19, 21, 43, 90).

Providing targeted organisational support to facilitate SCP implementation may prove more successful⁽⁴³⁾ than introducing non-specific institutional policies. Project management approaches are critical⁽²²⁾. It is also important to consider workforce education and workforce design⁽²²⁾.

The American Society of Clinical Oncology has created a framework for completing and sharing SCPs and setting clear expectations for survivorship care planning. Its 2014 statement encourages clinicians to recognise the importance of developing patient-centred SCPs, delivering the information to the patient and primary care practitioners and identifying barriers to completing and delivering SCPs effectively⁽²⁸⁾. Strengthening links between the primary and the acute sectors to develop shared understandings about the role and value of the SCP is required⁽²²⁾.

Implementing SCPs

SCPs are a flexible tool and can be adapted for use in varied settings. It is critical to remember that SCPs are a component designed to support survivorship care, not the solution to providing post-treatment survivorship care⁽²⁷⁾. Nor are they designed to replace post-treatment consultations⁽²⁸⁾. Consideration needs to be given to the context in which the SCP is delivered. The SCP itself is unlikely to be sufficient to ease the transition to post-treatment care^(27, 97) and the challenge of improving communication and care coordination may be beyond the reach of the SCP^(33, 76). However it is noted that primary care practitioners who receive the SCP from the patient's oncologist are more likely to have survivorship discussions with patients⁽⁶⁷⁾.

While SCPs' *potential* for improving care and care coordination gains more acceptance, numerous barriers to adoption have been identified. Attention to overcoming known barriers to implementation is required^(3, 22).

Models of care

Guidelines for health services regarding survivorship care recommend the development and delivery of SCPs within models of care^(3, 27, 70). There are a variety of survivorship models of care, including acute-based, shared and community-based care, as well as care led by oncology providers, nurses or primary care providers⁽³⁾. Patient-initiated models are also being explored⁽⁷⁰⁾. For sustainability, SCPs and other survivorship services are best delivered through models of care that fit an institution's needs and resources^(3, 19).

The actual delivery setting for SCPs is not well documented in the literature; however, it is reported that SCPs are more commonly delivered in the context of specific post-treatment clinics or provided at end of treatment⁽³⁾. Salz and colleagues (2012)⁽²⁶⁾ report on SCPs being delivered by nursing staff in a dedicated survivorship clinic post-treatment: one that is separate from the institution that delivered the cancer treatment⁽²⁶⁾. The intended audience of the SCP and where cancer treatment has been delivered can be used to guide the delivery setting for the SCP⁽³⁾.

Healthcare providers also need to consider the broad context in which the SCP is delivered. This includes multidisciplinary care; integrated care (the primary care and oncology team communicating to support the survivor); rehabilitation (promoting a return to functional capacity); and fostering patient self-management, including decision-making and problem-solving⁽¹⁶⁾.

Ideally, institutions should develop a protocol/risk stratification process to determine which patients would be most suitable for survivorship services^(19, 22, 27). Particular consideration needs to be given to the needs of the audience/s and the intended outcomes from provision of the SCP⁽²⁷⁾. Needs assessment tools can be used to individualise SCP content, to determine the frequency with which SCPs are revised and to direct delivery of the most appropriate resources^(22, 27).

For further information on needs assessment, refer to the ACSC [*Needs Assessment Tools for Post-treatment Cancer Survivors: Literature Review*](#).

Embedding SCPs in the survivorship care process is critical and has been successfully demonstrated. Jefford and colleagues (2011)⁽⁸³⁾ designed a model of care in which SCPs were embedded as a component of the process of care delivery. Bowel cancer survivors were provided with education materials, a tailored SCP and an individual nurse-led, face-to-face, end-of-treatment consultation along with three follow-up telephone calls⁽⁸³⁾. The model was reported as well received by survivors. *Supporting Cancer Survivors in Victoria: Summary Report* demonstrated successful delivery of SCPs in nurse-led and coordinator-led approaches involving similar structured post-treatment consultations⁽²²⁾.

Evaluating SCPs

To date, evaluating quality outcomes of SCPs has been limited as many of the intended goals for implementation of SCPs are long-term goals. Outcomes such as impact on health service and improved quality of life for survivors are not immediately measurable⁽²⁶⁾. Short-term evaluation of SCPs is often limited to the impact they have on survivor and health cancer professional satisfaction with the information provided; knowledge about survivorship care; and their experiences of care coordination and communication as a result of receiving the SCP⁽²⁶⁾.

It is recommended that standard methods of evaluating survivorship initiatives be developed to monitor and aid survivorship care^(18, 19) as well as to demonstrate outcome improvements for survivors and health service cost benefits⁽⁶⁰⁾. It is recommended this process be considered when planning to implement survivorship initiatives.

There are no specific tools developed to measure impact of SCPs, so choosing measures that are sensitive to evaluate SCPs is challenging and requires refinement^(22, 27). The impact of embedding the development and provision of SCPs into routine practice requires extended timeframes to measure long-term quality outcomes such as cost-benefit analysis, impact on patient lifestyle and health behaviours, the quality of communication and impact on transition of care between healthcare providers^(3, 22, 27).

Diversity

Rural and regional issues for implementing SCPs

Survival rates for Australians with cancer who live in rural and regional areas are worse than in metropolitan areas^(98, 99). Challenges reported for people with cancer who reside in rural and regional areas include fewer cancer services locally; having to travel for treatment; and financial, relationship and emotional impacts⁽¹⁰⁰⁾. Primary care practitioner follow-up supported by SCPs may be better suited and more convenient for rural and regional cancer survivors⁽¹⁰¹⁾. Outcomes of international studies that report on unmet needs for rural cancer patients may not be applicable to Australia due to different healthcare systems and different connotations of 'rural' in smaller countries⁽¹⁰⁰⁾. Few studies have explored the needs of rural and regional patients and health professionals in receiving and delivering survivorship initiatives. However, the delivery of quality survivorship care initiatives to these cancer survivors remains a priority.

SCPs and Indigenous communities

Indigenous Australians experience poorer cancer outcomes and have significantly lower 5-year crude survival from cancer when compared to non-Indigenous Australians (40% compared with 52%)⁽¹⁰²⁾. Survival rates are lowest for those living in more rural and remote areas⁽¹⁰³⁾. The value of SCPs in Australian Indigenous communities is unknown due to lack of relevant studies. Evidence is required to develop culturally sensitive survivorship care initiatives for Indigenous populations, which remain a key under-served group⁽¹⁰³⁾.

SCPs and culturally and linguistically diverse communities

There has been no research into the health impacts or satisfaction of receiving SCPs among culturally and linguistically diverse (CALD) communities in Australia. Each person's conception of cancer and cancer survivorship depends upon a variety of influences. Attitudes, cultural and personal meanings ascribed to a disease influence how an illness is embodied, lived and coped with, ultimately dictating adjustments to the meanings of a sickness⁽¹⁰⁴⁾. There is a need to use terms that match those used by individuals and cultural groups⁽¹⁰⁵⁾ and evidence is required regarding the specific needs and preferences of CALD survivors⁽²⁷⁾. The Australian Cancer Survivorship Centre in collaboration with Cancer Australia is developing culturally sensitive information resources for the post-treatment phase.

Engagement with primary care

Primary care

Strong evidence supports primary care follow-up for some low-risk cancer groups as being equivalent to hospital-based care⁽¹⁰⁶⁾. Aligning survivorship care to chronic disease management models of care and primary care working processes may promote primary care engagement and shared care^{(107), (22)}. SCPs are promoted as a communication and care coordination tool for primary care providers as well as hospital-based specialists with information detailing roles and responsibilities in cancer survivorship care^{(85), (18), (22)}. SCPs can promote survivorship discussions between survivors and primary care providers⁽⁶⁷⁾. They can be used to facilitate survivor acceptance of and transition to primary care follow-up and/or to shared care⁽¹⁰¹⁾ and discussions between survivors and GPs regarding post-treatment care⁽²²⁾. SCPs may be linked to GP Chronic Disease Management Plans and Team Care Arrangements⁽¹⁰⁸⁾ and SCP information presented in chronic disease management terms can facilitate this process⁽²²⁾.

General practice nurses already play a critical role in chronic disease management and development of chronic disease management plans⁽¹⁰⁹⁾. Their skills are underutilised in cancer survivorship.

The Victorian experience with SCPs

In 2011 the Victorian Government funded 6 two-and-a-half year pilot projects to trial models of survivorship care through the Victorian Cancer Survivorship Program. The projects targeted different populations, different age groups and different geographical locations, addressing different aspects of survivor care in the post-treatment phase⁽²²⁾.

Five out of the six projects developed SCPs as part of the project. All were developed in partnership with survivors. The name and format of the plan varied according to the aim of the project and their target population: for example, 'Follow-up care plan' (Breast cancer project), 'Your Personal Melanoma Diary' (Melanoma project) and 'My health and wellbeing plan' (Moving forward with confidence project). Broadly, SCPs were positively received and viewed as a valuable communication tool by participants, hospital-based healthcare professionals and GPs. The role of SCPs as a tool to motivate participants to self-manage their healthcare was highlighted for some projects.

Not all participants discussed their plan with their GP. Models of shared care resulted in more likelihood of GPs discussing the SCP with the participants. Strategies included linking the SCP to GP Chronic Disease Management Plans and Team Care Arrangements⁽¹⁰⁸⁾ and presenting information in chronic disease management terms. Time to develop and implement SCPs within existing resources was viewed as a challenge for sustainability for most projects. Refer to Table 6 for information regarding SCPs and the Victorian Cancer Survivorship Program pilot projects⁽²²⁾.

Table 6: Development and use of SCPs with the Victorian Cancer Survivorship Program pilot projects

Most projects	<ul style="list-style-type: none"> • SCPs were delivered at one time point only (i.e. they were not in a format that could be updated) • SCPs included prevention, surveillance, intervention and care coordination, as recommended by the Institute of Medicine, although the emphasis varied across projects • Survivors were asked to make an appointment to discuss their SCP with their GP • Hardcopy SCPs and/or one-page summaries were sent to GPs
Some projects	<ul style="list-style-type: none"> • Developed and delivered SCPs following a nurse consultation • Included additional correspondence to the GP detailing that the survivor was participating in a survivorship project • Evaluated the use of SCPs over time, with many survivors still using and referring to their SCP after more than 3 months • Reviewed/updated the SCP at identified times over many months

Note: Further details regarding the projects are available from the Australian Cancer Survivorship Centre website (www.petermac.org/cancersurvivorship)⁽²²⁾.

Recommendations

Despite limited evidence of long-term outcomes of SCP provision, short-term benefits have been identified. Recommendations for SCP implementation and use remain strong, as does a call for more long-term studies. When choosing to implement SCPs, it is critical to consider the key recommendations and success factors identified from the literature and those based on expert opinion and what is considered best practice.

This review has been developed with an accompanying toolkit to assist with the implementation and delivery of SCPs in organisations. We recommend the reader consult the toolkit as it provides a detailed and practical guide to implementation of SCPs in the clinical area. The toolkit can be found [here](#). Table 7 contains a summary of the key recommendations/success factors resulting from this literature review.

Table 7: Key recommendations/success factors for SCPs

Recommendations/success factors	
Organisational support	<ul style="list-style-type: none"> • Develop a business case for SCP implementation • Provide or encourage strong clinical leadership for SCP implementation • Use project management principles for system-level implementation • Orient the culture to one of care transition and integration if necessary • Raise organisational awareness • Assess workforce competency and capacity • Attend to overcoming identified barriers
Engage with primary care	<ul style="list-style-type: none"> • Align SCPs with chronic disease management plans • Communicate the rationale for SCPs with GPs and general practice nurses
Engage with consumers	<ul style="list-style-type: none"> • Involve consumers in development and review of SCPs
One size does not fit all	<ul style="list-style-type: none"> • Determine which patients require an SCP using risk stratification • Recognise that health professionals and survivors have different needs and preferences • Develop or use plain language, patient-centred documents for survivors • Ensure culturally sensitive and relevant content • Needs assessments • Provide more detail in SCPs for health professionals • Consider one-page summaries
Preparation	<ul style="list-style-type: none"> • Consider flexible templates and electronic solutions • Designate personnel/administrative support required for SCP development, updating and implementation
Delivery	<ul style="list-style-type: none"> • Consider model of care within which the SCP is delivered • Embed into usual care • Consider timing (e.g. end of treatment, more than one time point) • Determine the most appropriate format (electronic or paper-based) • Identify and prepare health professional/s to deliver SCPs
Evaluation	<ul style="list-style-type: none"> • Consider a standard process when planning initiatives

Conclusions

Evidence regarding the benefits of SCPs is accumulating. The perceptions of SCP value for survivors are generally positive. A number of potential benefits have been identified for both survivors and health professionals.

Healthcare providers need to consider the broader context in which an SCP is delivered. Enablers and barriers to SCP use have been identified. It is critical to address these when planning and implementing SCP initiatives and survivorship care in general. Electronic solutions and templates may streamline the SPC process; however, there is limited evidence generated in the Australian context.

There are no long-term outcome data and the long-term value of SCPs for patients and healthcare providers remains equivocal. In the interim, influential organisations in the United States and United Kingdom continue to recommend SCPs as a high priority and essential component of survivorship care. Pilot projects in Victoria have incorporated SCPs as part of survivorship care initiatives and recommend them to be embedded into usual care. There is call for improved processes and policies to facilitate the implementation process.

Glossary

Adjuvant treatment

Additional cancer treatment given after the primary treatment to lower the risk that the cancer will come back. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, targeted therapy or biological therapy⁽¹¹⁰⁾.

Cancer survivor

The US National Comprehensive Cancer Network defines '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'⁽¹¹¹⁾. 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'⁽¹¹²⁾.

Cancer survivorship

Survivorship encompasses the health and life of a person with cancer from treatment until the end of life. It covers the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and treatment phases. 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⁽¹¹³⁾.

Chronic Disease Management General Practice Services (also known as a team care arrangement)

The Chronic Disease Management General Practice Services (formerly Enhanced Primary Care or EPC) enable GPs to plan and coordinate the health care of patients with chronic or terminal medical conditions, including patients who require multidisciplinary, team-based care from a GP and at least two other healthcare providers⁽¹¹⁴⁾. These services are funded through the Medicare Benefits Schedule.

Follow-up plan

A follow-up SCP should provide specific recommendations for ongoing care including (but not limited to) a schedule of visits, including with oncology specialists; surveillance testing for recurrence; identification and management of long-term and late effects; and health promotional strategies⁽¹¹⁵⁾.

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.

Plain English

Plain English is a message that is clear and concise, which is written with the reader in mind and uses an appropriate tone of voice⁽¹¹⁶⁾.

Risk stratification

Risk stratification is a process that can help determine which people in a population are at higher-than-average risk of experiencing adverse events (such as unplanned hospital admissions) that are undesirable for patients, costly to the health service and potential markers of low-quality care⁽¹¹⁷⁾.

Surveillance

Cancer surveillance provides a quantitative portrait of cancer and its determinants in a defined population. The core functions of cancer surveillance are the measurement of cancer incidence, morbidity, survival and mortality for persons with cancer. It also includes the assessment of genetic predisposition, environmental and behavioural risk factors, screening practices, and the quality of care from prevention through to palliation⁽¹¹⁸⁾.

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⁽¹¹⁹⁾.

SCPs

An SCP is based on the diagnosis and holistic assessment of the patient. The essential components will include identification of issues related to the diagnosis. It will need to prioritise the patient's issues and include a statement on the specific actions and approaches to address them, and recognise issues that may not be readily resolved⁽¹²⁰⁾. An SCP may include a treatment summary as well as a follow-up plan.

Treatment summary

The treatment summary should inform the follow-up SCP and include the following components: contact information for providers and centres that administered the treatment; basic diagnostic and staging information and information on surgery, radiation therapy and systemic therapy (chemotherapy and biologic therapies); and ongoing significant toxicities, including dates (year and maybe month but not specific days)⁽²⁸⁾.

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