

ORIGINAL ARTICLE

How will cancer survivors use survivorship care plans?

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ABSTRACT

Background: Survivorship care plans (SCPs) are internationally endorsed as an important tool to enhance post-treatment survivorship care. To support broad implementation of SCPs, we investigated survivors' preferences regarding SCPs.

Material and methods: The study was conducted at a comprehensive cancer center. Eligible patients from 10 clinical services, generally up to 12 months following end of treatment (EOT) were approached in clinics or via telephone. A purpose-designed survey assessed survivors' intended use of a SCP and preferences regarding format and content. Intended minimum sample size of 200.

Results: Two hundred and thirty surveys were returned (response rate 68%). Of the 230 participants, over 55% had completed treatment within six months, 35% between six and 12 months, and 10% were receiving ongoing treatments. Most (82%) had not received a SCP and more than one third (42%) reported receiving no information resources at EOT. Almost all (98%) desired further information. Most common information elements desired in a SCP: 'list of symptoms to watch out for and report' (76%), 'summary of treatment received' (70%) and 'things I can do to look after myself' (67%). Most common suggested uses were as: 'a record of cancer treatment' (63%), 'a reminder of things to do to look after myself' (57%) and 'to help me understand my cancer experience' (56%). Over half (52%) would share the information with their general practitioner. Most indicated preference for paper-based SCPs (91%). There was support for both brief (36%) and detailed versions (42%). Over half requested the information be delivered in a face-to-face discussion with a health professional. Regular telephone support from the treating health care team was most commonly suggested as an additional service to support survivors after EOT.

Conclusions: Although similar to international findings, results suggest alternate ways of providing the information that survivors desire. Most desired SCP elements have been defined. A flexible approach to SCP interventions is justified.

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The number of Australians with a personal history of cancer now exceeds one million [1]. Cancer survivors are at risk of other health problems and frequently have other chronic health conditions [2]. Strengthening relationships between oncology providers and primary care, community-based services and not-for-profit organizations is recommended to facilitate improved, sustainable survivorship care [3]. General practitioners (GPs, primary care physicians) play a key role in the cancer prevention, diagnosis and management of patients during and after treatment [4].

Survivorship care plans (SCPs) have been widely endorsed as a communication tool to support the transition from treatment to post-treatment and enhance patient-centred care [2,5–8]. Although SCPs were a key recommendation of the landmark US Institute of Medicine report 'From cancer patient to cancer survivor: Lost in transition' [2] and their use is a requirement for accreditation by the US College of Surgeons [6], provision of SCPs is not standard practice in Australia.

SCPs generally comprise a summary of a person's cancer diagnosis and treatment as well as plans for follow-up and information about staying well [2,5,7]. SCPs provide clarity for patients and health care providers (HCP) regarding follow-up and may support self-management and active patient participation in follow-up [3].

Reviews of SCP implementation report high levels of survivor satisfaction with SCPs [9,10]. Primary care providers who receive a SCP are more likely to engage in survivorship discussions with their patients [11].

SCPs are commonly delivered in the setting of dedicated post-treatment clinics or provided at end of treatment (EOT) [8]. A process of needs assessment is recommended to tailor a SCP to the individual's issues and concerns [3,12].

Published literature highlights challenges with the implementation of SCPs. For HCPs common barriers to using SCPs in clinical practice include: limited time [3,9,10,12–15]; concerns about cost and remuneration [3,9,10,13–15]; uncertainty about effectiveness and limited long-term outcome data

[3,9,12,14]; limited advocacy for SCPs from clinical leaders within health services [3,10,12,16]; lack of resources [3,8,9,12,13] and absence of clearly identified personnel responsible for preparation, delivery and update of the SCP [3,9,10,12,13,16].

At Peter MacCallum Cancer Centre ('Peter Mac', a comprehensive cancer center in Melbourne, Victoria, Australia), the Late Effects service has provided survivors with SCPs for some time. In 2011, a pilot project commenced aiming to provide survivors from four clinical services with SCPs. In 2013, the Australian Cancer Survivorship Centre, a Richard Pratt legacy (ACSC, a department of Peter Mac) evaluated the impact of the project [10]. Recommendations included creating systems to deliver post-treatment support, improved care coordination, and developing strategies to embed SCPs into usual care [10]. These recommendations were supported by an evaluation reporting the outcomes of six pilot projects across Victoria [3,12]. To date uptake of SCPs at Peter Mac remains limited.

To be sustainable, the introduction of SCPs should be aligned to a model/s of care and HCP capabilities [8]. Recognizing the challenge of providing all survivors with a comprehensive SCP, flexible approaches are recommended [3]. The needs of the audience/s requires consideration, however, gaps remain regarding what survivors consider to be the most important elements of a SCP [15]. To inform sustainable and flexible approaches to the delivery of SCPs at EOT, we surveyed a diverse population of cancer survivors. The aims of this study were to determine survivors' preferences regarding: 1) the most common valued information elements of a SCP; 2) preferred format for delivery of a SCP; 3) how survivors intended to use a SCP and 4) whether there were groups who felt they did not need a SCP.

Material and methods

Populations and setting

The study population consisted of a purposive sample of cancer survivors from Peter Mac. Ten clinical services participated [bone and soft tissue, breast, gynecology, upper gastrointestinal (GI), lower GI, hematology, head and neck, lung, melanoma, urology].

The intent was to recruit survivors considered disease-free and also include survivor groups with more chronic disease. To be eligible, participants were required to: have a diagnosis of cancer; have either completed cancer treatment in the previous 12 months or be receiving ongoing treatment (e.g. for a chronic condition such as multiple myeloma); be aged 18 years or greater; having follow-up care at Peter Mac; and able to complete study requirements in English. Refer to Table 1 for further details of the cancer group cohorts.

Procedure

Members of the research team screened outpatient clinic lists. Nurse coordinators from each service confirmed participant eligibility. Eligible participants were approached and invited to participate. Participation was voluntary and

Table 1. Cancer group cohorts.

^a Breast	Early stage breast cancer post-radiotherapy
^a Bone and soft tissue	Post end of treatment
^a Gynecology	Endometrial cancer post-treatment Cervical cancer post-treatment Vaginal cancer post-treatment
^a Lower gastrointestinal	Early stage colorectal post-treatment
^b Upper gastrointestinal	Neuroendocrine tumors – include ongoing treatment
^{a,b} Hematology	Multiple myeloma (can be on ongoing treatment) and post-transplant Lymphoma post-treatment Chronic myeloid leukemia – ongoing treatment
^a Head and neck	Post-radical radiotherapy
^a Lung	Post-radical radiotherapy
^a Melanoma	Thin melanoma, no sentinel node biopsy, post-treatment
^a Urology	Prostate cancer post-radiotherapy Prostate cancer post-robotic surgery

^aSurvivors post-treatment and considered disease-free; ^bSurvivors with chronic disease.

completion of the survey represented implied consent. Two methods of approach and survey delivery were used (see Figure 1).

Face-to-face: Reception staff approached eligible participants and handed out surveys, which participants self-completed.

Telephone: The nurse coordinator conducting telephone-based follow-up briefly explained the study. The study investigator (NK) contacted consenting participants by phone, asked the survey questions and recorded answers into a coded survey.

Instrument development

A survey was developed based on items used in other studies that have evaluated information preferences of cancer survivors [17–19]. The survey described a SCP as a written document containing information about treatments given, details about future checkups and cancer tests, information about possible effects of the treatment, and ideas to help people keep themselves as healthy as possible after cancer treatment.

Information elements to include and receive in a SCP at EOT were listed and divided into three sections: treatment summary, follow-up plan and wellbeing information. Participants first indicated as many of the information elements from each section they would like included. From these, participants were asked to rank what they believed to be the most important (top 5) elements. The survey also included questions on preferences for information format and delivery style, and asked participants about information received at EOT. Five survivors completed a pilot version of the survey. No survey refinement was required. The questionnaire is included in Supplementary Appendix 1.

Data analysis

All data from completed surveys was entered into Excel (Version 14, Microsoft Corporation). From the entered data, frequency and percentages were calculated. The percentage of missing data was calculated for each question. Content of

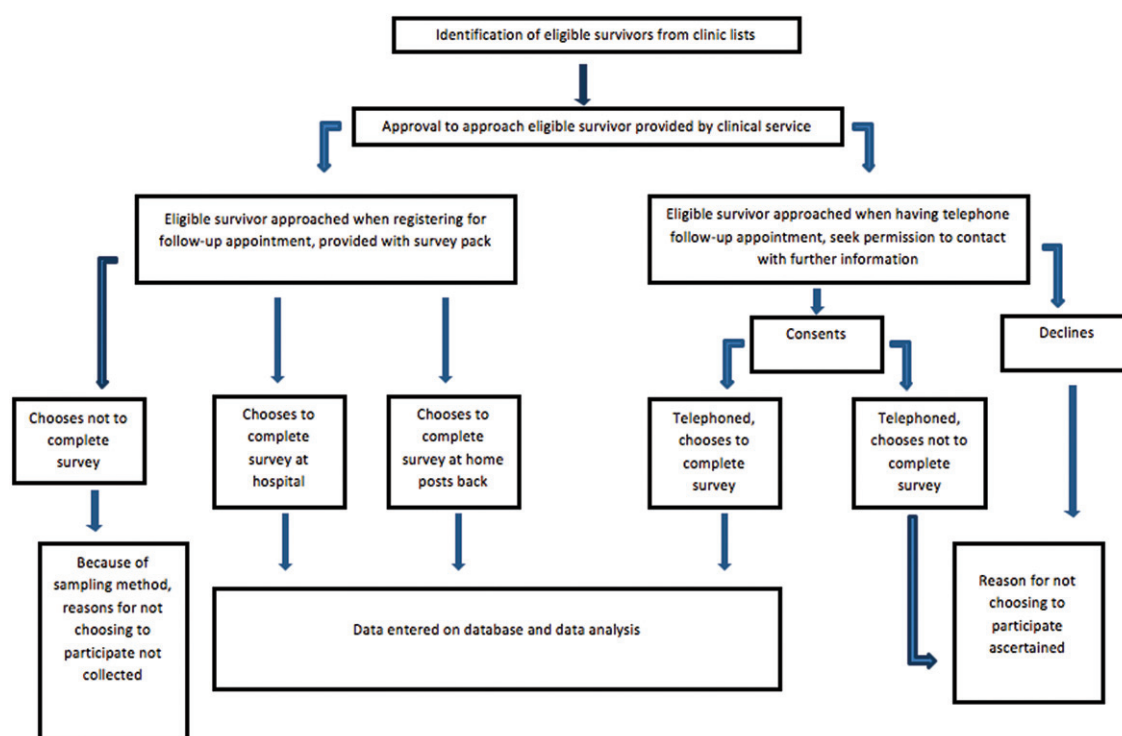


Figure 1. Study flow diagram.

qualitative data was analyzed to identify common preferences and themes.

Ethical considerations

The study was approved by the Human Research Ethics Committee at Peter Mac (Study number 15-103L) and conducted in accordance with ethical standards of the hospital and research committee and the Helsinki declaration of 1975 as revised in 1983. To ensure confidentiality, surveys were numerically coded. The survey was anonymous with participants advised not to write identifying information on the documentation. Only the project team had access to completed surveys.

Results

Participants

All of the follow-up clinic lists from participating clinical services were screened. A total of 3661 electronic records were accessed. Of these, 466 survivors were identified as being eligible. Commonly, reasons for people not being eligible were survivors were more than 12 months post-treatment or they did not fit the target criteria specified for each cancer group. Due to rescheduling of appointments, patients not attending or clinic workload, a total of 339/446 (76%) surveys were distributed. Response rate was 68% (230/339 surveys returned). Forty-three survivors declined to participate (9%, $n = 43/466$). Unreturned surveys were not followed up. Eleven returned surveys were excluded as participants indicated they were more than 12 months post-treatment. As a result, 219 surveys were included in the final analysis.

Table 2. Demographics of participants.

	Number	%
Age ($n = 213$)		
Median years	60	
Range	18–86	
Gender ($n = 218$)		
Male	103	47.3
Female	115	52.7
Cancer diagnosis ($n = 219$)		
Breast	20	9.2
Gynecology	45	20.6
Upper gastrointestinal	15	6.9
Lower gastrointestinal	16	7.3
Lung	1	0.5
Bone and soft tissue	36	16.4
Melanoma	7	3.2
Hematology	28	12.8
Prostate	33	15.0
Head and neck	18	8.2
Time since completion of treatment ($n = 200$)		
0–6 months	111	55.5
6–12 months	70	35.0
On therapy	19	9.5

Demographics of the participants are outlined in Table 2. Just over half of the participants were female (52.7%, $n = 115/218$). Median age was 60 years ($n = 213$). Just over half (55.5%, $n = 111/200$) were up to six months post-treatment, 35% ($n = 70/200$) were between six and 12 months from EOT. Almost 10% (9.5%, $n = 19/200$) were receiving ongoing treatments.

Information received at the end of treatment

Most had not (65%, $n = 141/217$) or were unsure (17%, $n = 36/217$) whether they had received a SCP. Of 207, 84 (41%) had received information at the EOT. For people who

had not received information at EOT, two thirds (67%, $n = 82/123$) would have found this information useful. Almost all (98%, $n = 214/219$) wished to receive a SCP.

How survivors might use survivorship care plans

Most commonly, participants indicated they would use this information as: 'a record of cancer treatment' (61%, $n = 127/207$), 'a reminder of things I can do to look after myself' (57%, $n = 117/207$) and 'to help me understand my cancer experience' (56%, $n = 116/207$). Over half (55%, $n = 114/207$), intended to share the SCP with family. Just over half (52%, $n = 108/207$), indicated they would share the SCP with their GP.

Information desired

The most commonly desired elements to include in a SCP were 'a list of symptoms to watch for and report' (74%, $n = 162/219$), 'a summary of the treatment received' (70%, $n = 153/219$) and 'a plan for when I should have follow-up' (70%, $n = 153/219$), 'a list of tests I am going to have and when' (69%, $n = 152/219$) and 'things I can do to look after myself' (67%, $n = 147/219$). Overall, least preference was demonstrated for information concerning 'quitting smoking' (10%, $n = 22/219$); 'fertility' (11%, $n = 23/219$); 'sexual health' (23%, $n = 50/219$) and 'support groups' (29%, $n = 64/219$). A small group (2%, $n = 5/219$) indicated not wanting any information at EOT (Table 3).

Survivors indicated what they felt were the most important elements ('top 5', see Table 4). These included 'a list of symptoms to watch for and report' (51%, $n = 100/195$), 'a

summary of the treatment received' (46%, $n = 89/195$) and 'things I can do to look after myself' (33%, $n = 63/195$). Priority of information elements varied across cancer groups ('top 5', see Table 5). For example, specific information regarding diet was only highly ranked by survivors of breast and lower GI cancers.

Additional supports

Emotional support (17%, $n = 16/96$) and regular telephone contact with HCPs post-treatment (10%, $n = 10/96$) were most commonly requested as extra supports. A small number (6%, $n = 6/96$) suggested offering information at different time points. For more details regarding extra supports requested see Supplementary Table 1.

Format and delivery of survivorship care plans

Almost all (91%, $n = 194/212$) had a preference for a paper-based format; with roughly equal support for a brief (one page) (36%, $n = 36/208$) or a more detailed (five pages) SCP (42%, $n = 88/208$). Over half (55%, $n = 116/212$) preferred that the contents of the SCP be delivered during a face-to-face discussion with a hospital-based HCP, most commonly a doctor (31%, $n = 66/212$) or specialist nurse (27%, $n = 58/212$). Small numbers indicated a preference to access SCP information via an internet site (12%, $n = 26/212$). Least preferred were smartphone applications (8.5%, $n = 18/212$).

Engagement with GPs

Just over half (51%, $n = 111/219$) desired information about when to contact their GP included in the SCP. Just over half (52%, $n = 108/207$) would share the SCP with their GP.

Table 3. Information desired by survivors at the end of treatment ($n = 219$).

	Yes	%
Treatment summary information		
Summary of treatment received	153	69.9
A list of symptoms to watch out for and report	162	76.4
Information about side effects of treatment I received	140	63.9
Pain and symptom management	101	46.1
Special instructions to follow after treatment	118	55.7
Name and contact details of who to call if I have concerns	143	65.3
When to contact the general practitioner	111	50.7
Follow-up plan information		
A plan for follow-up appointments	153	69.9
A list of tests I am going to have and when	152	69.4
Wellbeing information		
Things I can do to look after myself	147	67.1
Diet information	123	56.2
Exercise information	116	53.0
Support group information	64	29.2
Sexual health information	50	22.8
Fertility information	23	10.5
Quitting smoking information	22	10.1
Coping after treatment is over	94	42.9
Strategies for reducing worry about cancer coming back	119	54.3
Screening for other common cancers	119	54.3
Information for my family	77	35.2
Other	18	8.2
Detailed information pelvic floor exercises for men (5/18)	5	2.8
Provide none of the above information		
None of the above information ^a	5	2.3

^aOne participant indicated they wanted information and also ticked none of the above information.

Table 4. Information elements most desired within a survivorship care plan ('top 5') ($n = 195$).

	Number	%
A list of symptoms to watch out for and report	100	51.3
Summary of the treatment I have received	89	45.6
Things I can do to look after myself	65	33.3
Screening for other common cancers	63	32.3
A plan for follow-up appointments	60	30.8
Strategies for reducing worry about cancer coming back	60	30.8
A list of tests I am going to have and when	59	30.3
Diet information	55	28.2
Name and contact details of who I should call if I have concerns	54	27.7
Coping after treatment is over	47	24.1
Information about side effects of treatment I received	46	23.6
Special instructions to follow after treatment	44	22.6
Exercise information	41	21.0
When to contact the general practitioner	31	15.9
Pain and symptom management	26	13.3
Information for my family	24	12.3
Support group information	22	11.3
Sexual health information	12	6.2
Other	12	6.2
Fertility information	3	1.5
Quitting smoking information	2	1.0

Twenty participants who completed survey did not indicate from the information chosen, what would be their top 5; 16 participants did not include a total of five choices for their top 5; four participants indicated they did not wish to have any information so were not included.

Table 5. Information elements most desired within a survivorship care plan (top 5) per cohort.

	^a Breast	Gynecology	Hematology	Head and neck	^a Lower gastrointestinal	Upper gastrointestinal	Melanoma	Bone and soft tissue	^a Urology
Summary of the treatment I received	✓	✓	✓	✓	✓	✓	✓	✓	✓
A list of symptoms to watch out for and report	✓	✓	✓	✓	✓	✓	✓	✓	✓
Information about side effects of treatment I received	✓	✓	✓	✓	✓	✓	✓	✓	✓
A plan for follow-up appointments	✓	✓	✓	✓	✓	✓	✓	✓	✓
Strategies for reducing worry about cancer coming back	✓	✓	✓	✓	✓	✓	✓	✓	✓
Name and contact details of who I should call if I have concerns	✓	✓	✓	✓	✓	✓	✓	✓	✓
A list of tests I am going to have and when	✓	✓	✓	✓	✓	✓	✓	✓	✓
Things I can do to look after myself	✓	✓	✓	✓	✓	✓	✓	✓	✓
Screening for other common cancers	✓	✓	✓	✓	✓	✓	✓	✓	✓
Special instructions to follow after treatment	✓	✓	✓	✓	✓	✓	✓	✓	✓
Pain and symptom management	✓	✓	✓	✓	✓	✓	✓	✓	✓
Diet information	✓	✓	✓	✓	✓	✓	✓	✓	✓
Exercise information	✓	✓	✓	✓	✓	✓	✓	✓	✓
Support group information	✓	✓	✓	✓	✓	✓	✓	✓	✓
Coping after treatment is over	✓	✓	✓	✓	✓	✓	✓	✓	✓

^aSome topics had equal weighting (equally chosen as top 5) within breast, lower gastrointestinal and urology cohorts so more than five information elements indicated for these groups.

Almost one fifth (17%, n = 37/212) preferred to receive SCP information from the GP.

Discussion

Consistent with recent literature, our results demonstrate that survivors strongly support receiving a SCP at EOT [9,10,13–15]. Similarly, participants receiving ongoing treatments also desire this information. Those who had received a SCP at EOT valued it. A small group of participants felt they did not need a SCP at EOT, though there was no clear profile of this group (age, cancer type, etc.). Other studies have suggested that SCPs may not be valued if the information is perceived as having limited relevance or it is perceived to be the wrong time to receive the information [3,18].

Our results endorse the role that SCPs can have providing survivors with the information they need at EOT, to support self-management. Principal purposes for having a SCP were: ‘as a record of cancer treatment’, ‘as a reminder of things I can do to look after myself’ and ‘to help me understand my cancer experience’. Survivors also endorsed receiving ‘information about screening for other common cancers’.

Our results indicated commonly desired elements to include in a SCP at EOT were ‘a list of symptoms to watch for and report’; ‘a summary of the treatment received’; ‘a plan for when I should have follow-up’; ‘a list of tests I am going to have and when’ and ‘things I can do to look after myself’. This is consistent with other literature. However, unlike other studies [17–20] we asked survivors to prioritize the information and indicate what they considered to be the most important information to receive (top 5). In these circumstances receiving information regarding ‘screening for other common cancers’ and ‘strategies to reduce worry about cancer coming back’ were ranked as a matter of importance and need to be addressed. Much of this information can be provided using readily available evidence-based resources translating to a reduced burden in delivering aspects of SCPs, supporting sustainable survivorship care.

The study was not adequately powered to formally compare between cancer types and by other variables (e.g. time since EOT). We note that different survivor groups indicated different preferences for content. These apparent differences require further exploration.

One of the goals of a SCP is to improve care coordination and cross sector communication [2,20]. Our results confirm the regard survivors place on SCPs as a communication tool with just over half of the survivors planning to share it with their GP.

Healthy living recommendations are considered essential inclusions in SCPs [5]. Health professionals have an important role to play in delivering health promotional advice and supporting survivors to make lifestyle changes. Overall, our participants preferred general information, ‘things I can do to look after myself’ compared to specific healthy living advice. Evidence supports better health outcomes and quality of life for survivors who adopt healthy lifestyle behaviors [21]. A cancer diagnosis and the EOT can be a catalyst for making lifestyle changes.

Participants ranked 'strategies for reducing worry about cancer coming back' in their 'top 5' information elements to include in a SCP. Dealing with the fear of cancer recurrence is a commonly reported issue for survivors [22]. Both ASCO [7] and Livestrong [5] recommend that SCPs include elements related to the psychosocial impact of the cancer experience. Promoting the positive benefits of adopting healthy living on reducing the likelihood of cancer recurrence may be of value for some [23].

Our participants demonstrated a strong preference for paper-based resources, consistent with a recent systematic review by Klemanski and colleagues [15], which assessed preferences of cancer survivors and HCPs regarding SCPs, in which both groups favored a 'plain language, printable format'. Our results support flexible approaches to SCP delivery, with survivors supporting both brief and more detailed SCPs. Survivors indicate they would like appropriate information at various time points across their cancer experience [18].

Providing comprehensive SCPs at EOT may not be timely for some survivors [18] and a one size fits all approach is not ideal [20]. For some, delivering a range of existing, readily available evidence-based resources may be sufficient. Needs assessment tools administered at regular time points post-treatment can be used to identify survivors concerns, individualize information and SCP content, determine the most appropriate time to receive a SCP [24] and target those who may most benefit from more complex survivorship interventions.

Development and delivery of SCPs should be seen within the context of the whole model of care [8,9]. Our participants demonstrated a strong preference to receive the SCP during a face-to-face consultation with a doctor or specialist nurse; possibly reflecting traditional experiences of post-treatment care or indicating the significance placed on a face-to-face consultation [18]. Telephone or Skype may be effective in promoting healthy living recommendations for survivors [25].

Planned engagement with primary care seems limited, with only half of the participants wanting information about when to contact the GP at EOT and just over half planning to share the SCP with their GP. These results accord with other work suggesting limited survivor awareness of the role of the GP in post-treatment care [10]. The recent Lancet Oncology commission highlights the critical role of primary care in providing holistic care for survivors [4]. Acknowledgment of the GP as part of the care team; early promotion of the GP role in post-treatment care and fostering the survivor's confidence in primary care may increase engagement with primary care.

Limitations

There are limitations to this study. The survey population was from a single center and some patient groups are not well represented. The views of non-English speaking survivors are not represented. Due to the pragmatic approach to this study (including a deliberately heterogeneous group of survivors), for some cancer groups we had low numbers. As a

result of this, it was not possible to perform formal statistical testing.

The survey tool used was not validated. Participants only chose information elements to receive at EOT. The survey did not enquire about acceptability of telephone consultation. Unlike other studies, we did not provide participants with prepared SCP templates to review or direct them to websites [18,20]. Referring to the SCP as a paper-based document may have influenced choices.

Conclusion

Our findings support the growing body of evidence regarding survivors' preferences and support for SCPs. We did not identify groups who felt they did not need a SCP. Much of the information survivors' desire can be provided using readily available evidence-based resources. The SCP may be a tool to promote self-management. Early messages acknowledging the GP as part of the care team during and after treatment are required. Opportunities for further research exist to better establish survivors' requirements for SCPs, determine SCP uptake and use, and clarify the impact on health outcomes for survivors.

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Disclosure statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the manuscript.

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