



**Clinical
Oncology
Society of
Australia**

***COSA Survivorship Group
Model of Cancer Survivorship Care
Consumer Consultation Workshop Report***

Monday 30 November 2015

COSA Offices, Sydney

Report prepared by

Hayley Griffin, COSA Project Manager

Haryana Dhillon, Chair COSA Survivorship Group

1. Background

The Clinical Oncology Society of Australia (COSA) is the peak national body for multidisciplinary health professionals working in cancer care and control.

In February 2013, COSA established a multi-disciplinary Working Group, including a cancer consumer, to develop a position statement for COSA and its members and stakeholder groups regarding the critical components of cancer survivorship care in Australia. The guiding questions for the project were:

- What are the critical components of survivorship care in Australia?
- What defines quality survivorship and how can it be survivor-centred?
- How can we deliver a minimum standard of survivorship care in Australia?

A further objective was to develop an action plan to support staged implementation of Cancer Survivorship Care across a range of Australian healthcare settings.

During the process of identifying critical components it became evident that an ideal model of care was required to facilitate system change across the country. This was subsequently incorporated into the position statement.

The draft position statement, including the model of care, was sent to the COSA membership and key medical groups for feedback in September 2014. A subsequent face to face workshop was held in December 2014 prior to the COSA ASM in Melbourne to consider further amendments and discuss priorities to support development of the model. It was then presented at the Flinders Survivorship Conference in February 2015 to an audience that included cancer consumers, advocates, health professionals, and researchers. Due to the limited time available for feedback at this meeting, COSA recommended holding a specific consumer stakeholder consultation.

2. Purpose

The purpose of the Consumer Consultation Workshop was to obtain direct feedback from cancer consumers in relation to the draft COSA Model of Cancer Survivorship Care, including, but not limited to, the following areas:

- Definitions i.e. cancer survivorship and wellness
- Concept of self-management in the context of the plan
- Principles of survivorship care
- Model for wellness (Figure 1)
- Model components including stratified pathways of care, treatment summary, survivorship care plan, care coordination, time factors and tools
- Pillars of survivorship care: survivors, health professionals and community

- Health literacy skills required
- Implementation issues to consider
- Future work and recommendations.

Existing position statements and resources from cancer consumer organisations were also highlighted. See Appendix 1 for copy of those shared with COSA prior to the workshop.

3. Overview

The Consumer Consultation Workshop was held on 30 November 2015 at the COSA Offices in Sydney. Seventeen peak cancer consumer organisations were identified using lists from Cancer Australia¹, membership of the Australian Cancer Consumer Network (ACCN)² and key groups COSA had previously worked with (Appendix 2).

Letters were sent to the key cancer consumer organisations in October inviting them to nominate one representative to attend the face to face workshop. A survey was also provided on the draft document that could be completed and returned.

The workshop was facilitated by Dr Haryana Dhillon, COSA Survivorship Group Chair and attended by representatives from: Cancer Voices Australia; Cancer Voices NSW; Cancer Voices SA; CanSpeak QLD / Cancer Trials Consumer Network (CTCN); Melanoma Patients Australia (MPA); and Prostate Cancer Foundation of Australia (PCFA). Apologies were received from CanSpeak Australia. The list of attendees is shown in Appendix 3 and agenda in Appendix 4.

Surveys were completed by three of the cancer consumer organisations (see section 5).

4. Workshop Discussion

At the start of the workshop, Haryana Dhillon noted that the COSA Model of Cancer Survivorship Care had been developed from the perspective of wellness (the Six Dimensions of Wellness Model³ includes physical, social, intellectual, spiritual, emotional and occupational). Managing the balance between wellness and illness models is an important consideration for the model of care.

¹ <https://canceraustralia.gov.au/affected-cancer/cancer-support-organisations>

² <http://www.cancervoicesaustralia.org/wp-content/uploads/2014/12/ACCN-Whos-Who-2014-Directory.pdf>

³ Hettler B. Six Dimensions of Wellness Model. 1976.

In addition, while COSA acknowledges that the broad definition of survivorship includes the full gamut of patient experiences, it was previously agreed that completion of adjuvant treatment or definitive primary treatment would be the starting point for this body of work.

4.1 General Feedback

- Agree with most of the content
- Not very user friendly in current format
- Terminology could be sharpened
- Definition of survivorship and focus of this project would benefit greatly from expansion and supported by the inclusion of examples (for both men and women) e.g. the model includes watch and wait
 - The COSA model of care doesn't need to be exclusive and it currently is – patients with metastatic disease would not be covered by the current model
 - Starting the model at the time of diagnosis would not be too difficult as there is already reference to this time point in the document
- Peer support should be promoted to enhance the ability of survivors to self-manage
 - The value of peer support is sometimes unknown until it is used
 - Health professionals may not always recognise the value of referring patients to peer support
 - Patients may not be aware of peer support opportunities
 - Upfront needs assessment would be ideal (rather than waiting until treatment begins)
- Noted that trying to engage those who will be much less reliant on the health system
- Like the stratified approach, needs assessment and care plan; noted that compiling a directory of services has been difficult in SA; don't like the pillars of survivorship care as prefer to see these as being flexible
- Not 100% sold on the concept of a care plan, especially one that is separate to anything else that has already been provided, as there is little evidence for their usability
- Like minimum standard approach connected to community services so accessible to everyone; great to lift the credibility of community services and perhaps see this as its own specialist group
- The following question was posed: What makes this model of care for 'cancer' different from the model of care for other chronic illnesses? Is it possible to develop something for general use? It was agreed that while chronic illnesses are the same in terms of all patients having 1. Diagnosis, 2. Want to survive and 3. Fear of recurrence, the cost of care and relevant services need to be considered. In addition, some patients may find it hard to deal with psycho-social issues related to cancer

and treatment effects can be very different. The idea of a cancer specific minimum standard approach with access to existing programs is favoured.

4.2 Terminology and Definitions

It was acknowledged that the document has been through extensive consultation and as a result there are inconsistencies in the terminology used.

Consumer preferred terms were discussed at length so they could be presented to the Working Group for consideration post workshop:

- 'Model of Survivorship Care for Wellness' is preferred instead of other terms used throughout the document including 'model for wellness', 'model of survivorship care', 'wellness plan'
- 'Survivorship' is preferred instead of 'people living with a cancer diagnosis' as it is now very well-known and used extensively.

Definition of wellness, specifically the six dimensions, needs to be expanded and sexuality (and all aspects of sexual health) included. These things should also be discussed sooner/up-front with the health professional.

It was noted that there needs to be more communication between health professionals and consumers regarding the knowns and unknowns of each party e.g. sometimes the consumer may know more about a specific intervention than the health professional. It was suggested that the words 'in their area' be added the last sentence in paragraph 2 under the heading 'Recovery-oriented practice' on page 4.

4.3 Principles of Survivorship Care

The principles need to be patient centred. They should try to get across that this is a *partnership* between consumers and the community. Cancer patients are happy to be in the middle but want to hold hands.

It was suggested that the principles listed in the grey box on page 5 should:

- Form one list i.e. remove the 'we' and 'what'
- Change how the last three are described i.e. drop the ending
- Include 'accessible and equitable'
- Match those described in the text on page 7.

4.4 Model for Wellness (Figure 1)

It was noted that cancer consumers feel strongly that the care plan for survivors needs to cover the phase from diagnosis to start of treatment, so that information and support is provided up-front when required.

If the needs assessment box in Figure 1 on page 5 was stretched so it ran from diagnosis to end of primary treatment this would show that appropriate conversations could occur at any point during this time frame. Effective communication skills are important to ensure this is being done well from the beginning (COSA may be able to look at communication skills training for health professionals down the track).

4.5 Model Components

A glossary could be included showing how the five white boxes on page 6 (risk stratification, care plan, care coordination, time factors and tools) relate to Figure 1.

It was agreed that there needs to be a treatment summary at the end of acute or primary anti-cancer treatment, thereby making the survivorship care plan a lot leaner. Rehabilitation needs to be included in the care plan.

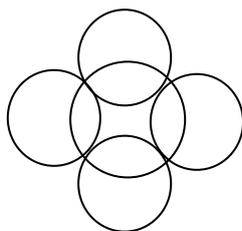
In terms of tools, not much more can be done except list what is available. Mapping the actual services is problematic and out of the scope of COSA's work. People need to find this information out for themselves in their local area.

4.6 Pillars of Survivorship Care and Integration of Care (Figure 2)

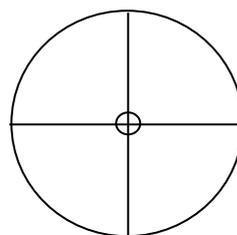
It was suggested that the three pillars of survivorship care and Figure 2. are redrawn to clearly show they are integrated, for example:

- Arrows between Figure 2 and the three pillar boxes
- New illustration with all in the one diagram with the patient at the centre:

A.



B.



'Pillars' could be changed to 'partners'.

On page 9, text regarding the pillars of survivorship care should include a description of peer support and community support groups, and the difference between them. Leonie Young is happy to draft the wording.

4.7 Health Literacy

There was agreement that the overall message is that health literacy is part of the process and survivor centred health professionals should be cognisant of it when writing materials.

It was questioned why there was a need to point out that health professionals are highly literate, as some may find this to be derogatory. Suggest removing 'themselves generally well educated and highly literate' from this section.

4.8 Wellness Plan

Change title to 'Survivorship Care Plan for Wellness' to be consistent.

4.9 Implementation Plan

It was noted that there needs to be a repository for accessing cancer services. The local government and the person giving the diagnosis both have a role to play in ensuring the patient is given information on relevant services.

There could be a role in the future for COSA or Cancer Australia to help identify health professionals working in cancer survivorship (i.e. accreditation).

5. Survey Results

A survey was developed as another means of collecting feedback from the invited cancer consumer organisations.

Surveys were completed and returned by John Stubbs (CanSpeak Australia), Amanda Pomery (PCFA) and Fiona Bennett (MPA).

Question: Do you think the COSA Model of Cancer Survivorship Care captures the critical components of survivorship care in Australia? Is there anything missing? If yes, please list.

CanSpeak	Self-management, full family engagement
PCFA	Nil
MPA	<p>Yes, the critical components of survivorship care in Australia are captured in the COSA Model. However I would like to make 4 points:</p> <ol style="list-style-type: none"> 1. Issues not addressed include the aspect of 'Giving Back'/Volunteering/Meaning Making which is very significant among survivors of most traumatic or life changing events including cancer diagnosis and survival, victims of crime, child sexual abuse survivors, other health issues such as HIV AIDS, multiple sclerosis. Most self-help, fundraising, group support agencies including MPA were started by survivors or loved ones wanting to make a difference based on their own experience which often includes not finding enough support when they needed it and wanting to fund raise for the cause involved or memorialise a loved one. Cancer groups like this include Mummy's Wish, Jane McGrath Foundation, Rare Cancers Australia, Be Uplifted, MPA, Can Speak, Whatever it Takes, MelanomaWA, MelanoimaTas etc. This aspect of meaning making should be acknowledged and support provided for people to give back or contribute as this human value has led to great social changes over the centuries. All the MPA Support Groups around the country are run by volunteers, most of whom are cancer survivors, a number with Stage 4 disease, as well as those who are carers or bereaved by a loved one's death from melanoma. 2. The significant secondary grief and loss aspects apparent in cancer survivorship should be acknowledged in the model and plan. These may include loss of future hopes and dreams including becoming a parent; having a normal sexual relationship; loss of one's hopeful assumptive world view; loss of life without fear of recurrence; loss of capacity both physical and psychological which may lead to loss of chosen career/goals/ability to travel/be independent; loss of life without anxiety (awaiting and confronting regular scans/tests/appointments). I do not believe these aspects are adequately covered under the spirituality nor psychological headings. 3. Will the survivorship model include palliative care or will people transfer from a survivorship plan to palliative care plan? A number of those with Stage 4 melanoma placed on palliative care plans are now being taken off these plans, with subsequent removal of support services, after responding so well to immunotherapy treatment. Where will these people go? The model needs to have a free flowing pathway that accommodates for these changing needs. Some of those who were told they would be dead in 6 months from advanced metastatic melanoma are still living 2 + years later. Similar to the HIV

	<p>experience, these survivors often have PTSD and find it extremely hard to adjust to 'living a full life after preparing for death', often continuing to live in a highly anxious, impotent state, 'waiting for the inevitable'.</p> <p>4. In terms of definition, MPA believes that as long as adjuvant treatment/definitive primary treatment includes surgical removal of the primary melanoma this will cover all those with this diagnosed cancer as the main form of treatment for the early stages of this disease is surgery to remove the primary. Melanoma can recur after 20-30 years, having been initially removed at an early stage and go on to being Stage 1, 2 or 3, all having no gold standard treatment options apart from surgery, with Stage 4 with unresectable tumours, now being offered immunotherapy treatment to which 20-40% have a good response.</p>
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Question: To what extent does the COSA Model of Cancer Survivorship Care fit with your perception of current practice?

CanSpeak	Very well
PCFA	Reasonably well
MPA	A little bit - I work as the National Support Manager of MPA as well as a hospital oncology social worker and am confronted with current gaps in follow up and provision of survivorship services especially between hospital and community, hospital and GP, the individual/family and support organisations

Question: Does your organisation currently have a position statement on cancer survivorship? If yes, COSA would be grateful if you could share a copy.

CanSpeak	Yes - provided
PCFA	Instead of a formalised position statement PCFA makes reference to: Survivorship focusing on the health and life of a person with cancer beyond the treatment and diagnosis phases. Survivorship includes issues relating to follow up care, late-effects of treatment, second cancers, and quality of life.
MPA	<p>Whilst MPA doesn't yet have an official position statement, our stance is: Survivorship, until recently, was not a concept that those with advanced melanoma could consider. However, due to recent advances in targeted and immunotherapies survivorship is becoming a more likely reality. MPA is actively exploring how we can better care for and support the needs of those living with Melanoma cancer.</p> <p>MPA has had representation at both the initial survivorship consultation process in Melbourne in 2013 and also at the Cancer Voices SA Survivorship Conference earlier this year. Karen van Gorp, one of MPA's Support Group</p>

	Volunteer Facilitators who has Stage 4 Melanoma attended this year's conference and reported back in detail. She also became a Survivor Teacher for future and current health professionals. She embraced the open definition of 'survivor' as starting from point of diagnosis as many of those with Melanoma face life long treatments/trials/surgeries and recurrences.
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Question: Have you encountered any problems advocating for alternate survivorship models of care?

CanSpeak	Yes - not really part of a hospital's agenda
PCFA	From the point of view of a not-for-profit peak health body, the integration of community services is significantly challenging. PCFA has a network of Affiliated support groups which struggle to be recognised, integrated and referred to within the cancer setting as a possible support service for men diagnosed with prostate cancer and their families. However, only a small percentage of men prefer to access support via groups, with the need to offer individualised and timely support. Specialist healthcare professionals determining the health literacy of patients and engaging them to seek support services is not part of standard practice. This inconsistent approach creates inequities across patient groups, and access to the right information and the right time. A significant issue for prostate cancer survivors is managing side effects from treatment. Referral to and awareness of long term support, similar to chronic illness, that extends and integrates patients beyond the initial health professional team involved in diagnosis/treatment is required.
MPA	N/A

Question: Do you foresee any challenges implementing the COSA Model of Cancer Survivorship Care?

CanSpeak	Yes - cost, extra duties
PCFA	The COSA model of Cancer Survivorship Care is good, however getting this implemented across the 3 areas (survivors, health care professionals and the community) will be extremely challenging without having one allied health sector taking responsibility for implementing and coordinating the care. Unable to comment further due to implementation plan not being outlined. Ongoing challenges often relate to paper vs electronic administration systems, regional/state/national based funding and delivery creating gaps or duplication in services.

MPA	Yes in terms of bridging the gaps in service delivery and information distribution. Staffing/time/priorities will need to be addressed by policy change, funding and re-education especially at the hospital/GP level where once a 'problem' is referred, treated, discharged then the follow up often stops with no clear plan or pathway and few options known. The issues of distance, ignorance, isolation, low socioeconomic factors, age and access to available Gold Standard treatments will also be challenges.
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Question: What role do you think your organisation can play in advocating for change to survivorship models of care?

CanSpeak	We have great relations with governments both state and federal, but it is at the local level that the real advocacy is required.
PCFA	Potentially include key elements of survivorship model by tailoring information programs for healthcare workers and survivors, with consideration given to prostate cancer patient groups with specific/higher support needs (e.g. CALD, younger men, partners/carers). Educating health professionals and support group leaders on the importance of having a survivorship model of care and how it can be implemented.
MPA	MPA can play a large role within the melanoma community in advocating for a sustainable survivorship model as it has over 2500 members on its database and thousands of followers on Facebook as well as support groups Australia wide and a national presence as patient advocate to legislators, stakeholders and regulators re access to current treatments, drug trials and support for its members.

Question: Are there any aspects of the COSA Model of Cancer Survivorship Care your organisation would not support? Why?

CanSpeak	No
PCFA	Yet to be determined
MPA	No

Question: Do you have any other feedback regarding the COSA Model of Cancer Survivorship Care?

CanSpeak	Physical and social issues, respecting the wants of the person at end of life, incorporation of personal directives. (via email) There is general agreement that we do not need another clinical
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	profession for this. We do not need a breast cancer/prostate cancer person. We really need a generalist who can address symptoms, diet, exercise, pain management and these people already exist. Needs to be a bit of awareness re clinical trials - mentoring, group therapy across all cancers.
PCFA	Some concern regarding the inclusion of the survivorship care plan. To the writer's knowledge, there has been insufficient evidence in its usability and effectiveness to maintain its inclusion in the model. Secondly, implementation needs to be considered at this stage in order to inform the development of a workable model to enable its transition into practice. A simple flow chart could be developed to guide consumers commencing from diagnosis until end of life would which survivors could use whenever the need arose.
MPA	MPA is keen to be involved in this conversation and to be part of the Plan's enactment as well as part of the education process both as participant and as educator of its members.

6. Summary of Proposed Amendments

The following list includes the key amendments agreed upon by attendees at the face to face meeting as being important for the Working Group to consider:

- **Add one page 'executive summary' and 'background' section to document**
- **Make terminology consistent throughout the document; preferred term is 'Model of Survivorship Care for Wellness'**
- **Change model of care starting point to be *time of diagnosis* and include relevant patient examples**
- **Include further definition on the six dimensions of wellness and include all aspects sexual health e.g. sexuality**
- **Page 4, Recovery-oriented practice: Add 'in their area' to last sentence in paragraph 2**
- **Page 5, Title: Remove 'A process for' so it reads 'Cancer Survivorship: Living well with and beyond a cancer diagnosis'**
- **Page 5, Principles:**
 - **Change heading to 'Principles of care'**
 - **Remove 'How we do it' and 'What we do'**
 - **Change the last three to 'promote, prevent, manage'**
 - **Add 'accessible and equitable'**
 - **Re-examine the principles to ensure they are patient centred**
 - **Ensure text on page 7 matches the final principles in grey box**

- **Page 5, Figure 1: change size of needs assessment box so it stretches from diagnosis to end of primary treatment**
- **Page 6, Model components:**
 - **Add glossary showing how the five boxes (risk stratification, care plan, care coordination, time factors and tools) relate to Figure 1**
 - **Include rehabilitation in the care plan**
- **Page 6, Figure 2: Redraw to show that the three pillars of survivorship care are integrated**
- **Page 9, The Three Pillars of Survivorship Care: Include a description of peer support and community support groups, and the difference between them (Leonie Young to draft text)**
- **Page 11, Health Literacy Skills: Remove ‘themselves generally well educated and highly literate’**
- **Page 12, Wellness Plan: Change heading to ‘Survivorship Care Plan for Wellness’**

7. Next Steps

Feedback from the Consumer Consultation Workshop will be presented to the Working Group for consideration at the next meeting on 8 February 2016.

Further consultation with key medical groups will occur in the first half of 2016 to generate additional feedback from these stakeholders.

The draft position statement, including the model of care, will be revised and refined by the Working Group based upon the above two processes.

An implementation plan will be developed in broad consultation with professional groups to understand the landscape which is outside traditional cancer treatment centres including GPs, community services etc.

Working Groups will then be formed to address the issues identified as priorities in the development of the model such as survivorship care plans, implications for implementation, workforce issues, education and training, integrating services, advocacy and tools.

8. Acknowledgments

COSA wishes to thank the cancer consumers who attended the Consumer Consultation Workshop and/or completed the survey on the COSA Model of Cancer Survivorship Care for their valuable feedback.

Appendix 1 Consumer Organisation Position Statements and Resources

A. CANCER VOICES AUSTRALIA POSITION STATEMENT

Cancer Voices Australia
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cancer voices australia

Position Statement 16 March 2015
Cancer Survivors' Framework for Survivorship Care

ISSUE: Australian cancer survivors are calling for a high level framework offering best practice recommendations for survivorship for people diagnosed with cancer.

BACKGROUND: There are almost one million (AIHW) cancer survivors who will benefit from a clear framework. This number will increase greatly with our aging population and continuing improvements in diagnosis and treatment.

Definition: An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition. *Adapted from the National Coalition for Cancer Survivorship <http://cancercontrol.cancer.gov/ocs/statistics/definitions.html>, quoted by COSA Position Statement.*

A framework about evidence based best practice survivorship for people diagnosed with cancer and their carers should address **what to expect and how to navigate** the post diagnosis cancer journey and beyond. This form of best practice guide is the basis for accreditation of cancer centres in some other western countries and a similar reference guide is urgently needed here in Australia. Such a framework (alongside the [Flinders Charter of Cancer Survivorship](#)) would also help health professionals, including cancer specialists and allied health providers in service provision and delivery.

Cancer consumers recognise that:

- Survivorship begins as first diagnosis and is ongoing
- Best practice service delivery must address both physical and psychosocial needs
- Best practice requires coordination of services and communication between professional involved in care and monitoring

RECOMMENDATIONS: We recommend that a framework be developed with cancer consumer/survivor input to address the following matters:

- means of surveillance for recurrence of the primary cancer and metastases
- commencement and reviews of diagnostic details (eg stage, progression, recurrence), treatment summary and care plan for follow-up
- monitoring and managing treatment and psychosocial effects (immediate and late)
- providing follow-up recommendations for detection of second cancers
- providing information about survivorship issues, physical, practical and psychosocial) and how to find it
- promoting wellness and well-being, not just a focus on illness, including healthy lifestyle strategies, information & support
- communication with GPs and coordination of "shared care" between community care, hospital care and charity/volunteer organisations
- empowering survivors to self-manage and advocate for their own health needs
- rehabilitation around physical, practical (eg "financial toxicity", return to work) and psychological impacts of cancer & its treatment
- management of the presence and/or development of comorbidities which impact on cancer outcomes.
- collect better data about survivorship, with measures that enable national and international comparisons of survivorship outcomes across all stages and social groups

Cancer Voices Australia is the independent, volunteer voice of people affected by cancer - since 2000



B. CANSPEAK AUSTRALIA POSITION STATEMENT



Cancer Survivorship Care

Context

We support protocols established with a vision to optimise the health and wellbeing of cancer survivors, their families and carers beyond treatment completion.

Programs must ensure cancer survivors are better supported as they 'get back on track' with their lives following treatment. Programs are to encompass medical follow up and care planning, supportive care, health surveillance, self-care, late effects of treatment, educational opportunities and information links. The post treatment phase sits on the continuum of cancer experience, programming directed towards life after treatment will be informed by, and integrate with, care provided during the treatment phase.

Survivorship Care programs support Jurisdictional Cancer Action Plans, which state as a priority the development of innovative models of follow up and outpatient care to address the physical and psycho-social care needs of survivors, their families and carers. Additionally, plans state the importance of training of the cancer workforce around survivorship issues.

The needs of survivors of childhood cancer are separately highlighted. Gaps in service for this group are addressed by Canteen and COSA through a Federal Grant under the AYA plan.

Models of care and resources developed by the Jurisdictions may have application nationally. The Models of Care are supported by the most current research and contribute to the growing body of knowledge being developed in this area.

Standards

- All initiatives will be evidence based and patient centred, and will involve experienced professionals who are accountable and appropriately qualified.

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W: www.CanSpeak.org.au

- The Framework for Survivorship Care embraces the five inter-related domains of Supportive Care (as defined by the Department of Health): physical, social, psychological, spiritual and information.
- The Plan recognises that people affected by cancer need survivorship care that is tailored to their needs and sensitive to their age, gender, language, culture, sexual preference, spiritual beliefs and socioeconomic status
- The appropriateness and effectiveness of Survivorship Care programs must be continuously monitored

Purpose

CanSpeak supports strategic priorities related to the design and delivery of evidence based, coordinated, patient-focused Survivorship Care.

July 2012

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C. SOUTH AUSTRALIAN STATEWIDE SURVIVORSHIP FRAMEWORK

Development of a statewide approach to Survivorship Care in South Australia

Hislop C¹, Doherty T¹, Cameron K¹, Eckert M², Marker J³, Christensen C³, Fitzgerald M⁴, Loft N⁵, Turpin K⁶, Osborn M⁶, Poprawski D⁷, Bessen T³, Stajic J¹ & Koczwara B⁴

1. SA Cancer Service; 2. Cancer Council SA; 3. Cancer Voices SA; 4. Cancer Services, Flinders Centre for Innovation in Cancer; 5. Central Adelaide Local Health Network; 6. Women's and Children's Health Network; 7. Country Health SA Local Health Network

Background Information

Key drivers for change

- Cancer survival continues to increase with improvements in early detection, diagnosis, technology and treatment modalities
- 9 398 new cancer diagnoses were made in South Australia in 2011, with a projected 11% increase over the next 3 years to 10 456
- Traditionally survivorship care focussed on late-effects, surveillance and follow-up provided by cancer specialists
- Additional needs of survivors that require addressing including ongoing toxicities; physical, psychosocial and economic impacts; co-morbidities (prevention and management) and general health promotion
- A realisation that quality survivorship care requires a holistic, patient-centred approach within and beyond the cancer specialist setting
- SA Health is currently transforming services to ensure patients receive the best care, first time, every time

Aim

To develop a statewide Survivorship Framework that will outline the minimum agreed standard of care for all patients treated with curative intent irrespective of:

- Tumour type
- Age
- Geographical location
- Ethnicity
- Socioeconomic background
- Co-morbidities
- Service or setting (eg. public or private)

This will ensure the needs of consumers are being met and enable consistency and monitoring of the quality of care delivered whilst promoting the ongoing self-improvement of the system.

Method

SA Cancer Service in collaboration with key stakeholders is leading the development of the Survivorship Framework. Six major components of work are informing:

1. Literature Review
2. Survivorship Steering Group (multi-disciplinary governance group)
3. Stakeholder Consultation (consumers, non-government organisations, providers, researchers)
4. Pilot Initiative Trials
5. Health Economic Modelling
6. Survivorship Data Registry – Development and Trial (patient-reported outcomes)

Results to date

Various existing survivorship models (including the COSA Model for Wellness¹) and strategic documents have been reviewed and utilised as a starting point to inform the Survivorship Framework. Overarching principles were adapted from the new SA Transforming Health Initiative and Implementation principles have been established for the Survivorship framework. Successful engagement of a broad range of stakeholders has ensured steady progress on areas of:

1. Treatment Summaries
2. Needs Assessment and Risk Stratification
3. Care Planning

The following diagram outlines key time points to develop and apply these components along the care pathway.



Figure 1. Key time points to develop and apply components

Tools and templates are currently being established and trialed to support the implementation process. The following diagram (Figure 2) outlines the key components and continuous improvement cycle to measure, inform and refine the proposed framework.

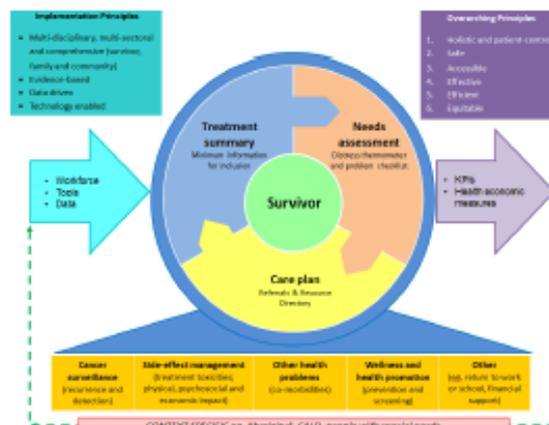


Figure 2. The initial proposed Survivorship Framework for South Australia

Project Phases

2015

- Ongoing engagement and consultation with stakeholders
- Theoretical framework developed
- Health Economic Modelling completed
- Pilot projects commenced – tools and resources refined

2016

- Implementation and sustainability plan developed
- Long-term implementation and scale up plan established
- Link with companion projects i.e. Data, Aboriginal and Torres Strait Islander, Culturally and Linguistically Diverse (CALD) initiatives
- Link with research program on survivorship established
- Clinical education needs defined

2017 – 2019

- Statewide implementation and adaptation

Conclusion

Whilst many survivorship initiatives, programs and research exist or are being undertaken across Australia, South Australia is unique in developing a statewide, population approach. The outcomes and learnings from the implementation of the Survivorship Framework may inform opportunities to adapt a similar model across other health services and jurisdictions.

Acknowledgements

This project is funded by the Australian Health Ministers' Advisory Council (AHMAC) and reports to the National Cancer Expert Reference Group (NCERG).

References

1. Clinical Oncology Society of Australia (COSA) Position Statement on Critical Components of Cancer Survivorship Care (2014)

Appendix 2 List of Invited Organisations

CANCER CONSUMER ORGANISATION	INVITATION ADDRESSE
Brain Tumour Alliance Australia	Ms Susan Pitt, Chair
Breast Cancer Network Australia	Ms Christine Nolan, CEO
Cancer Action Victoria	Dr Pamela Williams
Cancer Trials Consumer Network (CTCN)	Ms Leonie Young, Chair
Cancer Voices Australia	Mrs Sally Crossing, Convenor
Cancer Voices NSW	Mrs Sally Crossing, Chair
Cancer Voices SA	Ms Julie Marker, Chair
CanSpeak Australia	Mr John Stubbs, CEO
CanSpeak QLD	Ms Leonie Young, President
CanTeen	Mr Peter Orchard, CEO
ConsumersCan	Ms Rosanna Martinello
Consumers Health Forum of Australia	Mr Tony Lawson, Chair
Melanoma Patients Australia	Ms Ashley Dionysius
National Breast Cancer Foundation (NBCF)	Ms Jackie Coles, Acting CEO
Prostate Cancer Foundation of Australia (PCFA)	A/Prof Anthony Lowe, CEO
Rare Cancers Australia	Mr Richard Vines, Chair
Unicorn Foundation	Ms Simone Leyden, CEO

Appendix 3 List of Attendees

WORKSHOP ATTENDANCE			
Name	Representation	Present	Apology
Haryana Dhillon (Chair)	COSA Survivorship Group Chair	Y	
Amanda Pomery	PCFA Manager, Support & Community Outreach	Y	
Chris Christensen	Cancer Voices SA Deputy Chair	Y	
David Campbell	Cancer Voices Australia member	Y	
Elisabeth Kochman	Cancer Voices NSW Deputy Chair	Y	
Fiona Bennett	Melanoma Patients Australia National Support Manager	Y	
John Stubbs	CanSpeak Australia CEO		X
Leonie Young	CanSpeak QLD President & CTCN Chair	Y	
OTHER ATTENDANCE			
Emma Lonsdale	Cancer Australia Senior Policy Officer	Y	
Hayley Griffin	COSA Project Manager	Y	
Marie Malica	COSA Executive Officer	Y	

Appendix 4 Workshop Agenda

AGENDA ITEM	ATTACHMENT	SPOKESPERSON	TIME
1. Welcome and Introductions		Haryana Dhillon	10.00am
2. Background to Workshop <ul style="list-style-type: none"> • Definition of survivorship • Need for model of care • COSA survivorship project <ul style="list-style-type: none"> – <i>Objective</i> – <i>Scope of work</i> – <i>Working party members</i> – <i>Consultation process</i> 	Haryana Dhillon	10.05am	
3. Purpose and Objectives of Workshop		Haryana Dhillon	10.20am
4. Model for Wellness <ul style="list-style-type: none"> • Definition of wellness • Recovery-oriented practice • Principles of survivorship care • Figure 1. Model for wellness in cancer survivorship 		All attendees	10.30am
5. Model Components <ul style="list-style-type: none"> • Stratified pathways of care • Treatment summary • Survivorship care plan • Care coordination • Time factors • Tools 		All attendees	11.15am
6. Pillars of Survivorship Care <ul style="list-style-type: none"> • Survivors • Health professionals • Community 		All attendees	12.00pm
LUNCH			12.30pm
7. Health Literacy		All attendees	1.00pm
8. Wellness Plan			
9. Implementation Plan			
10. Future Work and Recommendations		All attendees	1.30pm
11. Other Position Statements and Resources		All attendees	1.45pm
12. Workshop Close		Haryana Dhillon	2.00pm