Acknowledgements

In 2009, the Australian Cancer Survivorship Centre (ACSC) was established with funding from The Pratt Foundation, the Victorian Department of Health and the Peter MacCallum Cancer Centre (Peter Mac). The ACSC is located at Peter Mac and provides expertise in survivorship care, information, support and education. Our purpose is to provide excellence in survivorship care both locally and externally which optimises the health and well-being of cancer survivors and their carers.

Peter Mac is able to undertake local improvements in survivorship care, thanks to the vision of and funding provided by The Pratt Foundation. This work is enhanced thanks to our involvement in and learnings gained from the Department of Health’s Victorian Cancer Survivorship Program.

Survivorship care plan implementation has occurred in a number of clinical services at Peter Mac, thanks to the commitment of service chairs and the dedication of nurse coordinators who document and deliver post-treatment care plans. The implementation of Survivorship Care Plan (SCP) in these clinical services has occurred with the support and leadership of the ACSC; we acknowledge that the clinical services undertook the work without additional funding or resources.

The ACSC would like to thank all patients, clinical service chairs, allied health professionals, nurse coordinators, and General Practitioners who provided their time to participate in this evaluation. We hope this report adequately and accurately reflects the valuable feedback provided by multidisciplinary teams.

This report has been written by Ms Nicole Kinnane, Ms Linda Nolte, Ms Priscilla Gates, Ms Pauline Shilkin and Associate Professor Michael Jefford.

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A copy of the report can be obtained via the ACSC website www.petermac.org/cancersurvivorship.
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Part A: Introduction, summary of key findings and recommendations

Introduction

The Peter MacCallum Cancer Centre (Peter Mac) is committed to improving post-treatment care for all patients who have received cancer treatment. A pivotal report released in 2005 from Institute of Medicine (IOM), recommended that every cancer survivor be given a treatment summary and follow up care plan together referred to as a Survivorship Care Plan (SCP) at the end of their initial cancer treatment, to enable smooth transition into the post-treatment phase[1].

In 2011, Peter Mac commenced a pilot project titled Survivorship Care Planning (referred to in this report as the SCP Project). It was initiated with two main aims, these being:

a. to improve post-treatment care coordination and transition;
b. to improve information for and support of cancer survivors and their carers.

The project included administering a SCP to patients in four of the clinical services at Peter Mac.

In 2013, a qualitative evaluation of the SCP Project was undertaken, which examined the impact of survivorship care planning for patients, General Practitioners (GPs) and hospital-based staff. This report also identified enablers of and barriers to SCP implementation and uptake with feedback provided by patients, healthcare professionals and General Practitioners.

Key findings

- The majority of patients found their SCP to be very useful or somewhat useful, and half reported that, compared to other written types of information, the SCP was very important in helping them to understand their cancer experience.

- Over three-quarters of the patients had read their SCP. While more than half of the patients had not discussed their SCP with their GP, 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 SCPs.

- The majority of GP reported that they had received a copy of the SCP and most had had the opportunity to read it. While few GP had discussed the SCP with their patient, 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. SCP only resulted in the development of two chronic disease management plans reported GPs.

- The themes that emerged from semi-structured interviews with multidisciplinary team members at Peter Mac included: lack of awareness of the SCP project, limited leadership and commitment within the organisation, and a lack of resources and limited time for implementing SCPs.

Recommendations

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 survivorship care plans 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.

5. 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.
Part B: Executive summary

Background
Sixty-six per cent of people with cancer in Australia will survive more than 5 years[2]. Survivors may experience many different issues after completing treatment, including physical, emotional, psychosocial and practical effects[3]. A pivotal report by the US Institute of Medicine (IOM) 2005, recommends that every cancer survivor be given a treatment summary and follow up care plan together referred to as a survivorship care plan (SCP) at the end of initial cancer treatment, to facilitate a smooth transition into the post-treatment phase[1].

The SCP is a patient-owned document which aims to raise awareness of the importance of surveillance, healthy living and a coordinated plan of follow-up care[1]. Despite support for SCPs as illustrated in Salz et al 2012, few centres nationally or internationally have routinely implemented SCP resulting in limited understanding of the impact of SCP for patients and healthcare professionals alike.

The Survivorship Care Planning (SCP) Project
The Peter MacCallum Cancer Centre (Peter Mac) is committed to improving post-treatment care for all patients who have received cancer treatment.

In 2011, Peter Mac commenced a pilot project titled Survivorship Care Planning (referred to in this report as the SCP Project). An example of a SCP is provided in Appendix 1. It was initiated to (1) improve post-treatment care coordination and transition and (2) improve information for and support of cancer survivors and their carers. Cancer survivors were defined as patients who had received and completed definitive treatment.

The SCP Project included:
- the development of treatment summary and survivorship care plan (SCP) templates for a sample of clinical services
- survivorship care education and training for nurse coordinators
- consumer and health professional information resource development
- implementation of SCP
- related data collection.

The project included completion and delivery of an SCP. The SCP was generated and delivered by a nurse coordinator to patients in four clinical services at Peter Mac: the gynaecology, haematology, late effects and urology services. A copy was sent to patients’ General Practitioners (GPs).

Evaluation of the SCP Project
In 2013 the ACSC instituted an evaluation of the impact of the SCP Project, including the enablers of and barriers to SCP, as well as the impact of implementing SCP for patients, GP and hospital-based staff.

Patients who received a SCP in the gynaecology, haematology, late effects and urology services from October 2011 were invited to participate. Those who consented to take part received a questionnaire to complete. The questionnaire asked about the timing of delivery of the SCP, its level of detail and its usefulness in helping them adjust to life after cancer and in discussion with their GP.

Nurse coordinators delivering SCP from the gynaecology, haematology, late effects and urology services were invited to participate. Those who consented completed an online questionnaire asking about their experience of delivering the SCP developed for their clinical service, about usefulness, feasibility and barriers to implementation.

Participating, through semi-structured interviews, nurse coordinators representing the remaining seven Peter Mac clinical services not engaged in SCP implementation, clinical service chairs, and all heads of allied health departments. They were asked about awareness of SCP and their implementation at Peter Mac, the feasibility of implementation, the role of the GP and the transition of follow-up care to the GP, and the key enablers of successful SCP implementation.
GP of patients who had consented to be part of the study and had received a copy of an SCP were contacted by telephone and invited to participate. They were asked about the usefulness of the SCP, its level of detail, translation into a chronic disease management care plan, and discussion with their patient.

**Findings of the Evaluation**

**Patients**
Fifty patients consented to participate in the study: a 42% response rate.
Over three-quarters of the patients found their SCP to be very useful or somewhat useful; over half agreed the SCP was delivered at the right time; and half reported that, compared to other written types of information, the SCP was very important in helping them to understand their cancer experience.

Over three-quarters had read their SCP and nearly all found the it easy to understand.

“It gives an overview of everything that happened with, during, before and after your treatment. I think it’s great that the GP gets a copy as well because quite often they’re the first place you go for help and it then means you don’t have to explain everything from scratch” (ID code 37).

More than half had not discussed their SCP with their GP; just over half reported that the SCP would help them discuss their cancer experience with their GP.

**Nurse coordinators engaged in delivering SCP**
Seven nurse coordinators engaged in delivering SCP participated: an 88% response rate.
All of the engaged nurse coordinators found the SCP to be a very useful or somewhat useful tool for their clinical practice and all found it easy to understand. Nearly all reported that the SCP improved their communications with their GP.
Timing of delivery of care plan varied across all the services – with the least amount of time from treatment to delivery being 1 week post-surgery for urology patients. Only one service reported administrative support to prepare the care plan which was not adequate.

Time to develop and deliver the SCP was highlighted by all but one of the Nurse Coordinators as a critical barrier to implementation. Despite competing demands in their roles, they continued to be engaged in delivery as they firmly supported the project as improving patient outcomes.

“Time, however it is an essential part of our service” (ID code 4).
Three out of seven (42%) Nurse Coordinators commented that the SCP was too long and taking on average 60–90 minutes (or more) to complete. Complexity of patient history, length of time to complete contributed to one service ceasing delivery of SCP.

“Complex patients….. Incredibly time consuming; have been unable to commit to providing additional SCP despite being supportive of the implementation and dissemination” (ID code1).

**General practitioners**
Eighteen GPs consented to participate: a 38% response rate.
Most GPs reported that they had received a copy of the SCP and most had had the opportunity to read it. Few had discussed the SCP with their patient. Only two had created a chronic disease management plan for their patient since completion of treatment with one using the SCP to “create a more comprehensive one”. One GP (8%) said they would create one in the near future and one (8%) stated:

“I do not see my patient as chronically ill” (ID code 4).
Half (50%) preferred to receive the SCP electronically.

Most GPs felt that the SCP would improve communications with the patient regarding their cancer experience and over half felt that the SCP would improve communications with cancer treatment providers. Three quarters (76%) agreed that the SCP clarified their role in facilitating survivorship care.
“Provides avenue for who to contact - clearly states this. Indicates what we should look for - any abnormalities and this makes it easier to communicate with the treatment providers” (ID code 4).

43% acknowledged challenges in providing follow up care to patients who have completed their cancer treatment, mostly associated with limited GP exposure.

“Lack of knowledge - no idea of potential side effects for chemo, what are the appropriate screenings and tests need to be done…. wasn’t aware of the cardio toxic effects of chemo until much later.” (ID code 2)

Almost half (48%) expressed interest in attending a 1-2 day placement programme in an oncology setting to update them regarding follow-up care of patients who have finished cancer treatment.

Other hospital-based staff

Semi-structured interviews were conducted with nurse coordinators who were not engaged in delivering SCP (n=8), heads of allied health departments (n=4) and clinical service chairs (n=7): 100% response rate for nursing and allied health and 50% response rate for clinical chairs. Notes from the interviews were transcribed and the combined data was examined for themes and issues.

The participants found SCP to be resource intensive. Critical to implementation into standard practice across all clinical services is organisational leadership and commitment, a multidisciplinary approach, resourcing, and an efficient information technology (IT) solution.

Conclusion

In summary, this study set out to describe the impact of and enablers and barriers to implementing SCPs, for patients, nurse coordinators, GPs and other hospital based staff.

All participants considered SCP to be useful. However, GPs said they had limited time to consult the SCP and few used the SCP to create a chronic disease management plan. SCPs were described as resource intensive for hospital-based staff.

The researchers identified a lack of awareness and engagement in the SCP project by hospital-based staff and noted the need for resources, time and more efficient IT solutions.

Organisational commitment and executive and clinical leadership are required for ongoing SCP implementation and prior to extension into other clinical services.

Recommendations

The following recommendations, arising from the SCP Project and evaluation, are made to help improve the development and delivery of SCPs to patients across all tumour streams at Peter Mac.

These recommendations are considered essential elements for any organisation implementing a sustainable model of survivorship care into standard post-treatment practice.

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 for, and extend and embed survivorship care plans into standard post-treatment care.
   a. Define and agree an organisational and/or clinical service survivorship model of care, considering process of care.
   b. Strengthen project management, governance, stakeholder engagement, communication strategy, risk management, and reporting.

2. Cancer survivorship education across all sectors is required to improve understanding, awareness and provide tools for practice.
a. Provide skills-based education and training to multidisciplinary clinical staff including nurse coordinators and allied health professionals.

b. Provide access to survivorship guidelines (literature review), resources and tools to support the implementation of SCPs.


d. Define the appropriate time to deliver the SCP for each clinical service.

3. Efficient IT systems are required to support the implementation of SCPs.

a. Engage health information services to produce electronic, auto-populated templates that can be accessed by the multidisciplinary team.

b. Build in mechanisms for the collection of key data items to monitor the implementation of SCPs and performance.

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

a. Work with clinical services to review and redevelop the SCP template to ensure it meets the needs of the patient, GP and multidisciplinary team.

b. Include needs assessment and risk stratification to prioritise patients most in need of a SCP.

c. Strengthen patient education and self-management principles to optimise the benefit and utilisation of the SCP.

d. Redevelop the SCP template to optimise and support GP communication, utilisation and transition to a chronic disease management plan.

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

5. The SCP Project should be evaluated in relation to cost–benefit analysis, impact on patient lifestyle and health behaviours, and the quality of communication and transition of care.
Part C: Survivorship Care Plan Review

Background
Between 1995-2007 the relative survival rate from cancer has improved with Australia ranking within the top three countries amongst the International Cancer benchmarking partnership group [4]. The 5-year survival rate in Australia for all cancers combined increased from 47% in 1982–1987 to 66% in 2006–2010[2]. In 2008 the Department of Health Victoria released The Victorian Cancer Action Plan which outlined strategic targets for cancer care over the subsequent five years. Survivorship transition and follow up care was illustrated as a key focus point and acknowledged that healthcare professionals play a key role in supporting patients in the transitional phase[5]. The number of cancer survivors has been estimated at more than 775,000 at the end of 2007, and is increasing as our population ages[6]. The US National Cancer Institute estimated that, as of January 2012, there were 13.7 million cancer survivors in the US, and this number was expected to grow with continued advances in cancer therapy and the aging of the population[7].

Survivorship care plans
Cancer survivors face challenges and uncertainty regarding follow-up care[3]. The Institute of Medicine in a landmark report from the United States in 2005 recommended that all patients who have completed primary treatment for cancer be provided with a comprehensive treatment summary and follow up care plan together referred to as a Survivorship Care Plan (SCP)[1]. A SCP includes a treatment summary and health behaviour recommendations for patients who have finished or completed cancer treatment. Recommendations include that the SCP be reviewed with the patient during an end-of-treatment consultation and communicated with the GP to foster improved care coordination[1]. Despite these recommendations and the suggestion that SCPs are an essential component of care it has been identified that practical barriers exist in the creation, dissemination and coordination of the SCP between healthcare professionals, patients and the wider community[8].

The essential elements for the SCP[1], include:

- diagnosis
- dates of treatment initiation and completion
- treatment given, including chemotherapy agents and doses, radiotherapy sites and doses, surgery and transplantation
- toxicities experienced during treatment
- information on possible and actual late effects of treatment
- description of recommended cancer screening and screening schedule
- recommendations for healthy behaviours (e.g. healthy diet, exercise, healthy weight, sunscreen use, and smoking cessation/avoidance)
- psychological and other supportive services provided
- a list of cancer-related resources and information (e.g. websites and major cancer support agencies)
- contact details of treating centre and team, identification of a key point of contact and the coordinator of continuing survivorship care.

A SCP is intended to give cancer survivors a customised road map for their lives following cancer treatment [1, 9]. It includes tips for follow-up screenings and information about possible late effects of treatment and can enhance communication between healthcare providers, cancer survivors and carers[9, 10]. The concept is now recognised as a key part of facilitating the continued health of cancer survivors[1]. Beginning in 2015, the American College of Surgeons will require cancer centres seeking accreditation within the United States, to provide care plans to patients once they complete their treatment[11].
Survivorship Care Plan Project at Peter Mac

In 2011, the ACSC commenced consultation regarding implementing SCPs with clinicians representing the urology, gynaecology, haematology, lower gastrointestinal, upper gastrointestinal, head and neck, melanoma, late effects, sarcoma, lung and breast clinical services at Peter Mac. During this time, four clinical services committed to commencing the Survivorship Care Plan Review across the healthcare organisation.

The SCP Project included reviewing the SCP literature, developing treatment summaries and SCP templates tailored to individual clinical services, survivorship care education and training for nurse coordinators, information resource development, implementation of SCP, and related data collection. It also included the completion and delivery of an SCP. In most services, the intervention also included the use of the Peter Mac supportive care screening tool to identify unmet needs.

The SCP was generated and delivered by a nurse coordinator to patients in the four clinical services. In addition, a copy was sent to their GP.

The implementation of SCPs in these four clinical services occurred with the support and leadership of the ACSC and was undertaken by the clinical services without additional funding or resources.

Aims

This review aimed to:

- Describe the impact of an SCP for patients, nurse coordinators, heads of clinical services, GPs and allied healthcare professionals.
- Describe any enablers of and barriers to implementing SCPs for patients, nurse coordinators, heads of clinical services, GPs and allied health care professionals.

Method

Populations and setting

This is an exploratory review of six different population groups affected by the implementation of the SCP at Peter MacCallum Cancer Centre from 2011. The six involved groups were:

1. Patients who have received a SPC
2. Nurse Coordinators using the SCP from urology, gynaecology, haematology and late effects services
3. GPs linked to this patient group
4. Clinical Chairs of Services
5. Heads of Allied Health
6. Nurse Coordinators not using the SCP

Group 1: Patients who received a SCP

Method: Written Questionnaire

Tool: non-validated research questionnaire (non-piloted)

From October 2011, Patients who received an SCP in the gynaecology, haematology, late effects or urology were invited to participate in the exploratory project. Patients were selected from the Australian Cancer Survivorship Centre’s database.

Questionnaires were sent in the mail to patients who consented to take part. They were given the choice to complete the questionnaire in hard copy or electronically.

The survey included questions about the timing of delivery of the SCP, its level of detail and its usefulness in helping them to adjust to life after cancer and in discussion with their GP.
The following outlines the eligibility criteria for the patient participants:

- have received an SCP within the gynaecology, haematology, late effects or urology service since October 2011
- be aged over 18 years
- be able to complete study requirements in English.

Group 2: Nurse coordinators engaged in delivering SCPs
Method: Written Questionnaire (Electronic)
Tool: non-validated research questionnaire
Nurse coordinators delivering SCPs from the urology, gynaecology, haematology and late effects services were invited to participate in a survey.
The survey included questions about SCP usefulness, feasibility and barriers to implementation.

Group 3: General practitioners
Method: Questionnaire
Tool: non-validated research questionnaire
The GP of patients who had consented to be part of the study and had received a copy of an SCP were contacted by telephone and invited to participate in a survey questionnaire. They were asked to complete a questionnaire either via telephone or by completing a written questionnaire that was faxed or posted.
The survey included questions about the usefulness of the SCP, its level of detail, translation into a chronic disease management care plan, and discussion with their patient.

Group 4, 5, 6: Clinical Chairs of Services, Heads of Allied Health and Nurse Coordinators not using SCP.
Method: semi-structured interviews for provision of feedback related to the SCP.
Also invited to participate, were nurse coordinators representing the remaining seven Peter Mac clinical services not engaged in SCP implementation, all clinical service chairs, and heads of allied health departments.
All participants were asked the same questions, including questions about awareness of survivorship care and care plan implementation at Peter Mac, their views regarding the feasibility of implementation, their views regarding the role of the GP and the transition of follow-up care to GP, and the key enablers of successful SCP implementation.

The following outlines the inclusion criteria for Groups 2-6:
- a nurse coordinator within the gynaecology, haematology, late effects or urology service and have been involved with the implementation and delivery of SCPs
- a nurse coordinator representing remaining clinical services who had not been involved in the delivery of SCPs
- a chair of a clinical service
- a head of an allied health department
- a GP of a consenting patient who had received a copy of an SCP
- aged over 18 years
- able to complete study requirements in English.

Recruitment
Patient group
Randomly selected patients who had received a SCP were sent a letter of introduction. Seven days later, the study coordinator telephoned the patients, introduced the study, invited participation and asked for permission to mail out a one-page patient information letter and consent form (PICF) (Appendix 2) and the questionnaire (Appendix 3). Patients were asked to return the signed consent form and the questionnaire in the reply-paid envelope.
Australian Cancer Survivorship Centre, A Richard Pratt Legacy
The study coordinator called eligible patients up to three times (if there was no reply) to invite participation. The study coordinator also called patients up to three times if they agreed to receive the PICF and questionnaire but did not return it. The study coordinator also re-sent the PICF and questionnaire if the participant had lost or misplaced it.

**Healthcare professionals**

The study coordinator emailed eligible nurse coordinators (those engaged in SCP implementation) from gynaecology, haematology, late effects and urology services to inform them of the study. It was made clear that participation was voluntary and that consent was implied on return of the completed questionnaire. They could complete the questionnaire (Appendix 4) in a hard copy if they wished not to be identified.

The study coordinator telephoned eligible GPs, introduced the study, invited participation and asked for permission to complete a 10-minute questionnaire via telephone. If that time was not convenient, the study coordinator asked the GP to nominate another time or asked if it was more convenient to fax or post the questionnaire.

The manager of the ACSC or study coordinator arranged semi-structured, face-to-face interviews with:

- chairs of clinical services
- non-engaged nurse coordinators
- heads of each allied health department.

It was anticipated that each interview would last 20–30 minutes and include questions about (1) awareness of the SCP, (2) views regarding the SCP, (3) views regarding feasibility of implementation, and (4) views regarding survivorship care (Appendix 5). This semi-structured interview was minuted or recorded, as a quality control measure to ensure that a thematic analysis could occur.

**Data collected**

**Patients**

Baseline registration and demographic data were collected from the electronic patient records (known as Verdi) as follows:

- age (date of birth)
- type of cancer
- date of diagnosis
- date of delivery of SCP.

Patients completed the questionnaire (Appendix 3) and returned it in a reply-paid envelope to the study coordinator. Patients were also given the opportunity to complete the questionnaire electronically.

**Nurse coordinators**

Nurse coordinators from the gynaecology, haematology, late effects or urology services completed the electronic questionnaire (Appendix 4) and emailed it to the study coordinator.

Nurse coordinators not engaged in SCP implementation were interviewed by the study coordinator addressing key survivorship themes, including commitment to survivorship care, SCP and available resources.

**GPs**

Eligible GPs were contacted by study coordinator and completed the questionnaire (Appendix 6) via telephone or as a hard copy.
Chairs of clinical services and heads of allied health
Chairs of clinical services and allied health heads were interviewed by the Manager, ACSC or study coordinator addressing key survivorship themes including commitment to survivorship care, the SCP and available resources.

Data analysis
Notes from semi-structured interviews conducted with nurse coordinators who were currently not delivering a SCP, heads of allied health departments, and clinical service chairs were transcribed and the combined data was examined for themes and issues. As similar topics emerged, these were placed into categories. The data was re-examined for information and meaning relating to the identified themes. The name of each theme has been finalised, described and illustrated by quotes.

Ethics approval
The study was approved by the Human Research and Ethics Committee at Peter Mac.

Findings

Group 1: Patients
One hundred and eighteen patients were approached to participate. Seventy patients agreed to have the patient information consent forms mailed. Fifty consented and participated in the study, representing a 42% response rate. Of note: Not all patients completed all the questions in the questionnaire.

Twenty-one patients (42%) were from the late effects service, 20 (40%) from the urology service, seven (14%) from the gynaecology service and two (4%) from the haematology service. The median age was 45 years and the majority of patients were female (n=31, 62%).

The median time from completion of treatment to delivery of the SCP was 98 days with a range of 12 days to 58 years (Table 1).

<table>
<thead>
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<th>Patients</th>
<th>Gynaecology</th>
<th>Haematology</th>
<th>Late effects</th>
<th>Urology</th>
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<tr>
<td>Median time from treatment completion to SCP delivery (and range)</td>
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<td>238 days (92–383)</td>
<td>18 years (5–58)</td>
<td>12 days (9–15)</td>
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</tr>
</tbody>
</table>

Over three-quarters of patients (n=35, 78%) found their SCP to be very useful or somewhat useful; over half (n=29, 64%) felt the SCP was delivered at the right time; and over half (n=23, 51%) reported that, compared to other written types of information, the SCP was very important in helping them to understand their cancer experience (Table 2).
Over three-quarters of the patients had read their SCP and nearly all found the SCP easy to understand (n=39, 80%).

Over three-quarters of patients (n=35, 78%) found the SCP to be the right length, nearly all (n=37, 82%) felt that the SCP addressed the right topics and two thirds (n=29, 65%) reported that the SCP was the right title for the document.

More than half of the patients (n=28, 60%) had not discussed their SCP with their GP; however, just over half (n=26, 55%) reported that the SCP would help them discuss the cancer experience with their GP.

Nearly all (n=36, 78%) felt the SCP provided them with a clear and helpful summary of future appointments and over half (n=23, 52%) stated that the SCP helped them adjust to life after cancer.

The majority of patients (n=32, 68%) felt that the SCP identified their cancer treatment team and the relevant contact details, nearly all (n=36, 80%) found the side effects of treatment and symptoms to watch for useful and nearly all (n=38, 84.4%) found the importance of resuming or initiating healthy lifestyle behaviours following cancer treatment helpful.

Patients were asked whether, since receiving the information about healthy lifestyle behaviours following cancer treatment, they were already or were planning to undertake any healthy lifestyle changes (Figure 2).
Patients were asked who they had shared the information with. More than half (n=26, 59%) had shared it with their family, 15 (34%) with their GP, four (9%) with their medical specialist, three (6%) with friends, two (5%) with their workplace/employer and two (5%) with a nurse.

**Group 2: Nurse Coordinators engaged in SCP implementation**

Eight nurse coordinators engaged in SCP implementation engaged nurse coordinators were invited to complete the survey. Seven completed the survey. They included two representing the haematology service, two representing the gynaecology service, two representing the late effects service and one representing the urology service. One nurse coordinator declined. This represented an 88% response rate.

SCP were delivered to patients who had undergone a stem cell transplant or allograft bone marrow transplant (haematology service), had had robotic prostatectomy for localised prostate cancer (urology service), were five years post-curative treatment (late effects service), or had been treated for gynaecological cancer not including ovarian cancer (gynaecology service).

All of the Nurse Coordinators who completed the survey reported the SCP to be a very useful or somewhat useful tool for their clinical practice and all found it easy to understand (n=7, 100%). Nearly all reported that in their opinion, the SCP addressed issues that were important for cancer survivors.

The majority thought that the title was the right name for the document with two (ID code 2 and 3) suggesting ‘after treatment plan’ as an alternative name. All (n=7, 100%) sent the SCP to the GP and nearly all (n=6, 85.7%) felt that doing so improved their communications with the GP. All (n=7, 100%) reported sending additional information to support the SCP: this included a covering letter, most recent medical and nursing notes, GP follow-up guidelines (from late effects clinic) and pathology report.

Almost half (n=3, 42.9%) felt the SCP document was too long and reported taking 60–90 minutes to complete the SCP. Two (29%) reported taking 30–60 minutes, one (14%) under 30 minutes and one (14%) taking 120 minutes to enter the information. All (n=7, 100%) entered the information into the SCP themselves. One (14%) suggested a review of the document to determine the suitability of its structure.
The delivery of the SCP took place in the clinic environments at different times following treatment completion and nearly all (n=5, 71%) felt this timing was appropriate. Only one nurse led clinic was used for delivery of the SCP with the remaining services delivering the SCP to the patient following their medical consultation. All (n=7, 100%) discussed the content of the SCP with the patient; more than half (n=4, 57%) reported the length of this consultation to be 30–60 minutes.

Nurse coordinators from two services (Late Effects and the Gynaecology) reported using a formal assessment tool to assess supportive care needs of the patient after treatment completion and prior to developing and discussing the SCP with the patient.

Nearly all of the engaged nurse coordinators (n=6, 86%) agreed development and delivery of the SCP required medical and/or allied health care contribution. Suggestions for facilitation of this included involvement and education of team and incorporation of the development of the plan into the multidisciplinary team meeting.

Nearly all of the engaged nurse coordinators (n=6, 86%) reported time as a significant challenge in implementing SCP in their clinical service.

**Group 3: General practitioners**

Forty-seven GPs were contacted to participate in the study. Eighteen GPs consented, representing a 38% response rate. Fifteen GPs completed the survey over the telephone and three elected to complete the survey as a hard copy. No GP completed all items in the questionnaire and therefore the number of responses varies per item.

The majority of GPs (n=13, 72%) reported that they had received a copy of the SCP and most (12, 75%) had the opportunity to read it.

Only three (21%) had discussed the SCP with their patient. A larger percentage of patients (32%) stated that they had discussed the SCP with their GP.

Most GPs (n=10, 71%) felt that the SCP would improve communications with the patient regarding their cancer experience and over half (n=9, 64%) felt that the SCP would improve communications with the cancer treatment providers.

Only two GPs (15%) had created a chronic disease management care plan for the patient since completion of treatment. One (8%) reported they would create one in the near future. One (8%) did not see the need as did not consider the patient to be chronically ill.

Three-quarters of GPs (n=12) reported that they would like to continue to receive SCP for their patients after cancer treatment.

Nearly half of GPs (n=6, 43%) experienced challenges when providing follow-up care for patients after their cancer treatment mostly associated with limited exposure to this type of care.

Nine (64%) reported that ‘Survivorship Care Plan’ was the right title for the document.

Almost half (48%) expressed interest in attending a 1-2 day placement programme in an oncology setting to update them regarding follow-up care of patients who have finished cancer treatment.

Figure 3 summarises results showing GPs’ satisfaction with the SCP.
Nine GPs (70%) found the SCP to be very or somewhat useful; the majority (n=11, 85%) found the SCP easy to understand and addressed the right topics; less than half (n=6, 46%) found the SCP too long; and nearly all (n=12, 92%) found the SCP to be useful when discussing follow-up with the patient (Table 4).

Over half of the GPs (n=7, 54%) reported that the SCP helped them to understand the patient’s cancer diagnosis. Nine (69%) reported that it helped them understand the cancer treating team and 10 (77%) reported it helped them understand the need for ongoing screening; understand the tests required and the frequency. Nine (69%) reported that the SCP helped them to understand the need for follow-up to assess for late and/or chronic problems resulting from cancer treatment.

The majority of GPs (n=9, 69%) responded that the SCP informed them of the importance of resuming or initiating age-appropriate health maintenance practices following cancer treatment. For 10 GPs (77%), the SCP helped...
them understand their role in facilitating survivorship care and shared care with the oncology provider. Over half (n=8, 57%) felt that the SCP informed them of the resources available to cancer survivors/families (Figure 5).

Figure 5: The SCP helped the GP to understand ... n=13(%)

<table>
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<th>Moderately agree</th>
<th>Neither</th>
<th>Moderately disagree</th>
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<td>3;(23)</td>
<td>3;(23)</td>
<td>3;(23)</td>
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<tr>
<td>The team who treated your patient for cancer</td>
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<td>5;(38.4)</td>
<td>1;(7.6)</td>
<td>3;(23)</td>
<td>0</td>
</tr>
<tr>
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<td>4(30.7)</td>
<td>6; (46.1)</td>
<td>2;(15.3)</td>
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<td>0</td>
</tr>
<tr>
<td>The need for follow-up to assess for late and/or chronic problems resulting from cancer treatment</td>
<td>5;(38.4)</td>
<td>4;(30.7)</td>
<td>2;(15.3)</td>
<td>1;(7.6)</td>
<td>0</td>
</tr>
<tr>
<td>Which follow-up test(s) will be needed</td>
<td>4;(30.7)</td>
<td>6;(46.1)</td>
<td>2;(15.3)</td>
<td>0</td>
<td>0</td>
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<tr>
<td>How often follow-up tests should be performed</td>
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<td>5;(38.4)</td>
<td>2;(15.3)</td>
<td>0</td>
<td>0</td>
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<tr>
<td>The importance of resuming or initiating age-appropriate health maintenance practices following cancer treatment</td>
<td>5;(38.4)</td>
<td>4;(30.7)</td>
<td>1;(7.6)</td>
<td>2;(15.3)</td>
<td>0</td>
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<tr>
<td>Your (the GP) role in facilitating survivorship care</td>
<td>3;(23)</td>
<td>7;(53.8)</td>
<td>2;(15.3)</td>
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<td>0</td>
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<tr>
<td>How you (the GP) and oncology providers will share the responsibility of survivorship care</td>
<td>3;(23)</td>
<td>7;(53.8)</td>
<td>1;(7.6)</td>
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<tr>
<td>The resources available to cancer survivors/families</td>
<td>4;(30.7)</td>
<td>4;(30.7)</td>
<td>1;(7.6)</td>
<td>3;(23)</td>
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</tbody>
</table>

Mode of delivery
About one-third of GPs (n=5, 36%) asked to receive the SCP as a hard copy via mail or fax; the remainder preferred to receive it electronically.

Groups 4,5,6: Other hospital-based staff
A total of 19 other hospital based staff consented to participate in the study: nurse coordinators not currently delivering SCPs (‘non-engaged nurse coordinators’) (NCN, n=8), heads of allied health departments (AH, n=4) and chairs of clinical services (CS, n=7). Each completed a face-to-face semi-structured interview inviting discussion around factors affecting SCP implementation. The interviews were transcribed and the resulting data combined and examined for themes and issues. As similar topics emerged these were placed into categories. The data was re-examined for information and meaning relating to the identified themes. The name of each theme has been finalised, described and illustrated by quotes.
Support for SCPs
Just over two thirds (n=13, 68%) of the participants reported considering the SCP to be a useful document and important in the delivery of patient-centred care; and a transitional communication tool between health services and community based primary carers. However, they also expressed challenges which influenced their ability to embrace SCPs entirely.

Barriers and enablers to SCP implementation

Awareness
Although nearly all (n=17, 89%) reported awareness of the Peter Mac’s SCP, CS and AH participants (n=5, 26%) reported limited direct communication about the project. They also reported lack of knowledge regarding specifics of the development and implementation processes of for SCPs in tumour streams delivering them. There was limited knowledge regarding who was responsible for the SCP, or the content of ones that were developed and currently in use.

For example:
   “Aware that they [SCPs] exist but not had a lot to do with them.” (AH3)

Collaboration and engagement with hospital based staff
Participants from all three groups interviewed expressed lack of engagement with the project team. All nursing staff (n=8, 100%) had attended updates concerning the project although none had contributed to the current project. All allied health (n=4, 100%) reported lack of consultation or collaboration despite supporting services that were delivering SCPs.

For example:
   “No never been consulted. Suspect that this would be true for much of allied health”(AH1)
   “...there’s been no formal communication”(CS4)
   “....limited engagement regarding the project” (CS6)

Other hospital-based staff reported engagement enhanced by participating in the service delivering SCPs.

For example:
   “Late effects have been leading the work (around SCP)” (CS5)

Engaging with GPs
Despite the health care professionals acknowledging the value of the GP role in supporting patient transition to community based care there was limited demonstrated support or transference of care. Barriers identified included: GP level of knowledge and varying levels of expertise in cancer care (n=13, 68%); reluctance of health care professionals to share-care with community based services as they viewed some cancer groups and complex cancer patients not suitable for GP follow-up (n=3,42%).

For example:
   “Not all GPs are able to provide appropriate post treatment care, they need training” (CS1)
   “We are bad at involving, they see so few (lung) cancer patients, don’t have expertise in follow-up care”(NCN6)
   “Our patients are complex and later stage, question usefulness of share care arrangement...”(CS6)
Participants also identified lack of communication between the hospital and the GP about the primary carer’s role and responsibility in post treatment care and follow-up for patients.

For example:

“Not enough information. They don’t feel empowered to make decisions about patient care. They have a fear that they may make the wrong decision or miss something.” (NCN8)

Other factors identified as contributing to lack of GP engagement and reducing the capacity for share-care or ongoing GP follow-up to be effective were: the changing nature of GP practices; limited available appointments with the GP; limited ability for patients to secure appointments in a timely manner and increasingly people not having a regular GP. Half (n=9, 50%) acknowledged that GPs’ high workload and them being time poor has implications for services and patients feeling comfortable and confident about the care being transferred to them. Three participants commented on the relationship of the patient with the GP prior to or leading to the cancer diagnosis impacting on GP engagement.

For example:

“Main barrier is that GPs are time poor.” (NCN2)

“Can’t assume that every patient has a good relationship with GP” (NCN5)

Leadership and commitment
Leadership and direction from senior levels was deemed critical for successful implementation of SCPs into the care pathway. Leadership direction and commitment to the survivorship care planning process, fosters relationships amongst staff in terms of engagement, collaboration, resource allocation and project sustainability (19,100%).

For example:

“It has to have organisational leadership; there’s been no executive director leadership…. services were not supported in the past to do this work.” (CS4)

Ownership and responsibility
Nurse coordinators were identified (n=15, 80%) as being best placed to deliver the SCP however it was noted that it should not be limited to nurse coordinators. The critical role that allied health play should not be overlooked. 85% of these participants recommended that a MDT be approached to inform the development and coordination of the SCP.

For example:

“All members of the MDT need to be involved in development” (AH4)

“Primary team including the MDT should be involved in developing it but then it needs to be passed on to one person to ensure that the elements of the SCP get delivered.” (NCN1)

“Nurse Coordinators need to take ownership of this process; trained and credentialed to complete this work.” (CS5)

Resources
The resource-intensive nature of development and implementation of SCPs was a frequently reported barrier to their successful implementation. Almost all (n=16, 85%) identified one or more critical components of an infrastructure required to develop and implement SCPs. Funding appropriate staffing time, information technology support, and the foundation of a dedicated clinic were considered crucial to sustainability. Nurse Coordinators were identified as well placed to deliver SCPs, however sustainability of this was questioned due to their current workload and competing demands.

Australian Cancer Survivorship Centre, A Richard Pratt Legacy

Evaluation of the implementation of survivorship care plans at Peter MacCallum Cancer Centre
For example:

“Resources, resources, resources required; extra work needs funding.” (CS4)

“Needs to be formalised..... Make appointment for the delivery of the SCP by the nurse coordinators.” (NCN2)

“Difficult to do it. I see up to 60–70 patients at a clinic at a time.” (NCN4)

Risk stratification and Assessment tools

Participants were asked to comment on guidance and risk stratification in the context of survivorship. Less than half (8, 42%) specifically indicated that guidelines were important and required, and more (9, 47%) referred to using screening tools to identifying patients to receive a care plan to better target limited resources.

For example:

Needs assessments and risk screening are necessary”(CS1)

“Not all patients need SCP. Need to do more work around it – patients have different levels of need.” (NCN2)

“Essential component – if we get this right then it guides us more accurately to those patients with the greatest need.” (AH4)

Timing of delivery of the SCP

Almost half of the participants (8, 42%) identified concerns implementing the SCP across the patient illness trajectory. Of particular concern was the lack of clarity surrounding the definition of survivorship, stages of survivorship and when would be the most appropriate time to present a SCP to patients.

For example:

“(Need to) define where it fits in the pathway; pathway focus.” (CS7)

“Timing is important – some things are not an issue until later down the track, such as returning to driving.” (AH4)

“Issues may not appear until later, so what do we do? How do we meet patient needs consistently?” (AH4)

Discussion

Reactions of survivors to the SCP have been positive and demonstrate that they want information about ongoing prevention of recurrences, second cancers and other cancer-related health problems, a finding consistent with current literature[12-16]. In this report nearly all of the patients reported having read their SCP and finding information about side effects of treatment, what to expect, and the symptoms to watch out for useful. Just over half of the patients reported that, compared to other written types of information, the SCP was very important in helping them to understand their cancer experience. Most patients reported as helpful the emphasis on resuming or initiating healthy lifestyle which was developed in this version of the SCP. Similar results were documented in a 2013 study, in which over half of patients who had received an SCP reported that they had made or planned to make a lifestyle change in response to information they obtained from the care plan, most commonly dietary modification and increased exercise[11].

Of value to survivors is that the SCP can be instrumental in improving communication with the GP[13, 14, 17, 18]. GPs generally favour receiving a treatment summary,[18-21] and the use of SCPs[18, 20, 22, 23]. The GP is regarded as pivotal in the treatment of patients with cancer, yet they often lack the necessary information to do so[24, 25]. Studies have identified inadequate skills or training[22]; lack of established survivor care guidelines; no involvement with original cancer care; lack of care continuity; and lack of time and poor
reimbursement for services[3, 26]. The GP, as well as hospital based staff in our study, identified similar challenges. The GP expressed interest in attending a 1-2 day placement programme in an oncology setting to update them regarding follow-up care of cancer patients and hospital based cancer providers acknowledged they have a responsibility to provided GP education. Active engagement with the GP, providing education, encouraging patients to make an appointment with their GP at completion to cancer treatment to share the SCP, and providing the GP with clear guidelines regarding their role in after cancer treatment care can all contribute to increased confidence in providing survivorship care.

The valuable role SCPs play in helping people understand their cancer experience and assist them to undertake self-management is questionable outside of structured pathways and established models of care[27, 28]. This report has highlighted lack of infrastructure, staff engagement and commitment and how this impacts negatively on implementation of SCP in practice. The SCP exists in processes of care and models of care that can both aid and impede care coordination and communication and we cannot expect the document to do the work of a process or to fix a flawed process[29]. Survivorship care requires guidelines, a comprehensive multi-disciplinary care infrastructure or model of care[30]. Organisational leadership, commitment, and financial resources are an essential component to this process[27].

It is imperative that care is based on identified needs to ensure that people receive the support they require in the setting that they require[28]. In this evaluation, nurse coordinators were identified as best placed to deliver the SCP and the critical role allied health play should not be overlooked[28]. Nearly all nurse coordinators who provided SCPs felt that medical and/or allied health care professionals should contribute to the development and delivery of the SCP. Most made reference to the inclusion of medical colleagues, as supported by Hewitt et al.2007, who highlighted the importance of gaining the support of attending physicians. Models of care that support patients following completion of cancer treatment need to be explored and are not limited to nurse led clinics, suggest exploring different models of care and utilisation of different health care providers to facilitate SCP delivery across diverse clinical settings[31]. For some patients, GPs and practice nurses are well placed and highly experienced in providing management and coaching in healthy lifestyle behaviour. Jefford et al (2012) in a review of implementing post-treatment care for cancer survivors in England, with reflections from Australia, Canada and the USA suggests that specialists are not aware of alternative methods of post treatment care and support nurse-led care as a suitable alternative. Other studies also support the role of nurses in delivering self-management interventions in the post cancer treatment phase and promote a model of cancer care that involves providers forming partnerships with patients and families which enable and empower patients and their families to achieve their own goals of care at all phases of the cancer care trajectory[32]. Whilst further reports suggest a sustainable model of care involving face-to-face motivational interviewing techniques and stress reduction strategies to encourage adoption of healthy lifestyle behaviours with a further two nurse-led telephone consultations to reinforce the intervention and to identify and respond to any new concerns[33].

The delivery of the SCP in this study took place in the clinic environment at different times after treatment completion and nearly all nurse coordinators felt that between three to four months following treatment was appropriate. Dulko 2013 recommended that the optimal time to complete the care plan visit is three to six months after treatment. Survivors’ opinions about the timing of SCP delivery vary, with some preferring to receive the SCP at the last visit and others well afterwards[26, 34]. Of note, is that almost one-quarter of patients in our study reported being unsure of the usefulness of the SCP or dismissed the notion that it was of use to them, and nearly one-third felt that the SCP was delivered too late[35]. The majority of these patients received their SCP via the late effects clinic and were all at least 5 years post-completion of treatment. This highlights the changing needs of cancer survivors in their post treatment time and raises issues about the type of patient or disease state that would benefit most from SCP and interventions[36]. Distress screening at treatment completion and risk stratification are methods to identify patients with unmet needs / risks at completion of treatment; this enables Australian Cancer Survivorship Centre, A Richard Pratt Legacy
supports to be put in place and allows resources to be directed where they are needed. However, Watson et al, 2010 caution that risk stratification should only be undertaken for outcomes where there are effective interventions[37].

Although oncology providers report that providing SCPs can be useful, time constraints are identified as a barrier to implementation[18, 38, 39]. Without dedicated time for preparation and delivery, SCP implementation is compromised as SCP take more time than nurse coordinators have available to them. It has been suggested that automating completion of SCP by abstracting relevant information from electronic medical records may ease the time burden on oncology providers and aid implementation and assist with electronic delivery of the SCP to GP’s[3, 40]. Work to create an electronic template to self-populate patient data is currently underway at Peter Mac and will be piloted in the gynaecology service in the near future.

**Limitations**

Our survey population was small and was limited to patients who were at end of curative treatment and the care plan was delivered once. Our findings may not be transferrable to patients outside of this setting. We did not engage with carers in this review so are unable to determine the impact a SCP has on them. Our survey was limited to one cancer centre and not all head of clinical services were engaged. Using different methods to survey groups may also have impacted on the data collected. Salz et al 2012 in a review of SCPs in research and practice comment on the need to determine resource requirements for creating and implementing SCPs and consideration of whether costs outweigh benefits – we did not determine this in the capacity of this report.

**Conclusion**

In summary, this evaluation study of the SCP Project set out to describe the impact of and enablers of and barriers to implementing SCPs for patients, nurse coordinators, GPs and other hospital-based staff in a comprehensive cancer centre.

Our findings highlight patient and health care professional support for the SCP and the challenges faced by cancer services in the delivery of high-quality care and informational support in meeting the survivorship needs of patients and families within current ambulatory care models in an Australian setting.

All participants considered the SCP to be useful. Over three-quarters of patients had read their SCP; however, 60% had not discussed it with their GP. The GP had limited time to consult the SCP and few used the care plan to create a chronic disease management plan.

The SCP was described as resource intensive for hospital-based staff, which also identified a lack of awareness and engagement in the SCP Project. The need for resources, time and more efficient IT solutions were identified by the multidisciplinary team members. Organisational commitment and executive and clinical leadership are required for ongoing SCP implementation and prior to extension into other clinical services.
Recommendations and future actions

The following recommendations are made to help drive improvements in the development and delivery of SCPs to patients across all tumour streams at Peter Mac. These recommendations are considered essential elements for any organisation implementing a sustainable model of survivorship care into standard post treatment practice.

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 for, and extend and embed survivorship care plans into standard post-treatment care.
   
   c. Define and agree an organisational and/or clinical service survivorship model of care, considering process of care.
   
   d. Strengthen project management, governance, stakeholder engagement, communication strategy, risk management, and reporting.

2. Cancer survivorship education across all sectors is required to improve understanding, awareness and provide tools for practice.
   
   e. Provide skills-based education and training to multidisciplinary clinical staff including nurse coordinators and allied health professionals.
   
   f. Provide access to survivorship guidelines (literature review), resources and tools to support the implementation of SCPs.
   
   g. Engage with GP regarding cancer survivorship education and clinical placement.
   
   h. Define the appropriate time to deliver the SCP for each clinical service.

3. Efficient IT systems are required to support the implementation of SCPs.
   
   c. Engage health information services to produce electronic, auto-populated templates that can be accessed by the multidisciplinary team.
   
   d. Build in mechanisms for the collection of key data items to monitor the implementation of SCPs and performance.

4. Project resources and support are required to ensure the SCP is an effective communication tool and to enable the implementation of SCP across clinical services.
   
   f. Work with clinical services to review and redevelop the SCP template to ensure it meets the needs of the patient, GP and multidisciplinary team.
   
   g. Include needs assessment and risk stratification to prioritise patients most in need of a SCP.
   
   h. Strengthen patient education and self-management principles to optimise the benefit and utilisation of the SCP.
   
   i. Redevelop the SCP template to optimise and support GP communication, utilisation and transition to a chronic disease management plan.
   
   j. Allocate project resources and support to ensure the SCP is an effective communication tool and to enable the implementation of SCP across clinical services.

5. The SCP Project should be evaluated in relation to cost–benefit analysis, impact on patient lifestyle and health behaviours, and the quality of communication and transition of care.
References


11. Hill-Kayer, C., Penn Medicine Study Shows Survivorship Care Plans Empower Cancer Patients 2013, Cancer in the News. For the members of ASCO.


34. Marbach, T.J. and J. Griffie. Patient preferences concerning treatment plans, survivorship care plans, education, and support services. in Oncology nursing forum. 2011: Onc Nurs Society.
Appendices

A1 Survivorship Care Plan – Generic Example

This Survivorship Care Plan summarises information about your diagnosis, treatment, follow-up care, symptoms to watch for, and steps you can take to stay healthy.

Keep this care plan: if you see other doctors and other health care providers in the future, it will tell them about your cancer, its treatment, and how best to monitor your health.

We consider adherence to these recommendations to be voluntary, with the ultimate determination regarding their application to be made by the doctor or nurse coordinator in light of each patient’s individual circumstances.

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TREATMENT SUMMARY

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Radiation Therapy

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Radiation Oncologist: ______________________

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Complications / Toxicities of Treatment

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<td></td>
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<tr>
<td>Dental</td>
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<tr>
<td>Other</td>
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<td></td>
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</tr>
</tbody>
</table>
FOLLOW-UP PLAN

Visit Schedule
Please refer to attached template.

Report these signs and symptoms if persistent
Some symptoms you experience may be normal. However, if you have any symptoms that are concerning you (new, persistent, or unexplained), please speak with your health professional. It may not be related to your previous cancer, but it is important to have it checked out.

Health Behavior Recommendations
Healthy Diet
A healthy diet is recommended to reduce the risk of certain cancers, include plenty of vegetables and fruits; a high fibre and low fat and salt diet. The following link provides information about the types of food that we should include or limit in our diets to help reduce the risk of cancer.

Maintaining a Healthy Weight
Research shows that a waistline over 100cm for men and 85cm for women significantly increases the risk of some cancers. The following link provides recommendations to maintain or develop a healthy weight.
www.cancervic.org.au/preventing-cancer/weight

Limit Alcohol
Drinking alcohol increases the risk of certain cancers. It is recommended people limit or avoid drinking alcohol. For people who do drink alcohol, no more than two standard drinks a day, avoid binge drinking and have at least 1 or 2 alcohol-free days each week. The following link provides information regarding alcohol intake.

Be Physically Active

Exercise is important to reduce the risk of many cancers. Up to 1 hour of moderate activity daily or 30 minutes of vigorous activity is recommended. The following link provides information about the recommended daily activity to cut your cancer risk.
www.cancervic.org.au/preventing-cancer/be-physically-active

Be Sun Smart
The sun’s ultraviolet (UV) radiation is a major cause of skin cancer. In Victoria UV levels generally reach 3 and above from September to April. At UV levels of 3 and above the UV can cause damage and increase your risk of skin cancer so a combination sun protection steps are needed. The following link provides information on taking a balanced approach to UV exposure to help with vitamin D levels while minimizing the risk of skin cancer with appropriate sun protection measures.
www.cancervic.org.au/preventing-cancer/be-sunsmart

Quit and Avoid Smoke
Smoking causes cancer. Smoke contains over 60 chemicals known to cause cancer. The following link provides information on Quitting and avoiding second hand smoke.
www.cancervic.org.au/preventing-cancer/quit-smoking
Find Cancer Early
Finding cancer early offers one of the best chances to cure the disease. The following link provides information on what to look for, what action to take and screening tests available to monitor for some cancers. www.cancervic.org.au/preventing-cancer/attend-screening

Health maintenance
Most healthy adults recover from influenza within a few days but some people, especially people living with chronic illnesses such as heart disease or cancer, can develop complications. It is therefore recommended that you receive an annual influenza vaccination. www.healthinsite.gov.au/topics/Influenza_Vaccine

Learning to Relax
The following link provides information on ways to relax. www.cancervic.org.au/about-cancer/types-treatments-trials/learning_to_relax

Information regarding your specific recommended health behaviors will be given by your doctor or nurse coordinator during your consultation.

Cancer-related resources

The Australian Cancer Survivorship Centre aims to improve health outcomes for cancer survivors, and provides timely and relevant information on important issues related to cancer survivorship. www.petermac.org/cancersurvivorship/Home

The Cancer Council in your state provides information and support for cancer survivors. The helpline runs a free telephone based support service called Cancer Connect, where you can speak with another cancer survivor: Telephone 13 11 20 for details. www.cancer.org.au

Obtain a free copy of the DVD ‘Just take it day to day, a guide to surviving life after cancer’ and the free booklet ‘Life after cancer, a guide for cancer survivors’ from the Cancer Council Helpline on 13 11 20 or the Australian Cancer Survivorship and Information Centre at Peter Mac: Telephone 9656 3547 or email pisc@petermac.org

<table>
<thead>
<tr>
<th>No.</th>
<th>Date</th>
<th>Investigations</th>
<th>Discipline</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td>Assessment</td>
<td>Specialist</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Discuss end of treatment plan</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>Assessment</td>
<td>Specialist</td>
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<td></td>
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<td>investigations</td>
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<tr>
<td>3</td>
<td></td>
<td>Assessment</td>
<td>Specialist</td>
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<td></td>
<td></td>
<td>Investigations</td>
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<tr>
<td>4</td>
<td></td>
<td>Assessment</td>
<td>Specialist</td>
</tr>
</tbody>
</table>

Surname
Given Names
Unit Number
Date of Birth
<table>
<thead>
<tr>
<th>Investigations</th>
<th>Specialist</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 Assessment</td>
<td>Specialist</td>
</tr>
<tr>
<td>6 Assessment</td>
<td>Specialist</td>
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<td>7 Assessment</td>
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<td>8 Assessment</td>
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<td>9 Assessment</td>
<td>Specialist</td>
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<td>10 Assessment</td>
<td>Specialist</td>
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<td>11 Assessment</td>
<td>Specialist</td>
</tr>
<tr>
<td>12 Assessment</td>
<td>Specialist</td>
</tr>
</tbody>
</table>

*Please note: This is a guide only and may change according to each patient's individual circumstances*
A2 Consent form

Consent form for the evaluation of the barriers and facilitators to implementing Survivorship Care Plans at the Peter MacCallum Cancer Centre

A study conducted by the Australian Cancer Survivorship Centre (ACSC) – a Richard Pratt Legacy at the Peter MacCallum Cancer Centre.

Investigators: Ms Priscilla Gates, A/Prof Michael Jefford and Ms Linda Nolte.

The Australian Cancer Survivorship Centre (ACSC) aims to improve outcomes for people affected by cancer. A Survivorship Care Plan (SCP) is a follow up plan that aims to raise awareness of the importance of surveillance, healthy living and a coordinated plan of follow-up care.

- This study looks at your views about receiving an SCP when your treatment for cancer finished. This study is also evaluating your GP and the hospital staff that are involved in your ongoing care.
- We will ask you to fill in a survey about yourself and your views about receiving the SCP. If you would like to fill out the same questionnaire electronically please access this link ..............
- By signing this form you agree to us collecting data about you including your date of birth, date of cancer diagnosis, type of cancer and date you received your SCP. We will also contact your GP, who also received your SCP, to find their views regarding the SCP document.
- Information collected from you will be kept and used only for this study.
- Your name will be kept separate from your survey answers.
- Feel free to discuss with a relative/friend/local health worker before deciding to take part in this study.
- You are free to join this study or not and your decision will not affect your care here at Peter MacCallum Cancer Centre in any way.
- You may choose to drop out of this study at any stage.
- This project has been approved by the Ethics Committee of Peter MacCallum Cancer Centre.
- Should you have any questions, feel free to speak to any member of the research team, Priscilla Gates 9656 5243 or Linda Nolte 9656 5247. Or if you have complaints about any aspect of this research, please contact the Ethics Committee secretary at 9656 1699.

By signing this form, I agree to take part in the ‘evaluation of the barriers and facilitators to implementing Survivorship Care Plans at the Peter MacCallum Cancer Centre’ study and consent to the details of this study as outlined above.

Full Name: __________________

Signature: __________________

Date: ____________________
A3 Patient Evaluation – Survivorship Care Plans

The Australian Cancer Survivorship Centre (ACSC) aims to improve outcomes for people affected by cancer. A Survivorship Care Plan (SCP) is your follow up plan that aims to raise your awareness of the importance of surveillance, healthy living and a coordinated plan of follow-up care.

If you would like to complete this questionnaire electronically please access this link ..........

1. Have you had the opportunity to read your Survivorship Care Plan? □Yes, □No, □Not sure.
   If no, or not sure, why? ____________________________________________
   ____________________________________________
   ____________________________________________

2. Have you found your Survivorship Care Plan to be useful?
   (please circle the answer that best suits how you feel)

   Please tell us why? ____________________________________________
   ____________________________________________
   ____________________________________________

3. Do you think you have received your SCP and the information it contains at a time that you needed this most?
   Was it given to you □Too early, □Too late, □Just right.

   If not the right time, when do you think you would benefit most from the SCP? ______________________________
   ____________________________________________
   ____________________________________________
   ____________________________________________

4. Your Survivorship Care Plan is easy to understand? □Yes, □No, □Not sure.
   If no, or not sure why? ____________________________________________

5. Your Survivorship Care Plan is too long? □Yes, □No, □Not sure.
   If yes, why? ____________________________________________

6. Your Survivorship Care Plan is too short? □Yes, □No, □Not sure.
   If yes, why? ____________________________________________

7. Your Survivorship Care Plan addresses the right topics? □Yes, □No, □Not sure
8. Do you think the Survivorship Care Plan is the right title for the document? □Yes, □No, □Not sure. If no, what is a better title for you? ____________________________________________
   ____________________________________________
   ____________________________________________
   ____________________________________________

9. Compared to other written types of information, how important was your Survivorship Care Plan in helping you to understand your cancer experience? □Very important, □Not important, □Not sure. If not important, what may have helped? ____________________________________________
   ____________________________________________
   ____________________________________________
   ____________________________________________

10. Have you discussed the Survivorship Care Plan with your General Practitioner (GP)? □Yes, □No, □Not sure. If no or not sure, why? ____________________________________________
    ____________________________________________
    ____________________________________________
    ____________________________________________

11. Do you think that your Survivorship Care Plan will help you to discuss your cancer experience with your GP? □Yes, □No, □Not sure. In no, what may have helped? ____________________________________________
     ____________________________________________
     ____________________________________________
     ____________________________________________

12. Did your Survivorship Care Plan clearly identify your cancer treatment team and the relevant contact details? □Yes, □No, □Not sure. If no, what may have helped? ____________________________________________
     ____________________________________________
     ____________________________________________
13. If you were referred to an allied health or supportive care service is the summary useful?
   □ Yes, □ No, □ Not sure.
   If no, what may have helped? ________________________________________________________
   ________________________________________________________

14. Did you find the side effects of treatment and symptoms to watch for useful?
   □ Yes, □ No, □ Not sure.
   If no, what may have helped? ________________________________________________________
   ________________________________________________________

15. Did you find the importance of resuming or initiating healthy lifestyle behaviours following cancer treatment helpful? □ Yes, □ No, □ Not sure.
   If no, what may have helped? ________________________________________________________
   ________________________________________________________
16. Since receiving this information about healthy lifestyle behaviours following cancer treatment have you already or are you planning to undertake any healthy lifestyle changes?

*To answer the following questions please circle the response that best describes you.*

<table>
<thead>
<tr>
<th>Health Lifestyle Behaviour</th>
<th>I already have</th>
<th>I am planning to</th>
<th>I am <strong>not</strong> planning to</th>
<th>Not applicable to my situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To have a healthy diet</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. To limit alcohol</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>3. To be physically active</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>4. To be sun smart</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<td>5. To quit and avoid smoking</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. To be aware of finding cancer early</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. To have overall health maintenance</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. To have good emotional health</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Anything else you would like to tell us? __________________________________________________________

17. Did you find the national and local cancer related resources for yourself and your carers relevant?

- Yes, ☐ No, ☐ Not sure.

If no, what may have helped? __________________________________________________________

18. Did your follow up plan provide you with a clear and helpful summary of your future appointments?

- Yes, ☐ No, ☐ Not sure.

If no, what may have helped? __________________________________________________________
19. Who have you shared the information on your SCP with?
   □ No one, □ Family, □ Carer, □ GP, □ Medical Specialist, □ Friends, □ Workplace/employer, □ Nurse, □ Other health care professional, □ Other,
   Did they find it helpful? If yes how?
   __________________________________________________________
   __________________________________________________________

20. Has your SCP helped you adjust to life after cancer? □ Yes, □ No, □ Not sure.
   If yes, how?
   __________________________________________________________
   __________________________________________________________

17. Is there anything else you would like to tell us?
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

Thank you for completing this survey. We appreciate you taking the time to share your experiences with us.

If you are posting your completed survey, please place it the addressed free post envelope supplied to you and place it in a post box.
A4 Nurse Coordinator Evaluation – Survivorship Care Plans

The Australian Cancer Survivorship Centre (ACSC) aims to improve outcomes for people affected by cancer. A Survivorship Care Plan (SCP) is a follow up plan that aims to raise the awareness of the importance of surveillance, healthy living and a coordinated plan of follow-up care.

1. Which clinical service do you represent?
   □ Urology, □ Gynaecology, □ Late Effects, □ Haematology

2. Which patient diagnostic group receives an SCP within your service?
   Please describe?

3. What treatment(s) have these patients received?
   □ Surgery, □ Chemotherapy, □ Radiotherapy, □ Transplantation, □ Other.
   Please describe?

4. Do you think overall the Survivorship Care Plan is a useful tool for your clinical practice?
   
   *(please circle the answer that best suits how you feel)*


   Please tell us why?

5. Do you think the Survivorship Care Plan overall is easy to understand? □ Yes, □ No, □ Not sure.
   If no, why?

6. Do you think the Survivorship Care Plan is too long? □ Yes, □ No, □ Not sure.
   If yes, why?

7. Do you think the Survivorship Care Plan is too short? □ Yes, □ No, □ Not sure.
   If yes, why?

8. Do you think the Survivorship Care Plan is the right title for the document?
   □ Yes, □ No, □ Not sure.
If no, what is a better title for you? ____________________________________________

________________________________________________________________________

9. Do you think the Survivorship Care Plan addresses issues that are important for cancer survivors?
   □ Yes, □ No, □ Not sure.
   If no, what may be helpful? _____________________________________________
   ______________________________________________________________________

10. How many SCPs have you delivered to patients in your service?
    Comments? _________________________________________________________

11. Who enters the information in the SCP?
    Please describe? _____________________________________________________

12. How long does it take you enter the information in the SCP on average?
    □ 0 – 30 minutes □ 30 – 60 minutes □ 60 – 90 minutes □ 90 – 120 minutes □ > 120 minutes.
    Comments? __________________________________________________________

13. Who discusses the SCP with the patient in your service?
    Please describe? _____________________________________________________

14. How long does it take you to discuss the SCP with the patient on average?
    □ 0 – 30 minutes, □ 30 – 60 minutes □ 60 – 90 minutes □ 90 – 120 minutes □ > 120 minutes.
    Comments? __________________________________________________________

15. Can you describe the environment and timing in which you discuss the SCP with the patient?
    ___________________________________________________________________

16. Do you think the timing for discussing the SCP with the patient is correct? □ Yes, □ No, □ Not sure.
    If no, when do you the patient would benefit most from an SCP? ________________
    ______________________________________________________________________
17. Do you have a dedicated end of treatment consultation to discuss the SCP with the patient? □Yes, □No, □ Not sure.
   If no, how may this help? ____________________________________________
   ____________________________________________

18. How long post treatment completion do you discuss the SCP with the patient?
   □ 0 -2 weeks, □ 2 – 4 weeks □ 4 weeks to 6 weeks, □ 6 weeks to 12 weeks,
   □ 3 months to 6 months, □ > 6 months
   Please describe? ____________________________________________
   ____________________________________________

19. Do you use a formal assessment tool to assess supportive care needs of the patient at treatment completion and prior to developing and discussing the SCP with the patient? □Yes, □No, □ Not sure.
   If no, are you assessing their needs in another way? ____________________________________________
   ____________________________________________

20. Do you think medical and/or allied health care professionals should contribute to the development and delivery of the SCP? □Yes, □No, □ Not sure.
    If yes, how may this be facilitated? ____________________________________________
    ____________________________________________

21. Do you send the SCP to the patient’s General Practitioner (GP)? □Yes, □No, □ Not sure.
    If no, why not? ____________________________________________
    ____________________________________________

22. When you send the SCP to the GP do you send any additional information? □Yes, □No, □ Not sure.
    If yes, what do you send?
    ____________________________________________

23. How many SCPs have you sent to GPs?
   Comments: ____________________________________________
   ____________________________________________

24. Do you think that the Survivorship Care Plan will improve your communications with the GP? □Yes, □No, □ Not sure.
    If yes, how?: ____________________________________________
    ____________________________________________

25. As a nurse coordinator what are your barriers to implementing SCPS in your clinical service?
26. As a nurse coordinator what would make it easier to implement SCPS in your clinical service?

Please describe: __________________________________________________________
__________________________________________________________

27. Is there anything else you would like to tell us?: __________________________________________________________

__________________________________________________________

Thank you for completing this survey. We appreciate you taking the time to share your experiences with us.
The Australian Cancer Survivorship Centre (ACSC) aims to improve outcomes for people affected by cancer. A Survivorship Care Plan (SCP) is a follow up plan that aims to raise awareness of the importance of surveillance, healthy living and a coordinated plan of follow-up care.

The Manager (ACSC) will arrange a semi-structured face to face interview with all heads of clinical services, non-engaged nurse coordinators and managers of allied health. It is anticipated that the interview will last 20-30 minutes. This semi-structured interview will be recorded as a quality control measure and to ensure that a thematic analysis can occur.

Questions

1. Are you aware of the development and implementation of SCP in some clinical streams at Peter Mac?
2. What should the SCP process look like at Peter Mac?
3. What are your views regarding SCP?
4. What are the essential components?
5. What are your views regarding the feasibility of implementation of SCP across clinical streams at Peter Mac?
6. What are your views regarding survivorship care as we progress towards VCCC?
7. Who should be involved in SCP development and delivery?
8. What are your views regarding the role and responsibilities of the GP in follow up care?
9. What do you think the barriers and facilitators are to GP follow up care?
10. What are your views regarding a survivorship symptom management clinics at Peter Mac?
11. What are your views on guidance/risk stratification?
12. How do you think ACSC can facilitate better survivorship care?
A6   GP Evaluation – Survivorship Care Plans

1. Have you received a copy of your patient’s Survivorship Care Plan? □Yes, □No, □Not sure.
   Comments  ____________________________________________________________
   ____________________________________________________________

2. Have you had the opportunity to read your patients Survivorship Care Plan? □Yes, □No, □Not sure.
   If not why?  ____________________________________________________________
   ____________________________________________________________

3. Do you think overall the Survivorship Care Plan is a useful tool for your clinical practice?

   (please circle the answer that best suits how you feel)


   Please tell us why?  ____________________________________________________________
   ____________________________________________________________

“I’m going to ask a few questions where the answers are on a 5-point scale, with strongly agree, agree, neither agree nor disagree, disagree and strongly disagree. Is that OK?”

4. Please indicate how much you agree or disagree with the following statement about the SCP:

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Moderately Agree</th>
<th>Neither</th>
<th>Moderately Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>
   a. The SCP is easy to understand | 1 | 2 | 3 | 4 | 5 |
   b. The SCP is too long | 1 | 2 | 3 | 4 | 5 |
   c. The SCP is too short | 1 | 2 | 3 | 4 | 5 |
   d. The SCP addresses the right topics | 1 | 2 | 3 | 4 | 5 |
   e. The SCP will be useful to use when discussing follow up with the patient | 1 | 2 | 3 | 4 | 5 |

5. The SCP helped you understand

<p>| Your patient’s cancer diagnosis | 1 | 2 | 3 | 4 | 5 |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>b. The team who treated your patient for cancer</td>
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<td></td>
<td></td>
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<tr>
<td>c. The need for routine cancer screening</td>
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<tr>
<td>d. The need for follow-up to assess for late and / or chronic problems resulting from cancer treatment</td>
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<tr>
<td>e. Which follow-up test(s) will be needed</td>
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<tr>
<td>f. How often follow-up tests should be performed</td>
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<tr>
<td>g. The importance of resuming or initiating age-appropriate health maintenance practices following cancer treatment</td>
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<tr>
<td>h. Your (the GP) role in facilitating survivorship care</td>
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<tr>
<td>i. How you (the GP) and oncology providers will share the responsibility of survivorship care</td>
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<tr>
<td>j. The resources available to cancer survivors/families?</td>
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</tr>
</tbody>
</table>

6. Do you think that the SCP will improve your communications with the cancer treatment providers?

☐ Yes, ☐ No, ☐ Not sure.

If yes, how?

________________________________________________________

________________________________________________________

7. Have you discussed the Survivorship Care Plan with your patient? ☐ Yes, ☐ No, ☐ Not sure.

If no, why?

________________________________________________________

________________________________________________________

8. Do you think that the SCP will improve your communications with your patient regarding their cancer
9. Have you created a Chronic Disease Management Care Plan for your patient since completion of treatment?
☐ Yes, ☐ No, ☐ Not sure.
If yes, did the SCP assist you to complete the Care Plan?
________________________________________________________________________
________________________________________________________________________

10. Would you like to continue to receive SCPs for your patients after cancer treatment?
☐ Yes, ☐ No, ☐ Not sure.
If yes, why?
________________________________________________________________________
________________________________________________________________________

11. Do you experience challenges when providing follow up care for your patients after their cancer experience?
☐ Yes, ☐ No, ☐ Not sure.
If yes, what are the challenges?
________________________________________________________________________
________________________________________________________________________

12. Do you think the Survivorship Care Plan is the right title for the document? ☐ Yes, ☐ No, ☐ Not sure.
If no, what is a better title for you?
________________________________________________________________________
________________________________________________________________________

13. What method would you like to receive a copy of the SCP from the cancer treatment provider?
________________________________________________________________________
________________________________________________________________________

14. Please tell us how we can improve the SCP?
________________________________________________________________________
________________________________________________________________________
15. Is there anything else you would like to tell us?: ____________________________
___________________________________________
___________________________________________
___________________________________________
___________________________________________

Thank you for completing this survey. We appreciate you taking the time to share your experiences with us.