MODEL OF SURVIVORSHIP CARE FOR WELLNESS

COSA WORKSHOP REPORT

Monday 1 December 2014

Melbourne Convention and Exhibition Centre

Clinical Oncology Society of Australia

Background

In February 2013 COSA established a Working Group to develop a position statement regarding the critical components of cancer survivorship care in Australia. 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.

The position statement, incorporating the model of care, was sent to the COSA membership for feedback in September 2014 and subsequent face to face workshop held December 1 2014 to consider amendment of the model, position statement, and priorities to support development of the model.

The workshop was attended by 130 registrants (see Appendix 2 for listing) and the program is included in Appendix 1.

The outcomes of the workshop included the simple statement of a case supporting improved survivorship care and a series of recommendations from roundtable discussions addressing areas of need identified during the stakeholder consultation. The roundtable discussions, facilitated by members of the Steering Committee included:

A. Survivorship Research
B. Survivorship Care Plans
C. Workforce Issues
D. Education and Training
E. Integrating Services
F. Tools
G. Advocacy
H. Learnings from Other Implementation Projects

The case for better survivorship care

Improving survivorship care should result in:

- Greater efficiency, effectiveness and value
- Fewer premature deaths
- Better quality of life
- Optimal functioning
- Ability to establish and maintain personal relationships
- Optimal psychological health and well-being
- Ability to work and ensure financial security

Major priorities

The five major priorities to come out of workshop via the roundtable discussions and the list of top priorities (see Summary of Priorities on pages 13-14) are shown below. It is important to note that there is a substantial body of ongoing work, as well as other priorities, not specifically discussed within the workshop that will contribute to our understanding of cancer survivorship, its associated challenges, and the development of the field. The information and priorities listed here are not exclusive nor are they exhaustive.

In order to progress these issues it was recommended that working groups be formed for each priority who would be responsible for identifying relevant key actions, both short and long-term. Future working groups will need to reassess the priorities as indicated within this report to effectively respond to a rapidly changing environment.

1. Build a community level conversation about improving care for cancer survivors to influence agenda for research and policy

2. Educate health professionals about self-management, wellness, and strategies for survivors and how they can access existing services

3. Build the evidence for survivorship care through research, initially identify gaps in research and knowledge

4. Influence research funding priorities to incorporate more survivorship research

5. Develop database of services in survivorship care.

A. Survivorship Research

The philosophical approach that will support building the evidence-base is ***'Research through service'*** where data will be routinely collected as part of clinical practice and used to report cancer and survivorship outcomes. However, achieving these outcomes requires facilitated communication between different levels of service providers, with tertiary cancer services facilitating research in the primary care setting.

Key recommendations

- Health economics of survivorship is critical but may be least achievable
- Evidence-base for SCP is thin and negative – needs evaluation
- Triage tools & risk stratification:
    - evidence-base needed
    - appropriate stratification (research through service)
- Quant survey of providers (nurses/MDT) – benefit to understanding qual exploration of the issues barriers to moving between models of care
- Updated research list in survivorship in Australia – ongoing
- Identify areas of disparity: underserved minority groups, CALD, low health literacy, SES, computer literacy, older versus younger groups.
- Generate a list of all those engaged with survivorship research and update regularly
- Priority to make survivorship care part of NHMRC/Cancer Australia research agenda. To do this consumer advocacy is required to change Priority Driven Research Support Scheme.
- Identify gaps in knowledge to drive research planning.

Survivorship care plans

- Notable lack of evidence for patient benefit from care plans but their use is likely to continue in the absence of evidence. Regardless, they should be rigorously investigated.
- Questions of importance:
    - Do or how do SCP help patient self-management?
    - What are the health economics of survivorship care?
    - Where does distress screening fit in survivorship care?
- Essential to identify the outcomes to measure, possibilities include:
    - Patient reported outcomes and/or quality of life outcomes
    - Adherence to surveillance protocols
- High burden of work to deliver SCP, unclear who should do this
    - Barriers to automated or semi-automated SCP exist; accessing and changing electronic medical records and output reports is a barrier.

Health Economics

- There are potential impacts on productivity and contribution of cancer survivors to the broader community. These factors need to be included in health economic considerations of survivorship and interventions to improve outcomes of survivors.
- Suggested priorities for research include:
    - Rehabilitation services and their integration to particularly manage:
        - Return to work

        - Chronic disability activities of daily living, can reducing obesity and increasing activity levels help
        - Fatigue
    - Long-term follow-up of survivorship interventions is necessary, and not usually done now
    - Health system and health service research must be factored into the research programs:
        - Patient led assessment of GP or nurse-led survivorship care would be beneficial – must start with the engaged practitioners
    - What are the appropriate measures? Global QOL scores may be relevant but suggest there is an important level of confounding and the measures are quite blunt instruments so may miss the nuances of patient experiences.
    - Carers are a poorly understood group as is their role in cancer management. It will be important to investigate the economic impact of cancer caring on an individual and societal level. Carers are frequently filling the role of care coordinator but outcomes of this are rarely considered. Recommend exploring any benefits of care coordination.
    - Disadvantaged groups must be prioritised as those most likely to need survivorship care and increased supports. High priority groups include: CALD, low socio-economic status populations, low health literacy populations.
    - Perceptions of medical specialist will be important to consider, particularly around their satisfaction with survivorship follow-up and care. Recommend qualitative research involving specialists to determine their perceptions and their impacts of changing models of care delivery.

Tools

The types of tools available for research and clinical practice were identified as:

- Triage tools: screening and risk stratification, unmet need tools possibly fits here too
- Psychological vulnerability
- Genomics: impact on risk of recurrence or risk of morbidity
- Consider surveillance of survivors of paediatric cancer as a model
- Usability of tools will be key, particularly considering the primary care and GP need for accessible, easy to use tools.

Competencies in delivery of care

It will be necessary to develop competency criteria to cover quality delivery of care for both the cancer and non-cancer health problems of cancer survivors. Examples include, mental health problems, drug addiction, etc. The complex concerns of many patients are not well managed at the moment. Health professionals specializing in cancer care rarely engage with these ‘non-cancer’ problems despite the high morbidity that results.

B. Survivorship Care Plans

- Different patient groups need different care plans, while there are common elements there are differences
- Timing of when to do care plans needs to be considered and factored in to models of care
- Time taken to do care plan – needs to be automated, especially the treatment summary which takes substantial amount of time
- Clearer guidelines about issues that may need to be addressed including the medical components, disease, and psychosocial issues
- SCP must identify main issues for the patient and provide support for healthy behaviours, behaviour change, or psychosocial support/actions, self surveillance role
- Linking SCP to chronic disease management plans may help to address some of the patient flow and access concerns
- To work SCP must address the need for rapid re-access, when to amend and update the SCP
- Prepare patient for care plan right from the beginning to support this and other requirements information education is key, as is access to patient resources
- Ease of access to care plan
- Triggers for care plan
- Practice nurses
- Communication between NGOs and health services needs to be increased and established effectively
- Sections for who is available and responsible
- Length of care plan needs to be considered
- Tailored for patient
- Purpose explained to patients
- Funding and infrastructure
- Terminology – needs to be addressed – how applicable & patient ownership
    - Shared care plan may be better descriptor than Survivorship Care plan
    - Rural and regional issues.

Action planning: Who, when, what & how?

Action plans for the patient, families, and primary healthcare relationship (GP) to work with oncology team are likely to be helpful and require collaborative relationships at all levels.

At the moment there is debate about when SCP should be done and who should do them. Recommend they are done at completion of primary treatment and include who is involved, how often then should be reviewed, which referrals are in place.

C. Workforce Issues

- Culture is a major issue and potential barrier:
    - Role clarification – assist all team members & appreciation of roles
    - Communication focus
    - Change champions are critical
    - Training & education to reinforce system change
    - Patient expectations – setting them around what the model of care is, particularly at start of treatment that discharge form acute care into the setting
    - Requires individuals within the culture to take ownership of management decisions related to individual patients and at the systemic level
    - Critical thought change: 'the specialist setting borrows individuals from the community to manage an aspect of their care'

- Funding:
    - Aligning funding to different roles
    - Who delivers survivorship care is influenced by funding models
    - Explicit funding through Medicare & private health

- Communication models and pathways:
    - Cross professional, cross sector, with patients as well
    - Model that encourages communication allowing new model of care to be conveyed to all members of the team

- Different Workforce models likely to be required:
    - GP, nurse, allied health led services.
    - Determine best mix for different tumour streams
    - Must include risk stratification to support

- Learn from what happens in other clinical streams – e.g. cardiac rehab, pulmonary rehab

- Conceptualisation of workforce considerations included:
    - Training to address skills gap, e.g. motivational interviewing
    - There are clear challenges in implementing a different model across an existing paradigm, especially when so much cancer care sits in the acute care setting
    - Need to determine what care sits in community and which in acute care, then determine what is needed to upskill each group.

D. Education and Training

It was clear from discussions that there is a need for additional skills in our existing workforce to enable them to deliver high quality survivorship care.

- Education and training is an essential component – but we need to be clear about who are we targeting and with which programs?
- Gain skills to deliver and support elements of care
- Motivational interviewing skills need to be developed
- Education and training modules will need to be developed to support this.
- Range of strategies: who need to partner with?
    - Professional organisations,
    - NGOs
    - CPD
- Seminars, CPD, webinars, fact sheets, etc.
- Online modules – partnerships with universities
- Aspirational ideas – face to face workshops
- Train the trainer – Cancer Councils, community workers, etc.
- Collaboration, partnership, Promotion!
- Build on the cancer learning survivorship module.

E. Integrating Services

- Model needs increased primary care engagement:
    - The systems are not yet in place to enable integration across systems
    - GP practices have e-health records but no connection to secondary or tertiary care or allied health
    - Require advocacy to provide incentives for government to implement policy change to support engagement strategies across primary, tertiary and allied health sectors

- Critical decision making time points of care handover must be identified to address:
    - Critical decision making
    - Care continuity
    - Communication strategies
    - Division of care - who does what
    - Patient centered care pathways

- Survivor engagement is important, it is a two-way conversation and we need to be clear about who is in charge:
    - To work we need survivors to own the outcomes to drive change
    - Pulling back clinician perceptions of ‘ownership’ of patients
    - Empower patients to seek information and services

- Community services need to be integrated:
    - Need to lose control currently sitting within tertiary services
    - This will challenge the medical model and there are barriers from HP, particularly around loss of control
    - Essential that we get HP to engage in the process to understand professionalism of not for profit sector

- Understand needs to address concepts that:
    - Giving information is not same as giving referral
    - HP engagement in referring to services is low
    - There is a huge untapped resource in peer-support
    - Medicalisation of survivorship will occur if it remains placed in acute care setting

- To succeed we need champions who are linked to outcomes and willing to lead

- COSA has a central role to place in the dissemination of models of care and bringing together stakeholders
    - Could COSA be the repository for listings of existing services and the portal for online access?

- Integrated services
    - Online database tool – who does what and where
    - Don’t duplicate lists and services, a centralize portal is likely to be optimal
    - Limited internet access in rural/remote areas

    - Carers need to access to information, support, and care. It is important that the system does not overburden the carers by shifting health change support to carers.
    - Discharge letters to GPs need to be implemented and integrated with SCP
    - Better communication

- National advocacy to recognise integration of survivorship care – best practice model is the evidence there.

F. Tools

There are multiple tools in use at present to monitor cancer outcomes, most in use are related to disease outcomes. Despite the availability of tools we have little understanding of the burden of cancer and cancer treatment related morbidity. Consolidating national agenda and activity will contribute to our ability to address care needs, build the evidence and tools to underpin these activities, and the sustainability of this approach.

- Need to move to a wellness model that:
    - Monitors and measures risk
    - Measures physical and psychosocial outcomes
    - Accesses health literacy
    - Assesses perceived need and ability of individuals to self-manage
    - Assesses when individuals are ready to adapt new approaches.

- To do this from national perspective is a key challenge

- Who would be central repository for information?

- Challenges:
    - risk measurement & management
    - health literacy
    - Standard monitoring tool

- Education of consumers and health professionals is important, all need to understand the value of this approach to support and advocate for policy change, increased clinical services based on risk stratification, and research

- Electronic tools are critical and we need to build on existing tools where possible:
    - Cancer registries
    - Cancer Australia common data set
    - Vulnerable groups
    - Different streams – diagnosis variations.

G. Advocacy

- Sustained pressure across the sector is required to keep survivorship care on the agenda
- Many components contribute to optimal survivorship care and changing the status quo including, medical, system, government, individual
- Survivors need to be driving this agenda – what is happening, what is not and what that means for them
- Communication is key:
    - Develop clear messaging around what happens when survivorship care doesn't go well
    - Equity of access is important
    - Advocating for a health workforce educated in cancer survivorship and with the resources to provide appropriate evidence-based support to individuals
- The issue has a community and societal impact, understanding and emphasizing this will allow people and communities ownership of their individual and community needs. We have large numbers & opportunity to drive change from grassroots level.

A priority for advocacy is the lack of consistent and coordinated care

- Push from ground up with networks of consumers have achieved changed.
- One challenge is the condition specific way our treatment systems are set-up, whereas survivorship cuts across all cancer types.
- Aiming to improve the survivor experience by addressing structural inadequacies in the system. The aim is to ensure coordinated, consistent, medical, psycho-social care with access to practice support for returning to work and financial management.
- How can we leverage on other successes
- Coalition of consumer groups with common goals, common language and messaging.

Don't know what you don't know

Partnership between consumer networks and clinical practice, research networks are essential in supporting advocacy efforts.

H. Learnings from Other Implementation Projects

A series of implementation projects have been taking place in different regions in Australia. One of the roundtable discussions focused around the topic of learning from implementation.

Key recommendations

- Budget planning: using modeling when setting up projects
- Business care for survivorship: how to deliver care in these models in tumour streams with low evidence base
- Build for sustainability from outset
- Modeling costs and involve policy makers
- Learning from others work across jurisdictions
- Flexibility – receptivity among survivors is critical so the system needs to be flexible
- When have people finished treatment? The concept of ‘end of treatment’ is artificial with some forms of treatment continuing.
- If rehabilitation is part of the program and one of the aims of care, this is even more likely to involve extended care
- Rigid timing – is problematic
- Navigating system is very important and without support to that many people will continue to experience poorly coordinated care. There must be processes in place, to do this effectively champions will be needed.
- Identify existing programs and build on them especially for regional/rural networks
- How to find survivors? How to get the message out to raise awareness of available services, amongst consumers and healthcare professionals.

Tools

- Which tools are used in needs assessment and valid at end of acute treatment?
    - Which tools are best for whom and for what purpose
    - Efficient needs assessment that can be delivered
    - Who can support self management – community based organisations
- Challenging to work in acute care setting
- Alignment of organisational goals are important, particularly when attempting to cross sectors (primary care, NGO, and tertiary care)
- Using practice nurses may be an optimal approach, allowing them to create programs and space to engage in survivorship care more effectively.

Summary of Priorities

All workshop participants were asked indicate their top priorities for focus and development within these broad areas. The results of this are tabulated below.
It should be noted that not all workshop attendees indicated priorities.

The suggestion that a federal government senate enquiry into the state of cancer survivorship care may provide the best springboard to effect change. The Working Group will consider this recommendation.

A. Survivorship Research	
1	Survivorship care planning – build the evidence
2	Health economics of survivorship care
3	Provider perceptions, barriers to care
3	Updated research list to facilitate cross collaboration
3	Underserved minority groups
B. Survivorship Care Plans	
1	Triggers for updates on Care plan – who is responsible, who can manage, link with chronic disease management plans, embed NGO role
2	Health behavioural strategies and psychological support to enact change are needed – ensure using an agreed action plan.
2	What is optimal content & timing of care plans? - Patient preparation for SCP from the beginning - Ease of access and updating, electronic & automate as much as possible - Rapid access - Timing can effect patient motivation - Time consuming without admin support and automation
3	Clear guidelines identifying issues likely to arise for patients Medical (diagnosis and treatment) Patient risks (psycho-social, non-cancer)
C. Workforce Issues **D. Education and Training**	
1	Educating clinicians about self-management, wellness, and strategies for patients
2	Resource referral – access to list of services that are useful
2	Ensure recognition of community care role in survivorship including GP, nurse practitioners, NGO's, allied health professionals and private practitioners
3	Changing undergraduate education programs to incorporate training in specific areas of study through collaboration with various universities
3	Communication to promote collaboration between treatment centres and survivorship clinics, include development of effective communication models.
E. Integrating Services	
1	Online database tool documenting services (who does what where)
2	Increased primary care engagement supported by appropriate systems, linking GP practice e-health records to hospital.
2	Increased psychological support for patients to facilitate health behaviour change
2	COSA's central role in bringing together stakeholders and advocating for policy change.

F. Tools	
1	Education of consumers & health professionals to promote benefits of Wellness Models of care addressing policy, advocacy, clinical services, risk stratification of patients (care plans), and research
2	Understand the burden of disease (not just cancer but co-morbidity)
3	What research is happening around the country now?
G. Advocacy	
1	Community level conversation leading to involvement and development of a coalition of consumer organisation aimed at improving care for cancer survivors to influence agenda for research and policy.
2	Focus on consumer/survivor/carers to develop groundswell of engagement and support to apply pressure for policy and system change
H. Implementation	
1	Planning for sustainability
2	Education
3	Strong business care (economic evidence)
	Champions
	Flexibility in timing, delivery mechanisms, survivorship needs

Appendix 1. Workshop Program

Time	Topic	Speaker
9:30 to 10:00am	**Coffee and Registration**	
10:00 to 10:45am	**COSA Cancer Survivorship Model** • Introducing the model • Stakeholder feedback to date.	Haryana Dhillon
10:45 to 11:15am	**Morning Tea**	
11:15 to 12:15pm	**Facilitated small groups discussion** • Survivorship Care Plans • Implications for implementation • Workforce issues • Education and training • Integrating services • Learnings from other implementation projects • Advocacy • Tools	All attendees
12:15 to 12:40pm	**Feedback**	All attendees
12:40 to 1:00pm	**Action plan, summation and close**	Haryana Dhillon
1:00 to 1:30pm	**Lunch**	

Appendix 2. Workshop Attendees

Name	Representation
Judy Allen	Eastern Health
Danielle Anthony	Psychology One
Angela Ardi	Epworth Freemasons Hospital
Chris Atkinson	St. Georges Hospital
Brandi Baylock	University of Sydney
Barbara Bennett	University of New South Wales
Joyce Bonello	Prince of Wales Hospital
Jenni Bourke	Peter MacCallum Cancer Centre
Joanne Brooker	Cabrini Institute, Cabrini Health
Gillian Buckley	Peter MacCallum Cancer Centre
Sue Butler	Concord Hospital
Monica Byrnes	Cancer Council South Australia
Rebecca Carlson	Deakin University
Lynda Carnew	Queensland University of Technology
Sally Carveth	Cancer Council NSW
Raymond Chan	Queensland Health
Marie-Claire Cheron-Sauer	Prostate Cancer Foundation of Australia
Brenda Clasquin	Cancer Council NSW
Richard Cohn	Sydney Children's Hospital
Wendy Dawson	Epworth Freemasons Hospital
Haryana Dhillon	University of Sydney
Tracey Doherty	SA Health
Ivana Durcinoska	University of Sydney
Marion Eckert	Cancer Council South Australia
Judy Evans	Peter MacCallum Cancer Centre
Amanda Fairclough	Royal Brisbane & Women's Hospital
Spiridoula Galetakis	Department of Health Victoria
Gwenda Gilligan	Menzies School of Health Research
Afaf Girgis	Ingham Institute for Applied Medical Research, UNSW
David Goldstein	Prince of Wales Hospital
Natalie Goroncy	Peter MacCallum Cancer Centre
Olga Gountras	Slater & Gordon Lawyers
Suzanne Grant	University of Western Sydney / Chris O'Brien Lifehouse
Maree Grier	Royal Brisbane & Women's Hospital
Georgia Halkett	Curtin University
Alix Hall	University of Newcastle
Louise Heiniger	University of Sydney
Lib Heyward	private practice-clinical psychologist
Alison Hocking	Peter MacCallum Cancer Institute
Janet Holland	The Bendigo Hospital
Paula Howell	North Eastern Melbourne Integrated Cancer Service (NEMICS)

Chris Hygonnet	Cancer Council South Australia
Michael Jefford	Peter MacCallum Cancer Centre
David Joske	Sir Charles Gairdner Hospital
Lynette Joubert	University of Melbourne
Billy Jovanovic	Mater Private Hospital
Emma Kemp	Flinders University
Liz King	CanTeen
Nicole	Peter MacCallum Cancer Institute
Laura Kirsten	Nepean Cancer Care Centre
David Kissane	Monash University
Man Ting Lai	Prince of Wales Hospital
Heather Lane	St Vincent's Hospital
Danette Langbecker	Queensland University of Technology
Mari Lashbrook	Riverina Cancer Care Centre
Dianne Legge	Austin Health Cancer Services
Wei-Hong Liu	Queensland University of Technology
Lisa Mackenzie	University of Newcastle; Hunter Medical Research Institute
Gillian Mackie	Queensland Health
Lea Marshall	Ballarat Health Services
Michael Marthick	Chris O'Brien Lifehouse
Sue McConaghey	Central Coast Local Health District
Sandy McKiernan	Cancer Council Western Australia
Fiona McRae	BreaCan
Susan Merchant	Royal Adelaide Hospital
Annie Miller	Cancer Council NSW
Jillian Mills	Cancer Council NSW
Donna Milne	Peter MacCallum Cancer Centre
Leanne Monterosso	University of Notre Dame Australia / St John of God Murdoch Hospital
Judith Morrison	St. John of God Ballarat Hospital
Hunter Mulcare	Northern Health
Andrew Murnane	Peter MacCallum Cancer Centre
Caroline Nehill	Cancer Australia
Kristy Nelligan	Calvary Rehabilitation
Linda	Peter MacCallum Cancer Centre
Inga O'Brien	University of Otago Wellington
Clare O'Callaghan	Cabrini Health
Amanda OReilly	Mater Hospital
Chris Packer	Hume Regional Integrated Cancer Service
Sharni Patchell	Peter MacCallum Cancer Centre
Allison Peace	Bendigo Health
Kim Pearce	Cancer Council NSW
Anna Petterson	Solariscare Foundation, Sir Charles Gairdner Hospital
Amanda Piper	Peter MacCallum Cancer Centre
Carlo Pirri	Murdoch University

Violet Platt	Department of Health WA
Melanie Price	University of Sydney
Nicole Rankin	University of Sydney
Faye Richards	Mercy Hospital for Women
Eli Ristevski	Monash University
Tim Rogers	Redkite
Patricia Rolls	Queensland Health
Meg Rynderman	Peter MacCallum
Emma	Health Issues Centre
Melissa Shand	North Eastern Melbourne Integrated Cancer Service (NEMICS)
Joanne Shaw	University of Sydney
Seleena Sherwell	Southern Melbourne Integrated Cancer Service
Cindy Tan	Concord Hospital
Geraldine Tennant	Auckland City Hospital
Stephanie Tesson	University of Sydney
Belinda Thewes	Menzies School of Health Research
Danielle Tindle	Queensland University of Technology
Jane Turner	University of Queensland
Megumi Uchida	Nagoya City University Graduate School of Medical sciences
Janette Vardy	University of Sydney
Fiona Walter	University of Cambridge
Anne Warby	Asbestos Diseases Research Institute / CeMPED
Kate Webber	University of NSW
Kate Whittaker	Cancer Council Australia
Margot Wilson	Cancer Society of New Zealand Inc.
Sophia Wooldridge	Calvary Mater Hospital Newcastle
Addie Wootten	Australian Prostate Cancer Research
Abby Zaat	Clinical Oncology Society of Australia
Bernadette Zappa	Eastern Health
Liz Zwart	Central Adelaide Local Health Network