COSA Survivorship Group
Model of Cancer Survivorship Care
Stakeholder Feedback Report

November 2014

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Overview

In September 2014, the draft COSA Model of Survivorship Care was circulated to COSA Survivorship Group members and a series of identified Survivorship Stakeholder Groups (Appendix 1) for consideration along with a link to an electronic survey (Appendix 2). Recipients were given one month to complete the survey containing 31 questions seeking to summarise the characteristics of the respondents and their feedback about the model, both positive and negative aspects.

Responses

52 responses were received, 50 responses to the online questionnaire, and two written responses. One person completing the online questionnaire also sent detailed written feedback on the Model of Care document.

Survey Results

A) State representation (n=49)

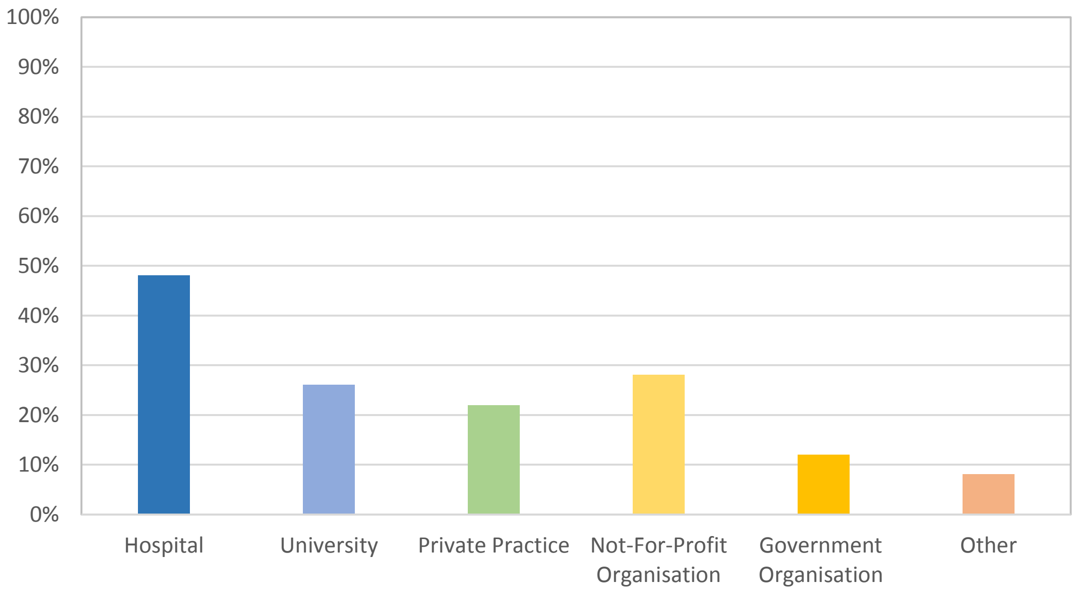
Region	Number	Percentage
NSW	11	22%
VIC	14	29%
QLD	10	20%
SA	1	2%
TAS	0	0%
WA	10	20%
NT	3	6%
ACT	0	0%

B) Professional group representation (n=50)

Professional Group	Number	Percentage
Nursing	17	34%
Psychology	5	10%
Medical Oncology	3	6%
Radiotherapy	3	6%
Surgery	3	6%
General Practice	2	4%
Psychiatry	1	2%
Exercise & Sports Therapy	3	6%
Dietetics/Nutrition	1	2%
Research/Academia	2	4%
Policy	1	2%
Other	9	18%

Groups with no response: paediatric/adolescent, pharmacy, rehabilitation medicine, social work, occupational therapy, physiotherapy, cancer consumers.

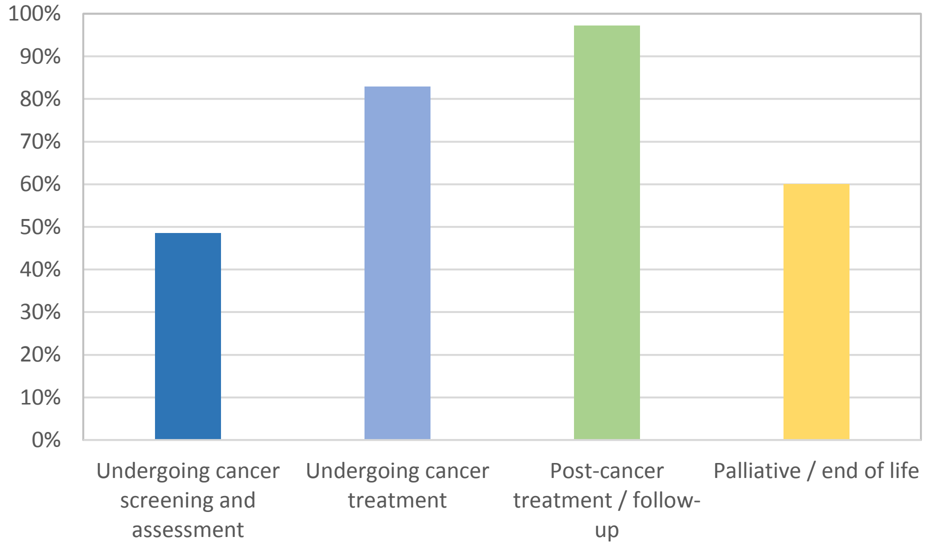
C) Area/s of practice (n=50)



D) Clinical contact with patients and at what stage of the cancer trajectory are they seen?

36 (72%) of the 50 respondents noted that they currently see patients. Of those who currently see patients, 35 (97%) answered the following questions:

- **Hours of clinical work completed each week**: Hours ranged from 4 – 50 per week. The majority (n=13) completed 30 hours or more per week.
- **Stage patients are seen:** Respondents could tick more than 1 category; all were seeing patients in the post-treatment phases and most (n=29) also during treatment.



E) Availability of survivorship service

Out of the 47 respondents who answered if they have a survivorship service or clinic, 11 (23%) had an established survivorship service or clinic, 21 (45%) were hoping or planning to start one, and 15 (32%) reported this was not necessary for their service.

In relation to the 11 respondents who did have an established service or clinic, 8 (73%) answered the following questions:

i) **Which patients are referred to the survivorship clinic?** Those completing adjuvant therapy (n=4), those with early breast cancer (n=2), survivors of haematological malignancy who have undergone stem cell transplant (n=1), a mix, including poor prognosis (n=1).

ii) Which health professionals are involved in the survivorship service/clinic and which professional group leads it?

Respondent	Health professionals	Professional group
1	Multidisciplinary – medical, nursing, allied health	Depends – not just one service
2	RO, haematologist, cardiologist, endocrinologist, neurologist, nurse, GPLO	RO
3	Doctor, nurse, dietitian	Doctor
4	Exercise physiologist, dietitian, clinical psychologist, radiation oncologist, medical oncologist, urologist, surgical oncologist, pulmonary physician, sleep specialist	Exercise physiologist
5	Breast care nurse, surgeon	Breast care nurse
6	Breast nurse	Breast team, surgery
7	Nurse, counsellor, therapist	Nursing
8	Allied Health – although assessment is completed by survivorship nurse	Nursing

iii) How do you currently interact with primary care and community-based services?

Respondent	Primary care	Community-based services
1	Various – including GPLO, SCPs, etc.	Various – run post-tx education forums with CC VIC
2	Principally by letter, and by GPLO	Via nurse mainly
3	SCP correspondence	Tailored referral
4	Patient's GP	We have extensive interaction with CC WA and CC QLD. Partnered with CC WA to provide the Life Now Exercise component
5	Fax and letter	Referral
6	Fax, phone if necessary	Refer as required
7	Phone, letter	Closely, collaborate with programs
8	Direct contact and document exchange	Not involved with look good feel better. Connected with Leukaemia Foundation and CCV

iv) Survivorship planning: What has been done? What has worked and what hasn't?

All respondents that answered this question indicated that planning around survivorship has been done within their workplace.

The survey requested a brief description of planning that has been performed. This identified that in addition to assessment tools being developed, work has also been done developing education programs for patients/survivors.

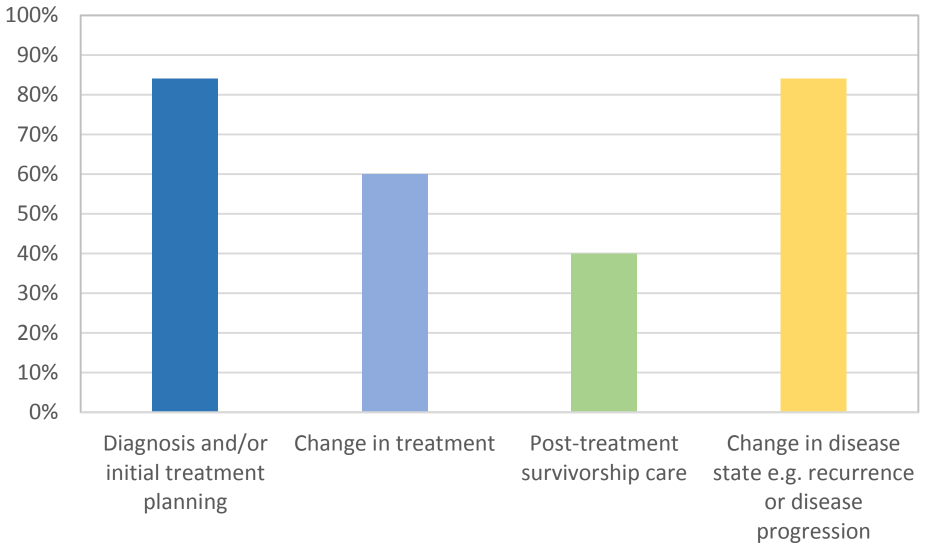
According to one, success has come with streaming patients to different weeks dependent on who will be present at the clinic and by referring to other clinics.

A common difficulty was the ability to engage and communicate with GPs. It was suggested that the key to success is close collaboration and partnership with medical clinicians.

F) Multi-disciplinary team meetings

25 (52%) of the 48 respondents indicated that they do participate in multi-disciplinary team meetings. Multi-disciplinary team involvement ranged from 1-12 with the majority of individuals being involved in only one (n=7) or two (n=8) teams.

The time points at which patients are discussed in these meetings is shown in the figure below (n=25), but most often this is at the time of diagnosis/initial treatment planning OR when there is a change in disease state (e.g. recurrence or disease progression):



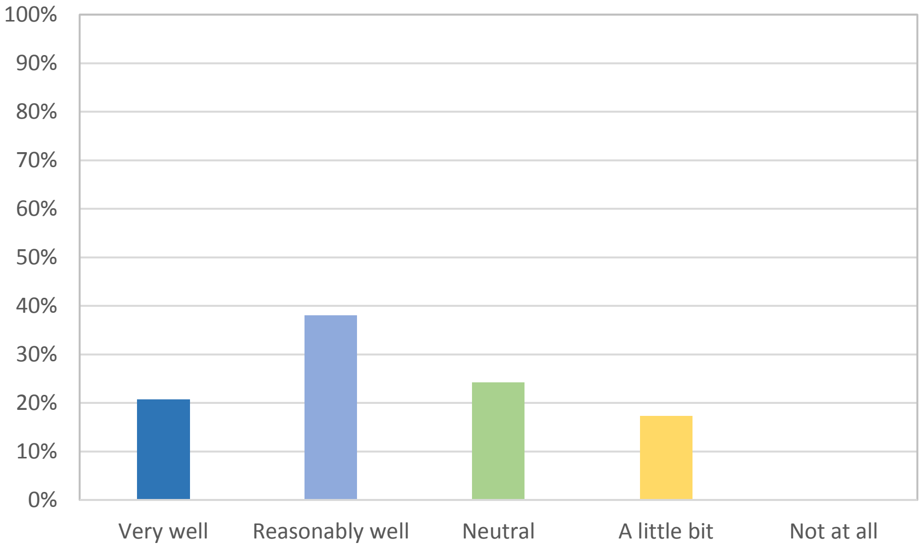
G) Do you think the COSA Model of Care captures the critical components of survivorship care in Australia? Is there anything missing?

Of the 28 (56%) of people who responded to this question nearly half (48%) indicated that they think the Model captures the critical components of survivorship care in Australia. The general consensus is that the Model is comprehensive but not without challenges to implement in practice.

Below is a list of suggestions that could be considered, as outlined by respondents:

- Highlight the importance of collaboration in the development of Survivorship Care Plans (SCP) that are not prescriptive, but are relevant and flexible for the individual and their families
- Emphasise medical aspects such as prevention/early detection or recurrence and late effects
- Further discussion on risk stratification
- Consideration of paediatric cancer survivors making the transition to adulthood and other challenges
- Greater emphasis on psychosocial issues
- Consideration of poor health literacy and access to services in remote areas
- Focus on community links
- Incorporate a strategy to enable implementation within existing infrastructure and resources
- Complementary therapies to assist with wellbeing

H) How well does the COSA Model of Care fit with your current practice? (n=29)



I) Similarities and differences between the COSA Model of Cancer Survivorship Care and current practice

24 (48%) of the 50 respondents answered these two questions.

The majority indicated that current practice incorporates most of the core components. The focus on wellness and self-management is highly recognised.

A number of differences in current practice were identified, mainly that current practice models are informal and are not delivered systematically. Other differences noted include:

- Limited wellness/self-management philosophy
- Lack of interaction with primary care and community
- Research and clinical practice improvement is lacking in the COSA Model of Care. There is no mention of how the Model will generate new knowledge.
- The COSA Model of Care lacks evidence in regards to risk stratification which could potentially encourage very sloppy practices in this area.

J) Implementation

28 (56%) of the 50 respondents answered all three questions regarding implementation of the COSA Model of Cancer Survivorship Care.

i) Barriers to implementation

The two most common barriers to implementing the Model effectively were identified to be funding and financial burden and a lack of resources across the continuum, including human/staff, community, time, IT and the health system. Other barriers identified include:

- The need for ‘buy in’ from specialists, Government health departments etc.
- Clarity of responsible roles
- Training
- Lack of evidence to guide risk stratification across most tumour streams
- Cultural shift
- Clients who are rural/remote, CALD, and are not health literate

ii) Most feasible components of the Model for implementation

Of the responses received regarding feasible components for implementation, development and use of SCPs were the most prevalent. Respondents also listed education as being feasible to implement. Some people also indicated that they felt all components of the Model were feasible for implementation as long as there was sufficient support. Additional components listed include:

- Wellness and health promotion
- Incorporation of self-management resources and programs
- Communication and coordination between GPs and other medical specialists

iii) Requirements to implement the Model into current practice

The majority of respondents identified funding as being important to aid the implementation of such a Model. According to these responses funding should be recognised for things such as:

- Providing late effects/survivorship clinics as a non-negotiable element of cancer care
- Creation of dedicated coordinator positions
- Breast nurses and exercise physiologists

According to the survey participants, advocacy and multi-level 'buy in' from all sectors and key stakeholders including but not limited to GPs, allied health, community, consumers, MDT's and other cancer related health care providers is necessary to aid implementation.

Other things that were noted as being useful for implementation included but were not limited to:

- Education and training – suggestion of COSA-led workshops
- Ability for health care providers to refer to community based care providers under Medicare (currently only GPs can do this)
- Improved communication
- Access to information and tools
- Evidence of patient benefit

K) Additional feedback

Additional feedback was requested at the end of the survey and 19 (38%) of the 50 respondents provided detail. It was noted that the document is very comprehensive, provides a good foundation and has covered the basics well.

The following suggestions were made by one respondent:

- Add something about 'failings' of current healthcare with respect to survivorship care
- Include the IOM 4 goals of post-treatment care
- There should be more about needs assessment (including how this contributes to SCPs)
- More information about what risks are being stratified (recurrence, late effect, psychological issues, RTW, social etc.) and how these can be integrated
- The current Model: underplays late effects; underplays medical role; underplays primary care

It was also noted that the term survivor is a little too optimistic and the emotional damage that a cancer diagnosis produces is under emphasised. It was suggested that a quality of life study might be pertinent.

Feedback from other respondents include:

- Trialling a Nurse-lead SCP clinic in a rural oncology setting
- One size does not fit all – some patients do not require such a complex model
- Fear that only some centres will be able to implement the Model (in WA) due to centralisation of some services and lack of funding
- Suggest looking at the MSKCC Survivorship Centre and their resources.

Outcome

Although the survey had a good number of responses overall and has provided valuable feedback, some of the key stakeholders did not respond. In order to provide a well-rounded Model it is important that all aspects are covered and therefore it seems pertinent to approach these stakeholders directly.

All suggestions will be taken into consideration and may be incorporated into the Model dependent on the outcome of further discussion with the Working Group.

APPENDIX 1

Survivorship Stakeholder Groups
September 2014

- Royal Australasian College of Surgeons (RACS)
    - Breast Group: Breast Surgeons of Australia and New Zealand
- Royal Australasian College of Physicians (RACP)
    - Australasian Faculty of Rehabilitation Medicine
- Faculty of Radiation Oncology, Royal Australian and New Zealand College of Radiologists (ANZCR)
- Australasian Society of Breast Physicians
- Australasian Lymphology Association
- Australian and New Zealand Bone and Mineral Society (ANZBMS)
- Royal Australian College of General Practitioners (RACGP)
    - Cancer/Palliative Care Special Interest Group
- Primary Care Collaborative Cancer Clinical Trials Group (PC4)
- Psycho-oncology Cooperative Research Group (PoCoG)
- Cancer Nurses Society of Australia (CNSA)
- Cancer Australia
- Cancer Institute NSW
- Cancer Council Australia
- State Cancer Councils: NSW, ACT, VIC, QLD, TAS, SA, NT, WA
- ICON Cancer Care
- Exercise & Sports Science Association
- Occupational Therapy Board of Australia
- Australian Physiotherapy Association
- Fertility Society of Australia
- CanTeen
- COSA Group Chairs: OZPOS, Nutrition, CITs, AYA, Pharmacy, Geriatric Oncology, Palliative Care, Rural & Regional, Familial Cancer

APPENDIX 2

COSA Model of Cancer Survivorship Care Stakeholder Feedback Survey

Clinical Oncology Society of Australia

1. **Name (optional) ________________________**

2. **Organisation (optional) ________________________**

3. **If you would like to receive a copy of the summary results from this stakeholder consultation please include your email address here ________________________**

4. **Discipline**

☐ Medical Oncology (adult)
☐ Radiotherapy
☐ Nursing
☐ Psychiatry
☐ Pharmacy
☐ Social Work
☐ Dietetics / Nutrition
☐ Exercise and Sports Therapy
☐ Policy / Public Health
☐ Other…………………..

☐ Paediatric / Adolescent Oncology
☐ Surgery
☐ General Practice / Primary Care
☐ Psychology
☐ Rehabilitation Medicine
☐ Occupational Therapy
☐ Physiotherapy
☐ Research / Academia
☐ Cancer Consumer

5. **State**

6. Area/s of practice (tick any that apply):

☐ Hospital	☐ University
☐ Private Practice	☐ Not-For-Profit Organisation
☐ Government Organisation	☐ Other…………………..

7. Do you currently see patients?

☐ Yes ☐ No

If yes, how many hours of clinical work do you complete each week (approximately)?

If yes, are they (tick any that apply):

☐ Undergoing cancer screening and assessment

☐ Undergoing cancer treatment

☐ Post-cancer treatment / follow-up

☐ Palliative / end of life

8. Do you specialise in the care of patients within one tumour group?

☐ Yes ☐ No

If yes, which one?

☐ Breast	☐ Colorectal
☐ Lung	☐ Prostate
☐ Genitourinary	☐ Gynaecological
☐ Head and neck	☐ Lymphoma
☐ Leukaemia	☐ Brain
☐ Melanoma/skin	☐ Other…………………..

9. **Do you participate in multi-disciplinary team meetings?**

☐ Yes ☐ No

If yes, how many different multi-disciplinary teams are you involved with? ………….

If yes, when are patients discussed (tick any that apply):

☐ Diagnosis and/or initial treatment planning

☐ Change in treatment

☐ Post-treatment survivorship care

☐ Change in disease state e.g. recurrence or disease progression

10. **Do you have a survivorship service or clinic (e.g. multi-disciplinary clinic for cancer survivors, nurse-led clinic assessment post-adjuvant treatment, etc)?**

☐ Yes

☐ No, but hoping or planning to start one

☐ No, not relevant / necessary for my service

If yes, which patients are referred?

Comment box

If yes, which health professionals are involved?

Comment box

If yes, which professional group leads it?

Comment box

If yes, how do you currently interact with primary care?

Comment box

If yes, how do you interact with community-based services (Cancer Council, Look Good Feel Better, Can Too etc.)?

Comment box

If yes, have you done any planning around survivorship within your work e.g. considered a model or set-up a clinic / other service?

☐ Yes ☐ No

If yes, please give a brief description:

Comment box

If yes, what has worked and what has not worked?

Comment box

11. **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 them:**

Comment box

12. **To what extent does the COSA Model of Cancer Survivorship Care fit with your current practice?**

☐ Very well
☐ Reasonably well
☐ Neutral
☐ A little bit
☐ Not at all

Comment box

13. **What is similar between your current practice and the COSA Model of Cancer Survivorship?**

Comment box

14. **How does the COSA Model of Cancer Survivorship Care differ from your current practice?**

Comment box

15. What are the barriers to implementing a Model like this?

Comment box

16. Which components of the Model are most feasible to implement?

Comment box

17. What would help to implement a Model like this in your practice?

Comment box

18. Do you have any other feedback regarding the COSA Model of Cancer Survivorship Care?

Comment box