

Australian Cancer Survivorship Centre

A Richard Pratt Legacy



Survivorship Care Plans: Toolkit



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Survivorship Care Plans: Toolkit

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Contents

Survivorship Care Plans: Toolkit	i
Contents	1
Acknowledgements	3
Disclaimer	4
Part I: Importance of SCPs	5
Introduction	5
Background to the development of the toolkit	5
Intended audience	5
Purpose of SCPs	5
Benefits of SCPs	6
Part II: Delivery and implementation	8
Introduction	8
How do you develop a successful model?	8
How do you decide who will get one?	9
Preparation of SCP	9
Delivery of an SCP	10
Overcoming barriers to implementation	12
Part III: What should be included in an SCP?	14
Introduction	14
What should be included in the SCP?	14
Essential elements of an SCP	14
Guide to completing the follow-up care plan	17
Part IV: Examples of international guidance and resources about SCPs	25
Introduction	25
United States	25
United Kingdom	26
Australia	26
Appendices	29
Appendix A: Groups for survivors and carers	29
Appendix B: Survivorship education programs	31
Glossary	32
References	34

List of tables

Table 1: Benefits of SCPs for patients/survivors	6
Table 2: Questions to consider when developing a successful model to implement SCPs	8
Table 3: Strategies to overcome barriers to implementation of SCPs	12
Table 4: Recommended topics for use in a treatment summary	15
Table 5: Recommended topics for use in a follow-up care plan	16

Table 6: National and international cancer survivorship clinical guidelines 18

Table 7: Healthy living guidelines20



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

The ACSC facilitates the VCSP Community of Practice, develops and distributes key survivorship resources, and provides survivorship education and training. The 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 literature review can be found [here](#).

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

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

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

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Disclaimer

This work is the result of a collaborative effort between the Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre and the 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.

Part I: Importance of SCPs

Introduction

The importance of survivorship care plans (SCPs) was first highlighted by the Institute of Medicine in its 2005 report *From Cancer Patient to Cancer Survivor: Lost in Transition*⁽¹⁾. The Institute of Medicine stated that patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. Evidence regarding the benefits of SCPs is accumulating, although long-term outcome data has not yet been identified. In the interim, consensus guidelines continue to recommend the use of SCPs (see the *Survivorship Care Plans: Literature Review*). This toolkit is designed to support healthcare professionals to develop and deliver high-quality care plans in the post-treatment phase.

Background to the development of the toolkit

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

The basis for this toolkit comes from the recommendations from the accompanying ACSC publication *Survivorship Care Plans: Literature Review*. The review can be found [here](#).

This document can be used to provide practical guidance to developing and implementing survivorship care plans. The authors acknowledge the complexities and differences between healthcare settings. The toolkit has been developed to provide a practical and relevant guide that can be applied to a variety of settings.

Intended audience

This document is intended to be used by healthcare providers to develop and deliver SCPs for consumers in the post-active-treatment phase (survivors).

As all health organisations are structured differently, this toolkit acknowledges that the responsibility of developing the SCP may be allocated to a different person/team dependent upon the facility.

Purpose of SCPs

The aim and intended purpose of an SCP is to deliver patient-centred care by enhancing communication between the oncology team and the patient as well as communication and coordination of care between the oncology team and the primary care provider⁽²⁾. 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⁽³⁻⁶⁾. An SCP comprises:

- a treatment summary suitable for health professionals as well as consumers
- a follow-up plan
- a post-treatment care plan.

An SCP should consider the information collected by needs assessment tools (see [Needs Assessment Tools for Post-treatment Cancer Survivors: Literature Review and Toolkit](#)).

Benefits of SCPs

Results regarding the benefits of SCPs are equivocal with current evidence focused on survivors' and healthcare providers' perceptions of SCPs. Evidence regarding benefits for patients and survivors are listed in Table 1. For more information on these benefits please refer to [Survivorship Care Plans: Literature Review](#).

Table 1: Benefits of SCPs for patients/survivors

Benefits of survivorship care plans for survivors	
✓	Survivor satisfaction in receiving the SCP
✓	Decreased health worry/increased peace of mind in cancer survivors
✓	Increased adherence to recommended medical surveillance
✓	Increased understanding of an array of survivorship issues
✓	Increased survivor knowledge regarding follow-up care
✓	Awareness of doctor responsible for follow-up care
✓	Survivors' improved knowledge of details about their diagnosis and treatment
✓	Improved communication with healthcare providers and/or between healthcare providers
✓	Survivors 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
✓	Reduced duplicative procedures
✓	Promotion of lifestyle and behavioural changes
✓	Promotion of healthy practices and enhancement of general knowledge about cancer for family members

Practice point

- The aim and intended purpose of an SCP is to deliver patient-centred care by enhancing communication between the oncology team and the patient as well as communication and coordination of care between the oncology team and the primary care practitioner. It is made up of three components: a treatment summary, a follow-up plan and a post-treatment care plan.

A survivor's experience

My name is Meg Rynderman, I am 65 years old, a wife, mother and grandmother and a volunteer with the Australian Cancer Survivorship Centre and with Cancer Council Victoria's Cancer Connect program. For the past 21 years I have travelled the cancer journey—originating with a diagnosis of Hodgkin's lymphoma, followed by two recurrences. I have experienced radiotherapy, chemotherapy, stem cell transplant, hormone therapy and surgery; I've been hospitalised and treated for a myriad of related side effects. The companions of my journey have been a formidable array of chemical compounds with intimidating names, usually accompanied by gloved, gowned and bespectacled attendants.

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

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

My own use and experience of the system has shown me gaps and cracks where patients, during and post-treatment can feel lost or overlooked. In the same way that a cardiac care plan assists patients post-heart attack or other cardiac episode, survivorship care plans are currently under development and trial. As a survivor, it is my hope that these care plans would outline diagnosis, fully explain treatment, list drugs administered along with explanations of side effects, possible late effects and directions as to whom to contact should they occur. Follow-up would be scheduled and monitored. Details of allied health professionals—psychologist, physiotherapist, mental health social worker, etc.—might also be included. Issues of case coordination, management and advocacy might be discussed openly in pursuit of a holistic bio-psycho-social model.

My sense is that having a care plan would have assisted me at the end of my initial treatment; it would have informed my general practitioner and subsequent specialists and would have been a valuable tool to accompany me on my cancer journey.

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

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

Part II: Delivery and implementation

Introduction

An SCP should be designed in such a way as to be empowering to cancer survivors and informative to members of their care team. It should contain important information about the treatment given, the need for future check-ups and cancer tests, the potential long-term late effects of treatment received, and ideas for improving health⁽⁷⁾. As survivor needs vary depending on their circumstances, disease and stage of survivorship, SCPs should be patient centred and dynamic and development should avoid a 'one size fits all' approach (see [Survivorship Care Plans: Literature Review](#)). They should also be able to be regularly updated.

All cancers and cancer treatments bring with them specific side effects. Depending on the type of treatment received, the type and risk of long-term and late effects will differ. SCPs should reflect the specific treatments the patient received (e.g. tumour-specific templates) and then be tailored to individuals' needs, goals and risks.

How do you develop a successful model?

Developing a successful model to deliver and implement care plans involves a collaborative effort between various stakeholders. Consider available resources and infrastructure (including staff time) as well as the anticipated volume of SCPs to be delivered prior to determining a delivery model that will suit your facility. Table 2 provides a series of questions that will help inform your model.

Table 2: Questions to consider when developing a successful model to implement SCPs

Question	
✓	What organisational support is there for SCP implementation?
✓	What key stakeholders need to be considered in the development stage?
✓	Who is the target survivorship group?
✓	Who will complete the treatment summary and SCP?
✓	What format will they be developed in?
✓	How will the plan be stored?
✓	How will the information be communicated?
✓	How will you ensure follow-up of the care plan contents?

It is not known who might benefit most from an SCP. Recognising that it may not be feasible for some organisations to deliver an SCP to all patients, it may be reasonable to target people with higher risk of complications and those who express greater unmet needs. It is recommended that health care services decide on a policy that determines the eligibility criteria for patients to receive an SCP. This is one factor that should be considered during planning to help to address the barrier of time and resources which may affect a service's ability to implement SCPs. The aim should be to develop a practical strategy to deliver SCPs to the majority of the eligible target population.

The Clinical Oncology Society of Australia's position statement 'Critical Components of Cancer Survivorship Care'⁽⁸⁾ identifies that stratified pathways of care will be influenced by:

- survivor ability and motivation to engage and self-manage
- assessing the level of risk for disease related comorbidity and recurrence dependent on the tumour type
- short, medium and long-term treatment sequelae
- existing comorbidities
- level of health professional involvement required.

An organisation needs assessment will inform the development and implementation process. The American Society of Clinical Oncology (ASCO) recommends conducting an organisational needs assessment to establish a clear picture of what services are readily available to be provided and by whom, and what resources are necessary but not in place⁽⁹⁾. The ASCO organisational needs assessment encompasses the development of a survivorship care program of which SCPs are a key component.

[Providing High Quality Survivorship Care in Practice: An ASCO Guide](#)

The use of needs assessment tools

It is important to acknowledge the role of patient needs assessment tools in the development and implementation of SCPs. Survivors' responses to the needs assessment tool should inform and define the content of an individual SCP. The ACSC recommends that a validated needs assessment tool be distributed to survivors for completion prior to the development of the SCP.

It is recommended that needs assessments be undertaken regularly and that the findings from these be used to update the SCP at regular intervals. The ACSC has published a literature review and toolkit to support individuals and organisations with the implementation of needs assessment. For more information on needs assessment refer to the ACSC publications: [Needs Assessment for Cancer Survivors: Toolkit and Needs Assessment Tools for Post-treatment Cancer Survivors](#).

How do you decide who will get one?

SCPs are intended for survivors and all healthcare providers involved in their care. The ACSC acknowledges that while the recommendation is for all survivors to receive an SCP, this can be difficult to achieve in a resource-constrained environment. The Clinical Oncology Society of Australia recommends that all patients should receive a care plan as part of their transition from the acute care setting back to the community⁽⁸⁾. The concept of risk stratification can be utilised in the planning stages. These include the risk of recurrence or late effects. Risk stratification will assist with appropriate service allocation (or referral) and will support a sustainable approach to delivering SCPs in your facility.

Preparation of SCP

The SCP is generally developed using a template (see Part III for the essential elements of an SCP) that is adapted to reflect the needs of a particular patient. It is recommended that SCPs are prepared in consultation with the survivor.

Where electronic health records are in use, preparation for the SCP should start early with initial entries being made, if feasible, from the beginning of treatment and continuing throughout treatment. Early preparation may assist with reducing the time taken to populate the SCP at the patients' end-of-treatment appointment.

Delivery of an SCP

Who should deliver the SCP?

The Institute of Medicine recommends that the SCP be written by the principal specialist(s) who provided the cancer treatment⁽¹⁾. This may refer to a medical, radiation or surgical oncologist or haematologist as well as a nurse practitioner or coordinator or other specialised nursing staff, depending on the circumstance.

The [Survivorship Care Plans: Literature Review](#) found varied evidence with regards to which member of the oncology team should prepare and deliver the SCP. In the absence of definitive evidence, the ACSC recommends the development and implementation of SCPs should consider who is the best person to deliver the care plans to survivors. This statement considers the organisational and structural support required to both implement SCPs as well as create a sustainable model of care. The person best placed to deliver the SCP may be the medical, radiation or surgical oncologist or haematologist, nurse practitioner, coordinator or other specialised nurse. Regardless of who is preparing the SCP, it is strongly recommended that the survivor be involved in the development process.

The ACSC also recommends that healthcare professionals responsible for the delivery of the care plans be formally trained in survivorship care. Recommended educational opportunities are listed in Appendix B.

Format

SCPs may be paper-based, electronic or web-based. They may be individually prepared or healthcare providers may use a template to print or add to the survivor's electronic health record. The preferences and needs of the audience (the survivor and their general practitioner) should be considered. The mode of delivery will be influenced by available resources. The ability of your healthcare service to establish a sustainable model of delivering care plans is determined by a number of factors including infrastructure (technology support) and staff time.

Signing off

SCPs are ideally prepared during a consultation with the patient's oncologist or another appropriate healthcare professional (e.g. nurse coordinator). Time should be taken to ensure that the patient understands and agrees with the content of the plan. Depending on the planned model of post-treatment care, it may be appropriate to emphasise transition from specialist-led care back to their general practitioner (GP) and other community-based supports.

The SCP may be signed off by a nurse practitioner or coordinator, medical oncologist or at a multidisciplinary team meeting. The sign-off process should take into consideration the size of the facility, time that responsible staff members have to complete and sign off the plan as well as the total number of SCPs. There is value in considering a sign-off process that will allow the patient's specialist team to provide a final endorsement of the SCP.

SCPs include a collaborative component with the survivor and so it is important they have the opportunity to have input into the final content of the plan, especially the wellbeing aspects. An SCP should identify and respond to a patient's needs and be agreed to and signed off by the survivor as well as the treating team.

Storing the SCP

The SCP and any updates made to it will act as an important reference for the patient as well as their treating oncologist and GP. Consideration also needs to be given to how the SCP will be stored so it is available to all members of the specialist care team, as well as what measures will be taken to notify the responsible party of when the SCP should be updated.

The following should be considered:

- Where will the plan be stored (e.g. in the medical record)?
- How will all members of the multidisciplinary team be aware an SCP has been completed?
- Will the SCP be easily accessed and updated if needed?

Reviewing and updating the SCP

The ACSC recommends health professionals consider the ongoing review of the SCP. The SCP should be a dynamic document regularly updated to reflect milestones and key changes in the post-treatment phase as well as the changing needs and priorities of patients.

Once an SCP has been delivered it should be revisited at regular intervals to ensure that the information within the plan remains current and relevant to the recipient. These intervals should be determined by the organisation but the ACSC recommends at a minimum that these plans are revisited with the survivor at subsequent visits and in response to changes in need (as identified by needs assessment).

The ACSC acknowledges that there is difficulty in ensuring that the SCP is updated as the patient receiving the plan has completed active treatment and so follow-up care may be delivered across multiple providers or institutions. Responsibility for updating the plan as well as following up with the survivor will be determined by the healthcare providers caring for the patient in the post-treatment phase (e.g. shared care or discharged to general practice). Roles and responsibilities regarding ongoing review and update of the SCP should be considered when implementing SCPs in your facility.

The use of SCPs in primary care

SCPs are promoted as a tool to support communication and care coordination between primary care practitioners and hospital-based specialists. For an SCP to be successfully implemented and delivered, it must include strategies to ensure that the plan is a useful tool in both the acute care system and primary care. A key strategy to make the tool useful to primary care is to include primary care practitioners in any working party considering SCP implementation.

The model of care chosen will determine the responsibilities of the GP in delivering and updating the care plan. For patients who will be discharged to primary care, clear guidelines must be developed for and in collaboration with GPs to ensure care is safely transitioned. These guidelines may recommend regular review and updating of the SCP by primary care, with consideration given to the logistics of the time and infrastructure needed to support this. Thought also needs to be made regarding how the SCP will be shared with the practice (i.e. electronically, paper-based).

To support their application in primary care, the ACSC recommends the SCP template and terminology be aligned with plans used commonly in general practice (e.g. chronic disease management plans and mental health treatment plans). Findings from the Victorian Cancer Survivorship Program pilot projects demonstrated that presentation of information in chronic disease management terms may support translation of SCPs to general practice chronic disease management plans.

Overcoming barriers to implementation

The ACSC identified a range of barriers to SCP implementation in the literature.

The ASCO report *Providing High Quality Survivorship Care in Practice: An ASCO Guide*⁽⁹⁾ recommended that organisations implementing a survivorship care program should consider potential barriers at the levels of providers, survivors and the healthcare system. In response, the ACSC suggests some potential strategies to overcome barriers, as shown in Table 3.

The ACSC recommends an organisational needs assessment be undertaken as a means of identifying the barriers most likely to be encountered in your organisation, along with resources that may help support implementation. The ACSC recommends that at a minimum, an organisation should aim to provide follow-up and wellness information to all survivors.

Table 3: Strategies to overcome barriers to implementation of SCPs

Barrier	Potential strategies/solutions
Feasibility of implementation, including concerns over duplication and allocation of resources and lack of coordination between oncologists and primary care practitioners	<ul style="list-style-type: none"> • Appoint clinical leader to lead development and implementation process • Involve primary care professionals and consumers during model development. • Identify SCP elements that are essential and feasible to collect consistently
Remuneration/reimbursement/cost	<ul style="list-style-type: none"> • Determine what resources are in place to streamline SCP development (e.g. electronic health records and administrative support) • Explore opportunity to integrate SCP delivery into existing clinical practice • Measure cost-effectiveness including impact on clinic visits • Include anticipatory budget in planning process • Engage and include knowledge of Medicare rebate item numbers in the planning process as this may help to influence the resources available to your organisation
Time/burden needed to complete SCP	<ul style="list-style-type: none"> • Determine what resources are in place to streamline SCP development (e.g. electronic health records, auto-population of some information, ability to collect information during treatment and access to administrative support) • Engage 'clinical champion' to advocate use of care plans in facility
Lack of personnel to complete SCP and lack of other resources, including systems insufficiency	<ul style="list-style-type: none"> • Access educational programs • Create local guidelines and identify how this process fits in with existing follow-up care • Explore opportunity to integrate SCP delivery into existing clinical practice

Lack of evidence/gaps in evidence to support the use of SCPs in practice	<ul style="list-style-type: none"> • Access educational programs • Use of evaluation strategies to measure outcomes
Lack of identification of personnel responsible for preparation, delivery and update the SCP	<ul style="list-style-type: none"> • Appoint clinical leader to lead development and implementation process • Engage 'clinical champion' to advocate use of care plans in facility
Lack of compatibility between templates and electronic health records	<ul style="list-style-type: none"> • Include all key stakeholders in development and implementation stage
Lack of advocacy for SCP use from clinical leaders	<ul style="list-style-type: none"> • Appoint clinical leader to lead development and implementation process • Access educational programs • Ensure buy-in from organisation and key stakeholders when considering implementation of SCPs into facility • Engage 'clinical champion' to advocate use of care plans in facility

Practice point

- An SCP should be designed in such a way as to be empowering to cancer survivors and informative to members of their care team. Developing a successful model to deliver and implement care plans involves a collaborative effort between the various stakeholders.

Part III: What should be included in an SCP?

Introduction

This section provides guidance regarding the development of an SCP template. It includes a number of recommendations for themes and sections that should be included within an SCP. It draws from relevant professional guidelines, grey literature and consensus documents.

SCPs should reflect the specific treatments the patient received (e.g. tumour-specific templates) and then be tailored to the individual's needs, goals and risks. The ACSC recommends referring to the ASCO two-page SCP templates as a starting point for developing a template appropriate for your population and organisation. The ASCO template and associated guidelines are available [here](#) and a range of templates used in the VCSP projects are available through the ACSC [Cancer Survivorship Online Collective](#). When developing a care plan template all members of the health care team, including consumer representatives, should be involved with the process.

What should be included in the SCP?

The ACSC supports the ASCO recommendations, which state that an SCP should include:

- information about the cancer treated and the type of treatments the survivor received
- short-term and long-term effects of treatment: what to be alert for and how frequently to visit the doctor for check-ups and screening (including information about psychosocial effects)
- how the survivor's follow-up care will be coordinated between the oncology specialist, GP, nurse specialists, etc., and who to contact in between follow-up appointments with any concerns
- lifestyle changes needed to reduce the risk and severity of treatment side effects, prevent comorbid conditions and promote better health (including information about diet, smoking, alcohol, obesity and weight management, exercise and sun protection)
- useful community resources, information and support options should the survivor encounter employment and insurance issues.

Essential elements of an SCP

General information

The beginning of a care plan should include basic patient information including name, date of birth, phone and email to ensure that there is clarity about who the care plan is for.

Treatment summary

A summary of treatment is important for health professionals as well as consumers. The type of treatment summary that you produce may differ depending on your target audience. Treatment summaries for consumers should be written in a way that it is understood by the consumer but also appropriate for consumers to present to healthcare professionals that they may be in contact with. Treatment summaries specifically for health professionals may require more detailed additional information, however they should remain concise; one-page summaries are optimal. The treatment summary should be used to inform the follow-up care plan⁽²⁾.

It is also important to consider the use of plain English when writing the treatment plan to ensure that the plan is easily accessible to the patient not just the medical staff. Treatment summaries can be at risk of including medical jargon that may not be understood by the patient, therefore reducing the effectiveness of the care plan for post-treatment patient care.

Further information about plain English writing can be found on the UK-based Plain English website [here](#).

Treatment summaries form part of the recommendations for care after initial treatment within the Victorian Department of Health and Human Services [Optimal Cancer Care Pathways](#). The ACSC, consistent with the Optimal Care Pathways and the updated ASCO guidelines⁽²⁾, recommends that a treatment summary should incorporate the topics listed in Table 4.

Table 4: Recommended topics for use in a treatment summary

Topics	Description
Diagnosis	Date of diagnosis and histologic subtype of cancer where necessary
Date of treatment	Start and finish date of treatment
Tumour characteristics	Tumour site, stage (if applicable), size, Gleason score, nodes, pathology findings, hormonal markers, haematology and stem cell transplantation (if applicable)
Treatment history	Including surgery, date of surgery with location on the body, findings, chemotherapy (including names of systemic therapy agents administered and end date of chemotherapy), radiotherapy (with anatomic area treated and end date of radiation treatment), hormonal therapy or any additional relevant treatment undertaken
Persistent symptoms or side effects at completion of treatment	Should identify areas that need to be addressed including potential long-term and late effects of cancer treatment
Genetic or hereditary risk factors or predisposing conditions	Including any genetic testing results if performed
Supportive services provided	Including any psychological support
Contact information for key treating institutions and providers	Including doctors, care coordinators, specialist nurses
Identification of a key point of contact and coordinator of continuing care	Including an explanation of how the survivor's follow-up care will be coordinated between the oncology specialist, GP, nurses and allied health professionals and who to contact with concerns in between follow-up appointments

Follow-up care plan

A follow-up care plan provides specific recommendations for ongoing care. A follow-up care plan should not be a static document; instead it should be reviewed at regular intervals in collaboration with the cancer survivor. Follow-up care plans form part of the recommendations for care after initial treatment within the Victorian Department of Health and Human Services [Optimal Cancer Care Pathways](#).

A follow-up care plan should provide clear information and instructions to the survivor as well as their primary care team. Identification of the roles and responsibilities for follow-up care is an important component of the SCP. Ensuring that both consumers and their GPs are aware of who is responsible for different elements of follow-up care is essential. The document should clearly set out the roles and responsibilities required to be undertaken by the GP in the survivorship phase. This section will also highlight who to contact for rapid re-entry into acute care.

Again the ACSC is in agreement with the updated ASCO guidelines information to be included in the follow-up care plan (Table 5).

Table 5: Recommended topics for use in a follow-up care plan

Topic	Description
Oncology team member contacts	Including the location and details of the facility where the survivor was treated
Need for ongoing adjuvant therapy	Including therapy name, duration and possible adverse effects
Treatment-related side effects	Short term, with likely course of recovery
Patient priorities/personal goals	With frequency and timing
Schedule of follow-up visits	In table format including who will provide, how often and where.
Periodic tests/surveillance tests and schedule	In table format including who will provide, how often and where
Cancer screening for early detection of new primaries	If different from general population, in table format including who will provide, how often and where
Possible late and long-term side effects	Including likely or rare but clinically significant side effects based on the diagnosis and treatment
Symptoms and signs of recurrence or second tumour	Or a general statement asking patient to bring any new, unusual, worrying or persistent symptoms to the attention of the healthcare provider
Financial concerns	Including inability to work due to illness, return to work, cost of treatment, etc.
Psychosocial concerns	Emotional, mental health, parenting, work/employment, insurance issues and a list of local and national resources to assist patient in obtaining proper services, also including rehabilitative issues and legal concerns and sexual functioning and fertility planning
Recommendations for healthy behaviour	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 along with sunscreen use and weight management; tailor to patient
Details of genetic counselling	If relevant
Chemoprevention	If appropriate
Relevant referrals	Include any referrals relevant that have been or need to be made
Resource lists	Including counselling services available in the local community. This should be considered in consultation with patient results from needs assessment

Who the plan was prepared by	Including date of delivery
Sign off	As appropriate. The SCP may be signed off by a nurse practitioner or coordinator, medical oncologist or at a multidisciplinary team meeting. There is value in considering a sign-off process that will allow the patient's specialist team to provide a final endorsement of the SCP

Guide to completing the follow-up care plan

Introduction

This section provides an overview of what information should be included under each of the topics (signified by headings) of the plan. The information provided to patients should be informed by national and international guidelines (see Table 6). While fear of reoccurrence is high in cancer survivors and routine follow-up screening is required, it is also important to recognise that cancer survivors are also at risk of developing a range of comorbid conditions. These conditions include (but are not limited to) obesity, diabetes, dyslipidaemia, menopause, decreased bone mass, hypertension and hypothyroidism⁽¹⁰⁾. The development of the SCP in conjunction with the survivor should include a discussion about the risk of these conditions and how to try to prevent them.

Oncology team member contacts

The plan should include the contact details for members of the treating team including the location and details of the facility where the survivor was treated. Where possible, the plan should also include the name and contact details of the survivor's GP.

Need for ongoing adjuvant therapy

Any adjuvant therapy should be clearly detailed for all members of the multidisciplinary team as well as the patient. This should include therapy name, duration and possible adverse effects.

Treatment-related side effects

Short-term side effects should be listed in the plan with strategies for coping with and addressing these. If a patient is experiencing pain, etc., strategies for managing such issues should be included.

Patient priorities/personal goals

When writing an SCP, consider including patient goals. These could include short-term and long-term wellness goals. The SMART (specific, measurable, attainable, realistic, time-based) philosophy of goal setting is a simple way to begin these conversations with survivors as well as their carers.

Schedule of follow-up visits and periodic tests/surveillance tests

A clear schedule should be incorporated into the plan that delineates roles and responsibilities—that is, who is responsible for surveillance and periodic tests. For example, if regular mammograms are required, details about where, when and how these will occur should be included along with who is responsible for making the appointment if it has not already been made.

Cancer screening

Many cancer survivors have an increased risk of developing another cancer when compared to someone who has never had cancer⁽¹¹⁾. Recommendations for relevant screening should be included within the plan where they exceed usual care, such as mammograms for women who are at a known higher risk of developing breast or ovarian cancer. Examples of nationally recommended cancer screening programs for consideration include:

- [Breast Screen Australia](#)
- [National Bowel Cancer Screening Program](#)
- [National Cervical Cancer Screening Guidelines](#)

Late effects

Late effects are side effects of cancer treatment that occur months or years after a diagnosis of cancer because of the related treatments, such as chemotherapy, radiation therapy or surgery⁽¹²⁾. As more is understood about the long-term screening, surveillance and symptom management needs of cancer survivors, ASCO and others are developing clinical guidelines to assist oncologists and other providers to address the ongoing care of this growing population⁽¹³⁾. Table 6 is a list of key national and international cancer survivorship clinical guidelines for long-term and late effects of cancer treatment.

[ASCO's Clinical guidelines](#) give guidance on the management of individual long-term and late effects.

[The Mayo Clinic](#) also provides a good overview of late effects for cancer survivors.

There are also dedicated late effects clinics in most states in Australia. To gain more information about these please contact the Cancer Council Information and Support line on 13 11 20.

Table 6: National and international cancer survivorship clinical guidelines

Organisation	Guidelines
Australian Cancer Survivorship Centre	<ul style="list-style-type: none"> • Follow-up of breast cancer survivors • Follow-up of colorectal cancer survivors • Follow-up of survivors of diffuse large B cell lymphoma (DLBCL) • Follow-up of survivors of Hodgkin lymphoma • Follow-up of prostate cancer survivors
Cancer Australia	<ul style="list-style-type: none"> • Recommendations for the identification and management of fear of cancer recurrence in adult cancer survivors
American Society of Clinical Oncology	<ul style="list-style-type: none"> • Screening, assessment and management of fatigue in adult survivors of cancer: an American Society of Clinical Oncology Clinical Practice Guideline Adaptation • Screening, assessment and care of anxiety and depressive symptoms in adults with cancer: an American Society of Clinical Oncology Clinical Practice Guideline Adaptation • Prevention and management of chemotherapy-induced peripheral neuropathy in survivors of adult cancers: American Society of Clinical Oncology Clinical Practice Guideline • Prostate cancer survivorship care guideline: American

	<p>Society of Clinical Oncology Guideline Endorsement</p> <ul style="list-style-type: none"> Fertility Preservation in patients with cancer: American Society of Clinical Oncology Update
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Psychosocial concerns

The post-treatment phase is one of uncertainty for cancer survivors. It is important to acknowledge the emotional impact a cancer diagnosis can have and the range of emotions that come with completing treatment and entering the period deemed 'survivorship'. Fear of cancer recurrence is among the most commonly reported problems and one of the most prevalent areas of unmet needs for cancer survivors and their carers⁽¹⁴⁾. Other concerns include managing expectations and finding a new normal as well as trouble coping after treatment. Further information about clinical guidelines can be found in Table 6.

ASCO recommends that the follow-up care plan include a statement acknowledging that survivors often face emotional or mental health, parenting, work/employment, financial, and/or insurance issues and that patients experiencing any of these issues may address them with their oncologist or GP⁽²⁾.

GPs can provide mental health plans for consumers. The Better Access to Psychiatrists, Psychologists and GPs through the Medicare Benefits Schedule (Better Access) initiative aims to improve outcomes for people with a clinically diagnosed mental disorder through evidence-based treatment. Under this initiative, Medicare rebates are available to patients for selected mental health services provided by GPs, psychiatrists, psychologists (clinical and registered) and eligible social workers and occupational therapists⁽¹⁵⁾. When explaining this to patients, it should be emphasised that they should make a longer appointment with their GP to complete the mental health plan.

Information for consumers regarding this service can be found at: <http://www.health.gov.au/internet/main/publishing.nsf/content/mental-ba-fact-pat>

There are also a number of community-based services and support groups available providing psychological support. Information about these services can be accessed through contacting the [Cancer Council Information and Support Line](#) on phone 13 11 20.

It is also important to acknowledge the psychological impact a cancer diagnosis has on a survivor's carer/s as well as their family members. Details of specific support services available are listed later in this section but it is important to encourage carers to seek support from their GP if needed.

Recommendations for healthy behaviour

SCPs should promote healthy living in the post-treatment phase. This includes giving survivors the resources required to empower them to develop their own healthy living goals. As part of the SCP development with the patient, the focus should move from treatment to an emphasis on wellness and self-management in the post-treatment phase. Motivational interviewing techniques support this approach. See Appendix B for relevant education programs for healthcare professionals.

The post-treatment phase is an opportune time to address the importance of healthy living. Research shows cancer risk is increased as a result of poor health habits. Implementing positive changes to health behaviour can also assist with preventing and improving symptoms of other chronic illnesses. The post-treatment phase is an opportunity to empower and encourage healthy changes as required. It is important to also consider possible existing comorbidities that survivors may have and how the recommended lifestyle changes can assist with reducing their risk and potential severity.

A number of key health issues should be considered in the SCP. Table 7 summarises them and lists key healthy living guidelines.

Table 7: Healthy living guidelines

Behaviour	Source	Information
Alcohol	Department of Health Cancer Council NSW	Guidelines and consumer friendly resource Position statement on Alcohol and Cancer
Bone health	National Comprehensive Cancer Network Breast Cancer Network Australia	Consumer resources Information relevant for all cancer types
Cancer screening	Breast Screen Australia National Bowel Cancer Screening Program National Cervical Cancer Screening Guidelines Cancer Council Australia	Australian government cancer screening guidelines Recommended Cancer Council Australia screening programs
Nutrition and healthy eating	National Health and Medical Research Council Cancer Council Victoria	Guidelines for Australian adults Consumer friendly resource Position statement on nutrition and healthy eating for cancer survivors
Physical exercise	Australian Department of Health Cancer Council Victoria	Australian physical activity guidelines Consumer friendly resource Guidelines for cancer survivors
Skin checks	SunSmart	www.sunsmart.com.au
Smoking cessation	QUIT	http://www.quitnow.gov.au 13 78 48 (13 QUIT)

Alcohol

Alcohol consumption has been shown to increase the risk of developing cancer. Cancer survivors should be made aware of this and education and information should be provided through the SCP. The Department of Health recommends that for healthy adults, consuming no more than two standard drinks on any day reduces the risk of harm from alcohol-related disease or injury over a lifetime⁽¹⁶⁾.

Bone health

People undergoing cancer treatment are at a higher risk of osteoporosis. Chemotherapy and radiation treatment as well as some medications and hormone treatments commonly prescribed during treatment can impact upon bone health⁽¹⁷⁾. The National Comprehensive Cancer Network⁽¹⁷⁾ provides resources targeted at consumers relating to bone health following cancer treatment. The Breast Cancer Network Australia⁽¹⁸⁾ provides information and guidance regarding bone health after treatment. The information they provide is also relevant for survivors of other cancer types.

Dental care

Cancer treatments can cause a number of short-term and long-term dental complications. Head and neck patients may experience dental issues from radiation treatments and any person receiving chemotherapy may experience complications. Survivors should be encouraged to speak to their dentist about strategies to address these concerns. Oral care before, during and after cancer treatment can prevent or reduce the incidence and severity of oral health complications, enhancing both patient survival and quality of life⁽¹⁹⁾.

Complications may include:

- oral mucositis
- infection
- mouth dryness
- functional disabilities
- taste alterations
- nutritional compromise
- abnormal dental development
- neurotoxicity (from chemotherapy)
- bleeding (from chemotherapy)
- radiation caries (from radiotherapy)
- trismus/tissue fibrosis (from radiotherapy)
- osteonecrosis (from radiotherapy).⁽¹⁹⁾

Diet and exercise

Studies suggest that cancer survivors who exercise regularly may feel better, have less fatigue and experience fewer symptoms after treatment compared to those who do not get regular exercise⁽²⁰⁾. Exercise may also reduce cancer recurrence and improve survival rates as well as prevent chronic disease. The importance of keeping within a healthy weight should be emphasised. Research shows that there is a known correlation between the impact of being overweight or obese on cancer development and recurrence⁽²¹⁾.

In Australia, recommendations for cancer survivors are no different from the recommendations for anyone who wants to improve their health: exercise, eat a balanced diet, maintain a healthy weight, avoid tobacco and limit the amount of alcohol you drink⁽²²⁾.

Recommendations for physical exercise are as follows:

- Doing any physical activity is better than doing none. If you currently do no physical activity, start by doing some, and gradually build up to the recommended amount.
- Be active on most, preferably all, days every week.
- Accumulate 150 to 300 minutes (2½ to 5 hours) of moderate intensity physical activity or 75 to 150 minutes (1¼ to 2½ hours) of vigorous intensity physical activity, or an equivalent combination of both moderate and vigorous activities, each week.
- Do muscle strengthening activities on at least 2 days each week.

Note: These recommendations are for all adults aged 18–64. For adults 65 years and older, recommendations are to be physically active for 30 minutes every day.

A doctor should be consulted prior to commencing an exercise routine especially if the survivor has in the past been sedentary.

Endocrine (hormonal) imbalances

Some cancers and their treatments may cause changes to the endocrine system. In particular, breast, ovarian and prostate cancer survivors as well as patients who have received radiotherapy to their head and neck area may be affected. These changes may cause early menopause (or menopausal-like symptoms in men), changes in menstrual periods, changes in thyroid function and other symptoms. The symptoms of menopause caused by cancer treatment may be worse than the symptoms of natural menopause because the decrease in hormones happens quickly⁽²³⁾.

Survivors who are at risk of long-term hormonal effects of treatment should monitor their hormone levels with regular blood tests.

Fertility

While fertility issues should be addressed prior to commencing treatment, additional resources may be appropriate for inclusion within a care plan.

Information about fertility after cancer treatment can be found on the [Cancer Council's](#) website.

Also refer to the current [ASCO guidelines for fertility preservation](#).

[CanTeen](#) also provides resources and information for young people regarding fertility issues.

Intimacy and sexuality

Sexuality issues affect all cancer survivors and should be considered an important effect of cancer and cancer treatment. As sexuality is a personal issue for each individual, basic assessment should be undertaken by the health professional in order to determine what is most appropriate for each patient.

Refer to Cancer Council Victoria's resource '[Sexuality, Intimacy and Cancer](#)'.

[Rekindle](#) is a private, personalised online resource that addresses sexual concerns of all adults affected by cancer. Cancer survivors, either in a relationship or single, and partners, are invited to use Rekindle. The program is tailored to meet individual needs.

Practical issues (money, work and study)

Cancer survivors may require support and guidance surrounding practical issues relating to money, work and study.

A number of services are available to assist cancer survivor's address these issues:

- [Centrelink](#) (13 27 17) provides information on employment, disability, sickness and carers payments.
- [Family Assistance Office](#) (13 61 50) provides information about help with childcare costs and eligibility criteria.
- [FIDO \(Australian Securities and Investments Commission\)](#) (1300 300 630) provides a range of financial advice services.
- [Moneyhelp](#) (1800 149 689) is a government service that offers free, confidential and independent financial counselling, information and advice for Victorians who are struggling to pay bills, their mortgage or rent, or who have experienced or are facing job loss or reduced working hours.
- [Disability Discrimination Legal Service](#) (03 9654 8644) can provide support and guidance for individuals experiencing discrimination in their area of employment relating to their diagnosis.

- [WorkWelfareWills](#) is a practical web guide to legal issues around health and life changes. It contains information about Centrelink entitlements, health privacy, powers of attorney, guardianship, superannuation, insurance, travel insurance, wills and workplace discrimination. It has been set up to provide legal advice to people with disabilities. Appointments can be made by calling the Chronic Illness Alliance (03 9882 4654). Free advice is available by telephone or by appointment.
- [The Cancer Council Information and Support line](#) (13 11 20) can provide contact details for many local services. There is also a range of useful materials on its website about dealing with practical issues and legal rights and responsibilities.

Skin checks

Survivors should be reminded of the importance of regular skin checks. Some cancer treatments can increase the risk of developing skin cancer. The importance of using sunscreen and protective wear should also be emphasised.

Further information can be found on the Cancer Council Australia's website: [Check for skin cancer](#).

Smoking cessation

Encouraging smoking cessation is important. Stopping tobacco use, even after a cancer diagnosis, can improve recovery and overall health⁽²⁴⁾. Health professionals can make an important contribution to tobacco control in Australia and to the health of the community by providing opportunities for smokers to quit⁽²⁵⁾. Health professionals should systematically identify smokers, assess their smoking status and offer them advice and cessation treatment at every opportunity. Where a client presents with a problem caused or exacerbated by smoking, it is of vital importance for health professionals to raise the issue of smoking cessation⁽²⁵⁾. Further information can be found on the [Quit website](#).

Genetic testing

Genetic testing should be considered for inclusion in the SCP if appropriate. If a patient has previously been positively screened, detailed information should be given to the patient about follow-up in the post-treatment phase. The ASCO policy statement [Update: Genetic and Genomic Testing for Cancer Susceptibility](#) provides further information.

Chemoprevention

Cancer chemoprevention is the use of natural, synthetic (made in a laboratory) or biologic (from a living source) substances to reverse, suppress or prevent the development of cancer⁽²⁶⁾. Examples of chemoprevention include tamoxifen for breast cancer patients.

Support services and other resources

A number of resources can be recommended for people following the completion of active treatment. See Appendix A for a list of support services and resources.

The ACSC recommends a number of companion resources to be used with an SCP. These provide evidence-based practical advice and assistance for survivors and their carers post-treatment. A recommended list of companion resources for SCPs is provided below.

Companion resources for SCP

The ACSC recommends that the following resources be given to people receiving an SCP along with any additional resources relevant to their diagnosis and situation:

- DVD *Just Take It Day to Day*
- A question prompt list (such as the ACSC resource '[Questions you may wish to ask in the time after treatment](#)')
- A practical guide such as the [Cancer Council's](#) *Living Well after Cancer* or *On the Road to Recovery* (including Cantonese, Mandarin and Greek versions; Arabic, Italian and Vietnamese resources are in development)

Practice point

- The ACSC supports the ASCO recommendations for what should be included in an SCP.
- Cancer survivors may experience a number of long-term and late effects from their cancer treatment.
- A number of cancer survivorship clinical guidelines have been developed to assist with these effects.
- Those responsible for completing the SCP should be aware of recommended healthy living guidelines and their role in the post-treatment phase.
- There are a number of consumer-focused resources and services from non-government organisations that may complement an SCP.

Part IV: Examples of international guidance and resources about SCPs

Introduction

A number of facilities and organisations globally have focused on the development and implementation of SCPs in response to the 2005 Institute of Medicine report *From Cancer Patient to Cancer Survivor: Lost in Transition*⁽¹⁾. A list of templates, tools and guidance regarding SCPs is provided below. Please note this is not an exhaustive list but provides examples that may be suitable to be adapted within your facility.

The ACSC acknowledges that the SCP template used by your facility depends upon your organisation, your patient population and the resources available. The examples below may help to guide decisions on suitable templates for the contexts in which you will be using them.

United States

American Society of Clinical Oncology

[The American Society of Clinical Oncology \(ASCO\)](#) released an updated version of its SCP template in October 2014. This version supersedes the original care plan template, which was released in 2005. ASCO promotes a treatment summary and follow-up care plan as two documents that make up an SCP⁽²⁾.

[ASCO Survivorship Care Clinical Tools and Resources](#)

Journey Forward

[Journey Forward](#) was established to develop concrete solutions for problems cancer survivors and their healthcare providers face⁽²⁷⁾. It has developed resources suitable for use by health professionals and consumers. Journey Forward is a collaboration between the National Coalition for Cancer Survivorship, the UCLA Cancer Survivorship Centre, the Oncology Nurses Society, Anthem Inc. and Genentech. They also have a 'survivorship library' of resources suitable for health professionals and consumers.

[Journey Forward Resources for Health Professionals](#)

[Journey Forward Resources for Consumers](#)

LiveStrong

The LiveStrong Foundation originally developed an online resource that allows cancer survivors to develop an SCP and treatment summary that can be given to their healthcare provider⁽²⁸⁾. Usage has changed over time to include health professionals as well as consumers, and the online template remains easy to use and incorporates key themes similar to other care plans. The care plan encourages communication and collaboration between consumers and healthcare professionals as well as enabling consumers to have autonomy over their post-treatment care.

[The LiveStrong Care Plan](#)

[The LiveStrong Treatment Summary Template](#)

United Kingdom

National Cancer Survivorship Initiative

The [National Cancer Survivorship Initiative](#) (NCSI) was a collaboration between Macmillan Cancer Support and the Department of Health and was supported by NHS Improvement. The NCSI closed in 2013 and the resources are available for ongoing use via their website.

The NCSI developed a 'recovery package' made up of four interventions completed throughout and after an individual's cancer treatment. The four interventions are:

- a holistic needs assessment
- a treatment summary completed at the end of each acute treatment phase, which is sent to both the patient and their GP
- a Cancer Care Review completed by the GP or practice nurse to discuss the patient's needs
- the opportunity for the patient to attend a patient education and support event, such as a health and wellbeing clinic, to prepare the person for the transition to supported self-management, which will include advice on healthy lifestyle and physical activity⁽²⁹⁾.

The treatment summary is a document produced by cancer care professionals at the end of treatment and sent to the patient's GP. It provides important information for GPs, including possible treatment toxicities, information about side effects and/or consequences of treatment, signs and symptoms of a recurrence and any actions for the GP⁽³⁰⁾. Patients also receive a copy of the document.

The Cancer Care Review is carried out by the general practice six months after a diagnosis of cancer and covers post-treatment support, financial impact of cancer, patient awareness of prescription exemptions, possible late effects of cancer and cancer treatment and other information needed to enable self-management⁽²⁹⁾.

[NCSI Cancer Care Templates](#)

Australia

The Victorian Department of Health initiated the Victorian Cancer Survivorship Program (VCSP) in 2011 to pilot new models of survivorship care within the health system. The program aimed to trial collaborative models of care across acute and primary/community care sectors; evaluate interventions for effectiveness, acceptability, sustainability and transferability; and facilitate survivor involvement and self-management⁽³¹⁾. The VCSP funded six projects, each of which included the development of an SCP. All of the projects also engaged GPs.

According to the summary report⁽³²⁾, overall, SCPs were positively received and viewed as a valuable communication tool by survivors, hospital staff and GPs. GPs were more likely to discuss SCPs with participants within a model of shared care. Information presented in chronic disease management terms helped translate the SCP for GPs and supported Chronic Disease Management Plans. Sustaining time-consuming SCP interventions within existing resources presented challenges for some projects.

Recommendations from the report were:

1. Organisational commitment to a comprehensive survivorship model of care, executive and clinical leadership, and multidisciplinary engagement are required to implement, define roles and responsibilities, extend and embed SCPs into standard post-treatment care in a cancer centre.
2. Cancer survivorship education across all sectors is required to improve understanding, awareness and provide tools for practice.
3. Efficient IT systems are required to support the implementation of survivorship care plans.

4. Allocation of project resources and support to ensure the SCP is an effective communication tool and to enable the implementation of SCP across clinical services.

Evaluate the SCP implementation project in relation to cost–benefit analysis, impact on patient lifestyle and health behaviours, the quality of communication and transition of care.

More information, including individual project reports and a copy of the VCSP Summary Report can be accessed [here](#).

Practice point

- A number of facilities and organisations globally have developed SCPs in response to the 2005 Institute of Medicine report *From Cancer Patient to Cancer Survivor: Lost in Transition*. The ACSC recommends that the SCP template used by your facility should take into consideration your organisational context and the resources available to you.

Case Study: SCP implementation, an Australian experience

In 2011, Peter Mac commenced a pilot project titled Survivorship Care Planning, which was initiated to improve post-treatment care coordination and the information and support needs of cancer survivors. Cancer survivors were defined as patients that had received and completed definitive treatment. The project intervention included the development and delivery of an SCP to patients within clinical services at Peter Mac.

In 2011, conversations commenced with ACSC staff and clinicians representing the urology, gynaecology, haematology, lower gastro intestinal (GIT), upper GIT, head and neck, melanoma, late effects, sarcoma, lung and breast clinical services at Peter Mac. Participating nurse coordinators received education from the ACSC survivorship nurse. The development of educational resources was undertaken including *Living Well after Cancer* booklet, *Just Take It Day to Day* DVD and fact sheets.

SCPs were developed and implemented at Peter Mac in the gynaecology, haematology, late effects and urology clinical services. An end-of-radiotherapy letter (treatment summary) was developed and implemented in the lung service.

SCP templates were developed for individual clinical services. Although each SCP contained disease- and treatment-specific information, there was also common content for SCPs across clinical streams.

Tailored SCPs were developed and distributed to patients:

- who had completed robotic-assisted prostatectomy in the urology service
- who had completed treatment for cervical and endometrial cancer in the gynaecology service
- attending nurse-led clinics post-allograft and -autograft in the haematology service
- attending the late effects clinic including survivors of haematological malignancies, central nervous system (CNS) tumours and solid tumours
- completing radiotherapy treatment in the lung service.

The need to provide GPs with a copy of the SCP has been universally recognised. A copy of the SCP was sent to each patient's GP to ensure they were kept up-to-date with information essential to monitoring survivors' health and able to provide informed support and advice and contribute to ideal patient care.

In 2013, a qualitative evaluation of the Survivorship Care Planning project was undertaken, which examined the impact of survivorship care planning for patients, GPs and hospital-based staff. The subsequent report identified enablers of and barriers to SCP implementation and uptake with feedback provided by patients, healthcare professionals and GPs.

The report found that the majority of patients found their SCP to be very useful or somewhat useful and just over half reported that the SCP would help them discuss the cancer experience with their GP. All of the nurse coordinators (NC) delivering SCPs reported the plan was a very useful or somewhat useful tool for their clinical practice. Nearly all reported that the SCP improved their communications with the patient's GP. Nearly half reported the SCP was too long, taking on average 60–90 minutes to complete; this and competing demands in the NC role impacted on one service's ability to continue to deliver SPCs. The majority of GPs reported that they had received a copy of the SCP. Most felt that the SCP would improve communications with the patient regarding their cancer experience; over half reported that the SCP would improve communications with cancer treatment providers.

The full report is available [here](#).

Appendices

Appendix A: Groups for survivors and carers

Listed here are groups that are recommended by the authors of this publication. We have also listed some of the resources provided by these groups. Please note these resources are being updated and new publications being developed all the time. The websites can provide you with a more extensive list of resources as well as additional information on the services and support these associations can provide. You may also be in contact with other local groups who have developed and published resources that are relevant to your practice.

Australian Cancer Survivorship Centre – A Richard Pratt legacy

Website: www.petermac.org/cancer-information/life-after-treatment

Email: contactacsc@petermac.org

The ACSC has developed a number of resources that are relevant to cancer survivors. These can be found online or obtained by contacting the ACSC.

The ACSC provides tumour-specific resources for: Hodgkin lymphoma, prostate cancer, bowel cancer, breast cancer and diffuse large B cell lymphoma. Additional resources include:

- managing long-term and late effects of cancer treatment
- dealing with money, work and study (practical issues)
- questions you may wish to ask about the time after your treatment
- coping with the fear of your cancer coming back.

In addition, a number of cancer survivors have shared their story of cancer survivorship. These stories are available [here](#).

Cancer Council Australia

Website: www.cancer.org.au (national website or contact your state branch)

Information and Support: 13 11 20

The Cancer Council provides a number of resources for cancer survivors. These include booklets and information on emotions, finances and employment, nutrition and exercise, sexuality and intimacy as well as caring for someone with cancer. There is also a valuable resource titled *Loss and Grief*, which addresses the possible grief caused by any loss or change in a survivor's life because of cancer; *Living Well after Cancer* is another useful resource. *On the Road to Recovery* has been developed for Chinese and Greek speaking survivors and Arabic, Italian and Vietnamese resources are being developed.

Cancer Council support organisations deliver group support through the Wellness and Life after Cancer program. The program includes practical information and encourages open discussion for cancer survivors, their carers and families.

Cancer-specific organisations

There are support groups and services for people with specific types of cancer. These include:

- [Bowel Cancer Australia](#)
- [Breast Cancer Network Australia](#)
- [Prostate Cancer Foundation of Australia](#)
- [Leukaemia Foundation \(information and support for those with Leukaemia, Lymphoma, Myeloma and other related blood disorders\)](#)
- [Myeloma Foundation of Australia](#)
- [Ovarian Cancer Australia](#)
- [Lymphoma Australia](#)
- [Melanoma Patients Australia](#)

Please note this is not an extensive list and does not include state-specific services.

Information for children and young adult cancer survivors

Child and young adult cancer survivors face unique challenges when compared with adult survivors. Long-term and late effects of cancer and treatments as well as the psychological impact of a cancer diagnosis at a young age are all important considerations when developing an SCP for a young person. The parents, carers and siblings of these survivors should also be acknowledged. A number of different organisations have developed resources targeted at survivors of childhood cancers as well as their parents and carers. These include:

CanTeen

Website: www.canteen.org.au/my-cancer/beyond-cancer/

Email: admin@canteen.org.au

CanTeen has resources (written and peer support) for young people (12–24 years) with or affected by cancer.

RedKite

Website: www.redkite.org.au

Email: support@redkite.org.au

RedKite offers support for young people (up to 24 years) with cancer. RedKite can assist with information and counselling, financial assistance, education, and carer and bereavement support.

Information for carers of cancer survivors

The ACSC acknowledges the significant impact that a cancer diagnosis can have on the carers of the survivor. The above-listed groups can also assist carers; they can be found online or contacted directly.

It is important to ensure that carers have adequate resources and information about where they can access support. It is also important to acknowledge the positive influence that a carer can have on a cancer survivor and the support they can provide in the post-treatment phase, particularly in motivating and encouraging survivors regarding healthy living and self-management.

Carers Australia: www.carersaustralia.com.au

Appendix B: Survivorship education programs

Delivering Innovative Cancer Survivorship Care

The ACSC runs regular workshops for healthcare professionals titled Delivering Innovative Cancer Survivorship Care. This introductory workshop is open to all nursing and allied health professionals. It provides participants with key knowledge, skills and resources for implementing cancer survivorship care into practice. The program covers principal elements of survivorship, the common experiences of cancer survivors, motivational interviewing techniques, chronic disease management in primary care, tools and resources, and group work to reinforce new skills.

Further details can be found [here](#).

Cancer Learning: Survivorship E-Learning Module

The [Cancer Learning, Survivorship E-Learning Package](#) was developed by the ACSC in collaboration with Peter Mac, the University of Sydney, Queensland University of Technology, and national survivorship experts. It provides evidence-based practical tools, tips, resources and learning modules.

The suite of evidence-based learning modules for health professionals explores contemporary knowledge around survivorship care as well as mechanisms on how to apply this knowledge into your daily practice.

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⁽³³⁾.

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'⁽³⁴⁾. 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'⁽³⁵⁾.

Cancer survivorship

Survivorship focuses on 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⁽³⁶⁾.

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 health or care providers⁽³⁷⁾. 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⁽²⁹⁾.

Optimal care pathways

Optimal care pathways describe the optimal cancer care for specific tumour types. They map the patient journey, aiming to foster an understanding of the whole pathway and its distinct components to promote quality cancer care and patient experiences⁽³⁸⁾.

Organisational needs assessment

An organisational needs assessment is defined as a systematic process to acquire an accurate, thorough picture of a system's strengths and weaknesses, in order to improve it and meet existing and future challenges.

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⁽³⁹⁾.

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⁽⁴⁰⁾.

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⁽⁴¹⁾.

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⁽⁴²⁾.

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⁽³⁰⁾. 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)⁽²⁾.

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