How survivors will use Survivorship Care Plans (SCPs) at Peter MacCallum Cancer Centre
Executive Summary 2016
**Background**

SCPs have been widely endorsed (2-5, 10). They generally comprise a summary of a person’s cancer diagnosis and treatment, as well as plans for follow-up, information about strategies to remain well and available resources (6).

Providing SCPs at end of treatment are not currently a standard of clinical practice in Australia. A SCP is reported as a document that can act to support transition from treatment to post-treatment; and enhance patient-centred care and health during cancer survivorship (10-14). It is described as a flexible communication tool and can be adapted for use in varied settings. A number of worthwhile benefits have been identified for both survivors and health professionals(15). SCPs potentially can play a critical role in promoting a more patient-centred approach; the importance of healthy living to survivors; supporting both survivor self-management and active participation in their follow-up(9).

At Peter Mac, the Late Effects service has provided patients with SCPs for some time. In 2011, Peter Mac commenced a pilot project, aiming to provide patients in four clinical services with SCPs. In 2013, the Australian Cancer Survivorship Centre, a Richard Pratt legacy (ACSC) evaluated the impact of the project including determining enablers of and barriers to SCP implementation; as well as the impact of SCPs for patients, GPs and hospital-based staff. Recommendations included creating systems to deliver post-treatment support and improved care coordination; and embedding SCP initiatives into usual care(7, 8). These recommendations are strongly supported by the recent ‘Supporting cancer survivors in Victoria: Learning from the Victorian Cancer Survivorship Program pilot projects 2011-2014’. This report summarised outcomes of pilot projects testing a range of survivorship initiatives in Victoria, all of which incorporated providing SCPs as part of their post-treatment care(9).

For sustainability, SCPs and other survivorship services are best delivered through models of care that fit an institutions needs and resources (14, 16). A one size fits all approach to SCPs is not ideal and one model of care is unlikely to be applicable in all circumstances(17). Particular consideration should be given to the needs of the audience/s and the intended outcomes from provision of the SCP(18).

**How will survivors use Survivorship Care Plans (SCPs) at Peter MacCallum Cancer Centre?**

Peter Mac recognises the challenge of providing all patients with a comprehensive treatment summary and care plan. To develop sustainable approaches to the delivery of SCPs, the ACSC aimed to explore preferences of cancer survivors regarding the format and content of a SCP and how they might use a SCP.

**Aims**

We surveyed cancer survivors to determine the following:

- If there were groups of survivors who feel they do not need a SCP
- What are the most valued elements of a SCP for patients when completing cancer treatments
- What is the preferred format for delivery of this type of information
- How cancer survivors plan to use this information

**Participants**

Ten clinical services participated from Peter Mac, East Melbourne campus (bone & soft tissue, breast, gynaecology, upper gastro-intestinal (GI), lower GI, haematology, head and neck, lung, melanoma, urology). The aim was to recruit a minimum of 200 survivors for participation in the study.

Participants were required to have either completed cancer treatment in the previous 12 months and/or be receiving an ongoing treatment (for patients with chronic conditions such as multiple myeloma, chronic myeloid leukaemia [CML], neuroendocrine tumours). Specific cohorts of patients within each
cancer group were indicated by the clinical team as ideal to approach. For example in the melanoma group, survivors who had a diagnosis of thin melanoma, post-surgery without sentinel lymph node biopsy were targeted.

**Method**

Between September 2015 and December 2015, eligible survivors were approached and invited to participate when presenting for follow-up. Two methods of approach and survey delivery were used across clinical services reflecting the model of follow-up (face-to-face or via telephone).

The survey was developed by the project team based on other studies undertaken in the United States, Canada and Australia (7, 17, 19-21). Information elements were divided into three domains: treatment summary information, follow-up plan information and wellbeing information (all commonly provided in SCPs at the end of treatment). From these, participants were asked to rank their ‘top 5’. Also included in the survey was a series of questions regarding information participants may have received already, preferences for format and delivery of information in a SCP, and preferences for a health care professional to deliver the information.

**Ethical considerations**

The study was approved by the Human Research Ethics Committee at Peter Mac (study number 15-103L). To ensure confidentiality, surveys were numerically coded. The survey was anonymous and participants were advised not to write identifying information on the documentation. Only the project team had access to the completed surveys.

**Survey findings**

230 surveys were returned (68% response rate). Eleven returned surveys were excluded as participants indicated that they were more than 12 months post treatment. A total of 219 surveys were included in the analysis.

**Information at the end of treatment**

Almost all participants (98%) indicated they wanted a SCP at the end of treatment. Most (82%) reported they had not, or were unsure if they had received a SCP at the end of treatment. More than half (59%) had not received or were unsure if they had received general information resources at the end of treatment to help prepare them for physical, practical, emotional or social issues they may experience post-treatment. Two thirds (66%) of this group indicated they would have found this information useful at this time point.

**Reason for wanting a SCP**

The principal purpose indicated for having a SCP was for personal use, ‘As a record of cancer treatment’ (61%), ‘As a reminder of things I can do to look after myself’ (57%) and ‘To help me understand my cancer experience’ (56%). More than half of the total participants planned to share the SCP with family (55%), with both head and neck (78%) and urology (72%) groups more likely to do so. In general, just over half of the participants indicated they would share the SCP with the GP (52%), more commonly survivors from the gynaecology (63%), urology (66%) and melanoma (83%) groups. Half of the participants indicated they would share the SCP with other specialist doctors and nurses caring for them, with urology survivors (81%) indicating they were most likely to do so. A small number of participants (4%) also indicated they would share the SCP with other cancer patients and friends.
Most important elements

Preferences for information elements to be included in a SCP varied according to the particular survivor cohort; however common elements were observed across all cancer groups. Broadly, there was a stronger preference for ‘treatment summary and follow-up information’ compared to specific ‘well-being information’. Generally, the most important information elements were ‘A list of symptoms to watch for and report to the nurse or doctor (74%), ‘A summary of the treatment received’ (70%) and ‘A plan for when I should have follow up’ (70%), ‘A list of tests I am going to have and when’ (69%) and ‘Things I can do to look after myself’ (67%). Just over half of the participants (51%) requested ‘Information of when to contact the GP’. Information regarding when to contact a GP was least requested from the bone and soft tissue survivor group (39%). For the most part, there was less support for healthy living recommendations. Although not analysed by smoking status, age, sexual activity or requirements for support, least preference was demonstrated for information concerning ‘Quitting smoking’ (10%) ‘Fertility’ (11%), ‘Sexual health’ (23%) and ‘Support groups’ (29%).

From the information topics chosen, participants were asked to rank their ‘top 5’ elements. In this setting, ‘Information about screening for other common cancers’ (32%) and ‘Strategies for reducing worry about cancer coming back’ (31%) were ranked in the ‘top 5’ elements alongside ‘A list of symptoms to watch for and report to the nurse or doctor’, ‘A summary of the treatment received’ and ‘Things I can do to look after myself’.

Differences in priority of ‘top 5’ information elements were identified across survivor cohorts. For example, the upper GI group included ‘pain and symptom management’ information in their ‘top 5’. Specific healthy living information regarding ‘diet’ was ranked in the ‘top 5’ by breast and lower GI survivor groups only, whilst ‘exercise’ information was ranked ‘top 5’ by the breast group only.

Additional supports

Emotional support (17%) and regular telephone contact with health care professionals post-treatment (10%) were most commonly requested as additional supports to offer at end of treatment. Just under one third (32%) indicated no additional assistance was required.

SCP format

Almost all participants (91%) indicated a preference for a paper-based SCP. There was almost equal support for both a detailed SCP with information about health and follow up care [5 pages] (42%) and a briefer version [1 page] (36%). Variation was observed across the cancer groups, for example a detailed SCP was most preferred by the upper GI (67%) and breast (50%) groups; a brief version was most preferred by the urology group (48%) and general information by the head and neck (39%) and melanoma (50%) groups. Booklet and information leaflets were favoured by some. Small numbers indicated a preference to access information via an internet site (12%). Least preference was for internet applications that run on smartphones and other mobile devices (8.5%).

SCP delivery model

More than half (55%) of the participants preferred SCP information be delivered in a face-to-face discussion with a hospital based health care professional, most commonly a doctor (31%) or specialist nurse (27%). More than half of the urology survivors (55%) receiving nurse-led telephone follow-up indicated a preference for nursing staff to provide SCP information. One third (32%) of participants indicated email delivery as acceptable, most commonly breast, upper GI and urology survivors.

Engagement with GPs

Overall just over half of the participants (51%) indicated they wanted information regarding when to contact the GP included in the SCP. Similarly, just over half (52%) planned to share the SCP with their GP.
Conclusion

To develop sustainable approaches to the delivery of survivorship care plans this study aimed to explore survivors’ preferences for the format and content of a SCP and how they might use a SCP. The vast majority of participants had not received a SCP and reported they would value receiving one. Principal purposes for having a SCP included it being a personal record, helping to provide context to the cancer experience, promoting self-management and as a communication tool. Most important information elements included ‘a list of symptoms to watch out for and report to a doctor and nurse’, ‘a treatment summary’ and ‘follow up plan’, ‘self-care information’, ‘screening for other cancers’ and ‘strategies for reducing worry about cancer recurrence’.

Overall there was less support for healthy lifestyle behaviour information in the first 12 months post treatment. There was a strong preference to receive a SCP in a face-to-face discussion with either a doctor or a nurse. Telephone contact with the treatment team was requested as an additional emotional support. There was an overwhelming preference for the SCP to be paper-based. There was almost equal support for both concise and more detailed SCPs documents.

Timing of information is critical. Early messages indicating the role of the GP during and after treatment are required. Impressing the value of sharing the SCP with GPs and other health care providers involved in a survivor’s care validates their role in the post treatment phase.

Clinical services are encouraged to consider the survey outcomes and recommendations when implementing SCPs within the models of care and to tailor these initiatives to match cancer types and survivors’ preferences.

Recommendations for Peter Mac clinical services

1. Provide survivors with more information at the end of treatment tailored to specific cancer type and survivor preference.

2. Utilise a range of existing, readily available evidence based resources. These include:
   - Cancer Council’s booklet ‘Living Well After Cancer. A guide for cancer survivors, their families and friends’
   - Peter Mac’s DVD ‘Just take it day to day. A guide to surviving life after cancer’
   - ACSC ‘Coping with the fear of cancer coming back’ fact sheet
   - ACSC ‘Emotional impact of cancer and its treatment’ fact sheet
   - ACSC ‘Questions you may wish to ask about the time after treatment’
   - Cancer Council ‘Get checked - women’ fact sheet
   - Cancer Council ‘Get checked – men’ fact sheet
   - Wellness and life after cancer consumer forums

3. Provide survivors with information about follow up. Tumour specific evidence based resources for both consumers and health care professionals have been developed. ACSC is planning to develop more. Available resources include:
   - Follow-up of survivors of breast cancer
   - Follow-up of survivors of bowel cancer
   - Follow-up of survivors of prostate cancer
   - Follow-up of survivors of Diffuse Large B Cell Lymphoma (DLBCL)
   - Follow-up of survivors of Hodgkin Lymphoma

4. Identify and prioritise groups of survivors to receive other aspects of SCPs

5. Aim to deliver a treatment summary at the end of treatment. The ACSC has commenced pilot work to deliver automated treatment summaries within some clinical streams.
6. Consider how SCPs can be delivered within the service and which staff are best placed to provide these, for example face-to-face within medical or nurse led end of treatment consultations; consider alternative methods of delivery such as telephone and email.

7. Further engage survivors with well-being and healthy lifestyle behaviour discussions, as the burden of acute side effects from treatment subsides.

8. Utilise the SCP to promote coordinated care between health providers

9. Provide early messages regarding the role of the GP during and after treatment
   - Send copy of SCP to the GP (include treatment summary and follow-up plan)
   - Impress the value of the SCP as a communication tool across multiple care providers, family and friends to promote self-management in the post-treatment phase and manage ongoing health issues
   - Use the SCP to prescribe and support healthy lifestyle behaviours as an integral component of ongoing cancer treatments and post-treatment phase.

10. Consider a process to update the SCP.
References